

Organ donation: Do families know the facts?



Poll report

Poll 16, October 2019

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Report highlights

- One in four parents have discussed organ donation with their teenager, with the leading reason being that they believe it is part of their job as a parent
- Thirty-one per cent of parents are not aware that not all children waiting for a transplant receive one
- Some parents hold misbeliefs about organ donation, believing that a child might suffer in the donation process (32%) or that a child might not receive all life-saving options if they were identified as a potential donor (36%)
- The vast majority of parents (81%) say they would be willing to donate their own organs in the event that they died, and two-thirds (66%) say they would consider donating their child's organs
- Only one in four (26%) parents have registered their decision about whether or not they wish to be an organ donor on the Australian Organ Donor Register

Organ donation can save the lives of people of all ages, including children. Currently 31 children under the age of 18 are on the national transplant waiting list in Australia. In 2018 there were 554 organ donors, 29 of these were children aged less than 18 years. When matching a donor to a recipient many factors need to be taken into account, including the size of the body and the organ. Some children require organ donations from other children, while others may be able to receive an organ or part of an organ from an adult donor.

There is limited information about the perceptions of organ donation among children and parents in Australia. In this poll, we sought to understand the knowledge, beliefs and intentions of Australian parents in relation to organ donation for themselves and their children.

Discussions about organ donation between parents and their children

Discussions about organ donation leads to an understanding of child's wishes

Organ donation can be a difficult subject for discussion, yet having a conversation about donation is one of the best ways to understand a person's wishes regarding donation. One in four (25%) parents of teenagers reported having discussed organ donation with their teen (see figure 1), and one in eight (12%) parents of primary school aged children reported having discussed organ donation with their child. The proportion of parents who had discussed organ donation with their child increased with the age of the child, with more than a third (34%) of parents of 17 year olds having discussed the topic, compared to 15 per cent of parents of

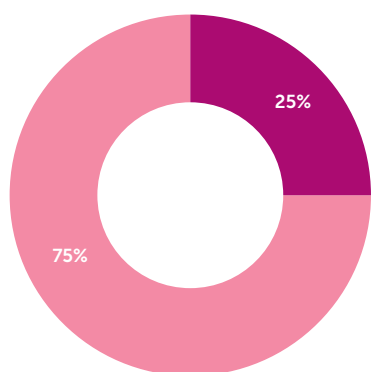
13 years olds. Among those parents who had discussed organ donation with their child (n=437), almost two out of three (62%) reported knowing their child's wishes about donation.

The most frequent reason parents gave for discussing organ donation with their child was that they felt it was part of their job as a parent (51%). One in four parents (25%) raised the topic with their child because they had been discussing it with their partner, and one in five (19%) raised it because they had seen the topic in the media or social media. In some cases the topic was raised with the parent by their child, with 18 per cent saying their child raised it because they had seen it in the media or on social media and 15 per cent reporting their child had learnt about it at school. One in six (16%) parents said they talked about organ donation with their child because they knew someone who had donated or received organs for transplant.

Most parents have never talked about organ donation with their teen

The majority (75%) of parents of teenage children have never discussed organ donation with their teen (see figure 1), with the leading reason for not having the conversation being that they haven't really thought about organ donation (52%). Other reasons for not talking about organ donation with teens include parents not wanting to think about their child becoming an organ donor (21%), feeling that it would be too upsetting for their child to talk about it (15%), feeling that their child was too young to discuss the topic (15%), not knowing how to start the conversation (12%) and believing that there is no need unless their child is sick or injured (10%) (see figure 2).

Proportion of parents who have discussed organ donation with their teen



■ Have discussed organ donation
■ Have not discussed organ donation

All parents (n=1022)

Figure 1.

Reasons parents have not discussed organ donation with their teen

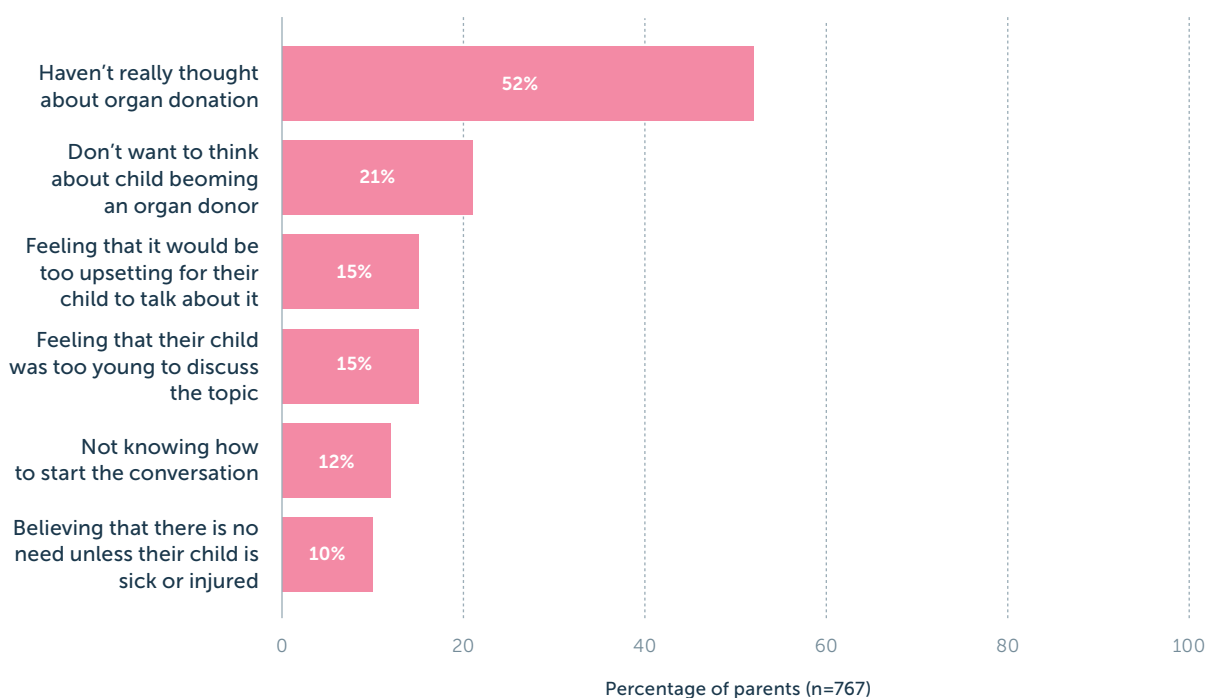


Figure 2.

Knowing when children are old enough to talk about organ donation

One in three (34%) parents are not sure at what age it is okay for a parent or carer to discuss organ donation with their child, and a minority (3%) believe it is never okay to talk about this topic with a child. Every child is different and it will depend on an individual child's maturity and development as to when they are ready to discuss this topic. Among those parents who indicated an age when it may be okay to discuss organ donation with their child (n=1185), the average age given was 13.6 years.

Knowing the facts about organ donation

Misbeliefs about organ donation are common among parents

A number of parents expressed beliefs about organ donation that are inaccurate. Almost a third (31%) of parents are not aware that not all children awaiting an organ transplant in Australia receive one. Half (47%) of parents are not aware that some children can receive organs from an adult donor. Many parents are not aware that young children can be organ donors, with 42 per cent of parents holding the misbelief that toddlers and pre-schoolers who have died are too young to donate organs.

Some parents hold misbeliefs about the process of donation, with 40 per cent being concerned that a parent would not be able to spend time with a child after they died if they donated organs, and a third (32%) worrying that a child would be likely to suffer in the process of donation. More than a third (36%) believed a child might not get all available treatment options to save their life if a decision is made to donate a child's organs. Importantly, a decision to proceed with organ donation would only ever be made once all lifesaving treatment options had been exhausted.

Willingness to donate organs

The vast majority of parents (81%) reported that they would be willing to donate their organs in the event that they died, with 10 per cent saying they would not be willing to donate their organs, and the remaining nine per cent being unsure (see figure 3).

Two thirds (66%) of parents said they would be willing to consider donating their child's organs if their child died, with 19 per cent saying they were unsure if they would be willing to consider it and 15 per cent reporting that they would not be willing to consider donating their child's organs (see figure 3). Parents of teenagers were slightly more likely (71%) to indicate a willingness to consider donating their child's organs than parents of children aged less than five years (64%). Willingness

Parent preferences about organ donation for themselves and their children

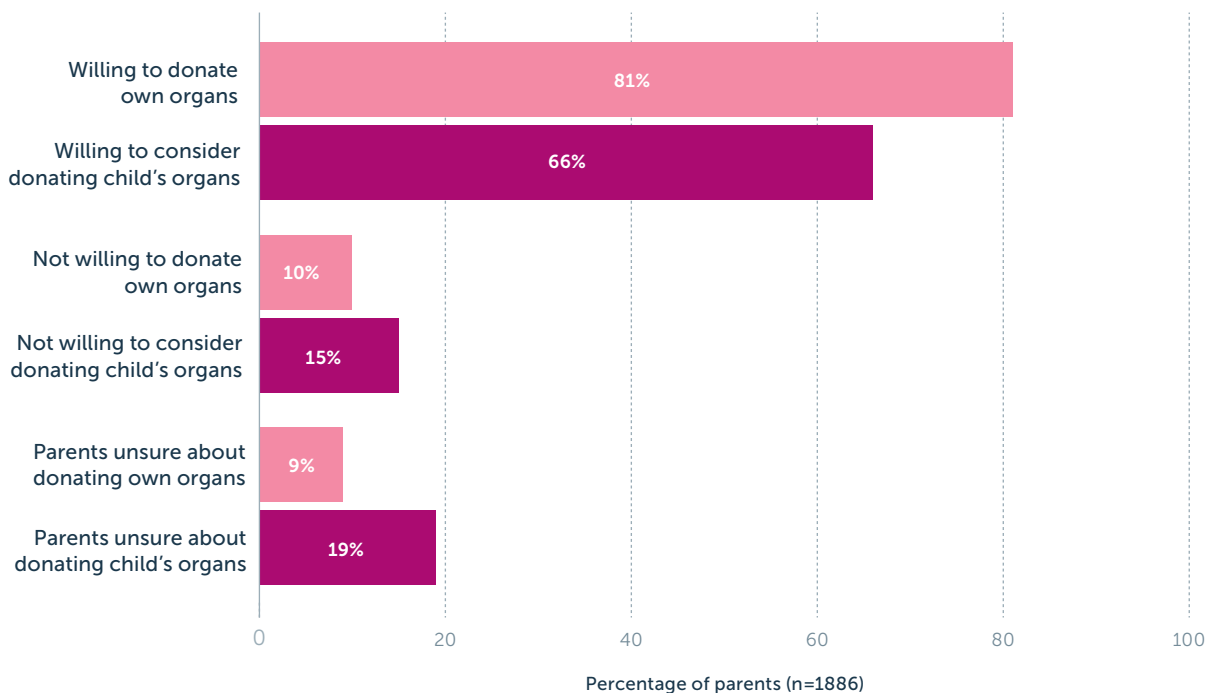


Figure 3.

among parents to consider organ donation for their child did not differ across level of education or country of birth, however it did differ across household income and language other than English spoken at home. Parents from low income households (less than \$1,000 a week) were less likely to consider organ donation for their child. Parents who reported speaking a language other than English at home were less likely to consider child organ donation (23%) than those who report speaking only English (38%).

The majority of parents (81%) who reported that they would be willing to become an organ donor themselves reported that they would also be willing to consider organ donation for their child.

Making a decision about organ donation known

The Australian Organ Donor Register is Australia's only national register that enables people to record their decision about becoming an organ donor for transplantation after their death. Only people aged 18 years and over can register their legally valid consent or objection on the Australian Organ Donor Register. People aged 16 or 17 years old can still register their intent to donate on the Australian Organ Donor Register. People aged less than 18 years can become organ and

tissue donors, although consent will need to be obtained from a family member at the time of death.

Most parents (70%) are aware that registering on the Australian Organ Donor Register is the most effective way to make their decision about donation known, yet only one in four parents (26%) report having registered. Among those parents who indicated they would be willing to donate their organs (n=1532) only one third (32%) have registered their wishes.

Two-thirds of parents (64%) said that talking to their partner or family about their decision is one of the best ways to make sure their decision is known. In the event that a person has died and a decision is being made about organ donation, it is ultimately the next of kin who will determine the decision, making it very important for people to discuss their wishes with their partner, family and close friends.

Of note, more than half (55%) of parents thought that registering their decision about organ donation as part of their driver's licence is one of the best ways to make their decision known. While this has previously been a valid process for registration, South Australia is now the only state where residents can record a donation decision via their driver's licence. In all other states and territories, people need to register their decision on the Australian Organ Donor Register, even if they have previously registered a decision via their driver's licence.

This study found that 17 per cent of parents living in states or territories other than South Australia had registered their organ donation decision on their driver's license and not on the Australian Organ Donor Register.

Implications

In this poll, the majority of parents indicated a willingness to donate organs for both themselves and their children, yet only a quarter indicated they had registered their decision about organ donation on the Australian Organ Donor Register. With growing numbers of children in Australia on an organ transplant waiting list, ongoing efforts must be made to encourage families to discuss organ donation and to record their decision about donation by registering it. The easiest way for people to register their decision on the national register is online at donatelife.gov.au

Many parents expressed concerns about organ donation that are based on inaccurate perceptions, suggesting a need for further education and awareness. Common misbeliefs include concerns that a child will suffer from the donation process or that family will not be able to spend time with their child after donation. It is important for parents to know that a decision to donate a child's organs will not negatively affect the medical and nursing care a child will receive in any way. All efforts will always be made to save the life of a child. The process of organ donation is only undertaken after a child has died and there is no potential for the child to experience any pain and no limit to the amount of time a parent can spend with their child.

Frequently, people have their first introduction to the topic of organ donation at potentially the most difficult moments of their lives, when their loved one has experienced a tragic event and is a candidate organ donor. Pre-emptive discussions about organ donation are an important way for family members to learn each other's wishes, including those of their children. Most parents felt it would be appropriate to talk about organ donation with their teen, although only one in four have done so, with many saying they simply hadn't thought about it and some saying they were not sure how to raise this potentially sensitive topic.

Children and their families should be given adequate opportunities to receive appropriate information, suited to their child's psychological and developmental age and stage, to enable and support informed discussions about organ donation. Primary care providers can be encouraged to address this topic with families, and may benefit from education to allow them to accurately address parent questions and concerns. Another channel for reaching children and parents with education and information on organ donation is through the school curriculum, as it is currently in place in some Australian states and territories. Although it can be difficult for

parents to even think about a situation where their child may become an organ donor, this study suggests a willingness among parents to discuss the topic and a desire for more information and resources to support them in this process.

Data source

This report presents findings from a nationally representative household survey conducted exclusively by the Online Research Unit for The Royal Children's Hospital, Melbourne. The survey was administered from May 20 to July 8, 2019, to a randomly selected, stratified group of adults aged 18 and older (n=1886). All respondents were parents or caregivers to children aged between one month and less than 18 years. Respondents provided data on a collective total of 3,251 children aged between one month and less than 18 years, including 1,022 children aged between 13 and less than 18 years. The sample was subsequently weighted to reflect Australian population figures from the Australian Bureau of Statistics. Among Online Research Unit panel members contacted to participate the completion rate was 61 per cent.

References

For full reference list please contact:
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