



Engaging with vaccine hesitancy in Autistic children and young people

For parents and carers

About this information sheet

This information sheet is for parents and carers supporting Autistic children and young people who experience vaccine hesitancy, prior to visiting a vaccination clinic.

It is designed to give parents and carers a better understanding of the concerns Autistic children may have about vaccination. It also makes suggestions about how to engage with children in ways that are more likely to open pathways to vaccination.

A shared experience

Over recent months, Amaze community members have reached out for guidance while trying to support their children to adapt to the COVID-19 vaccination process.

Some community members have told us the idea of vaccination poses a significant challenge to their children, prior even to visiting a clinic. These children experience a high degree of vaccine hesitancy despite parents and carers having introduced supports to promote their confidence in and access to the vaccination process.

These children may feel anxious and confused. Meanwhile, parents and carers may be concerned that their child is not receiving the best available protection from Coronavirus (COVID-19) through vaccination.

This can be a stressful situation for both the children experiencing vaccine hesitancy as well as their parents and carers.

If you are experiencing a situation like this alongside your Autistic child, you are not alone. There are many families and supporters who are dealing with similar challenges.

Why your child might be feeling hesitant

There are various factors that may contribute to vaccine hesitancy in Autistic children and young people, prior even to visiting a clinic. Common factors that members of our community have shared with us and have requested advice on, include:

- Needle distress and other fears associated with medical procedures (sometimes resulting from past negative experience).
- Overwhelm and anxiety due to changes in routines and unfamiliar processes.
- Anti-vaccine views picked up from friends, the schoolground and other social settings.

It may be difficult for parents and carers to identify what factors contribute to their child's hesitancy in the first place. Also, more than one of these factors may affect your child's attitude and feelings towards vaccination, and to varying degrees.

Listening and asking your child questions is key to understanding what factors are affecting them.

The following tips will help parents and carers to better understand the factors above. The tips will also guide parents and carers on how to approach promoting a child's adaptation to vaccination by addressing each of these factors.

Engaging with needle distress, fear and anxiety

1. Have patience: While getting a COVID-19 vaccination is important for the health and wellbeing of both your child and the wider community, recognize that a shift from vaccine hesitancy to acceptance will likely take time and be a process in itself.

2. Validate your child's response: If your child finds the idea of vaccination challenging, do not interpret or treat this as misbehaviour. Accept that your child's

experience of vaccination may cause them anxiety and fear. Allow for this to be their own response, even if it might seem disproportionate to you or unrelatable. Understand that this distress is partly a physiological response and that vaccination can become a traumatic experience for your child if their distress is not addressed.

Also, acknowledge their feelings of distress. Offer comfort and reassure them that their response makes sense. Use statements like “that sounds scary”, “I can see why you feel that way” and “I am here for you”.

3. Seek understanding: Make efforts to better understand their experience. For example, ask questions that allow you to discover whether their distress is concentrated in a certain phase of the vaccination process. Determine whether their distress surrounds the needle or some other element.

For example, you could ask them if they picture something in their minds while thinking about vaccination. Whether they feel something in their bodies before or during? What do they think is the effect of vaccination? What do they think will happen afterwards? Is there anything they are doubtful or uncertain about?

For younger children, you may need to ask more specific questions and offer suggestions. You could also try drawing together or pretend play.

4. Ensure your child is correctly informed: Correct any misperceptions they might have about what they need to do during the vaccination or what the vaccine is for. Make sure you are well-informed so you can explain to them.

5. Help your child to feel in control: If your child has experienced pain and anxiety during past medical procedures, they may associate these with the idea of vaccination also. Support your child to confront their fears by talking with them about strategies for regaining a sense of control.

For example, ask them to choose from a range of strategies, which will work best for them, including the use of: cold, vibrations, numbing cream, deep breathing

and distractions. Practice using the strategies they choose until your child is confident putting them into practice.

6. Know how to take an exposure-based approach: Gradual exposure to the fear-inducing situation is a science-based approach and may be useful to try. If you are using this kind of exposure-based approach, the aim of the steps should be for your child to practice facing their fear over time. The effect will be to normalise vaccination. You can try this with or without the help of a therapist or other health professional.

If you take up an exposure-based approach, these are the basic steps:

- Support your child to create a 'fear ladder'. Begin by identifying aspects of the vaccination process your child is worried about.
- Order these aspects of the vaccination process from least fear-inducing to the most.
- Help your child face their fear by experiencing each of these aspects of the process from least fear-inducing to the most. They should experience each aspect for as long it takes for their fear to go down, before moving to the next.

When your child puts the steps into action, check in with them. Provide encouragement and reward them when they progress to the next step on their fear ladder.

Seek professional guidance through your GP or a Disability Liaison Officer (if you are in Victoria) if you do require support implementing an exposure-based approach.

Engaging with overwhelm and stress due to change and the unfamiliar:

1. Support your child to prepare: Make sure your child knows what to expect of the vaccination process. Draw on the social scripts Amaze has developed to familiarize your child with what will happen during the appointment.

2. Arrange for reasonable adjustments: Make any adjustments to the environment that will help your child feel less overwhelmed or stressed. Consider organising a home vaccination visit through a Disability Liaison Officer if you live in Victoria or support your child to get vaccinated through their regular GP (if they have one).

3. Language: Use neutral language to describe the vaccination process. De-emphasise potential pain and focus on what your child is achieving by getting vaccinated instead.

4. Seek understanding: Identify what in the vaccination process is causing overwhelm and stress in your child, and why.

5. Introduce small changes over time: Gradually familiarise your child with the cause of overwhelm and any unknown aspects of the vaccination process. Do so by introducing small changes and working your way up. For example, incorporate a short amount of time in your child's schedule for getting comfortable with vaccination.

6. Reward your child: Try to make the vaccination-related activity enjoyable for your child so that they understand vaccination as a positive experience. Reward your child when they complete the activity. Increase the amount of time allocated to the task and increase the similarity of the activity to vaccination over time.

7. Acknowledge flexibility in older children: If your child is older, reward flexibility in your child. Explain to them that flexibility is very important, especially through the pandemic. Make the idea of flexibility something worth your child aspiring to. Point out when your child has been flexible.

Praise and reward them for it. Associate flexibility with vaccination. Allow them to associate flexibility during the vaccination process with getting something they like.

8. Take a strengths-based approach: View incorporating vaccination into your child's routine as an opportunity for their empowerment and growth. Take a strengths-based approach. Are there ways in which the strengths, interests and abilities of your child can be harnessed to make vaccination less daunting?

For example, if your child is a visual learner, consider using pictures to make sure they understand what is being asked of them and the process. Or, if your child has a special interest, find a way to work in a focus on this special interest during vaccination to distract them from the unfamiliar.

9. Support your child to practice independence: You can also use vaccination to teach your child how to search for information and weigh up pros and cons. You can support your child to learn about decision-making, become more confident in themselves and develop their independence.

Engaging with vaccine misconceptions and misinformation

1. Try these conversation strategies: If your child has been impacted by misinformation about vaccines, follow the guidelines below to start a conversation that promotes vaccine confidence.

- **Ask open-ended questions:** Ask questions starting with “what”, “how”, “why” and “tell me” to explore your child's experience of aversion. If your child is younger, you might need to provide more guidance. Pay close attention to non-speaking cues.
- **Affirm their concerns:** Validate the concerns they have. Do this by reflecting to them what their concerns are and responding to them with compassion and care.

- **Share your own experiences:** Tell your child about your own experiences of doubt or worry about vaccination. Talk about what made you decide to get vaccinated and how it has been a positive experience overall.
- **Share information:** For younger children, this may take the form of correcting misperceptions surrounding vaccines. For older children, you may do this by referring them to the sources of information you have relied on so they can explore these for themselves.
- **Be open-minded and curious:** Maintain a willingness to engage with beliefs, opinions and feelings that you disagree with or don't resonate with. The goal is to understand what your child's personal narrative and feelings surrounding vaccination are. Sometimes this is also about allowing your child to learn how to recognise what these are and to express them (whether in a speaking or non-speaking manner).

2. Aim to establish trust: You may need to have more than one conversation with your child and that is ok. The immediate aim is to establish trust and explore vaccination together, even while the longer-term goal is to support your child to become more vaccine confident.

3. Highlight the positives: When talking about vaccination, place emphasis on the benefits of vaccination, the benefits to the community and the genuine care that healthcare professionals feel for the community. Avoid risk comparison and using words such as 'freedom' and 'choice'.

4. Make consequences clear: Allow your child to be aware of the consequences of not getting vaccinated. For example, will they face any restrictions? Will they miss out on activities that they enjoy? Are there people they won't be able to visit? Will they have to do things they won't otherwise have to do?

5. Consider talking about the risks with older children: If your child is older, it may be appropriate to let them know some of the more serious health and community risks associated with not being vaccinated. But don't place too much emphasis on these.

Consider accessing external supports and services

If you have tried various options to promote vaccine acceptance in your child and they continue to find engaging with the vaccination process very challenging, you might consider getting assistance from external supports and services. Some of the external supports and services available, include:

- Assistance with attending a low sensory clinic
- In-home vaccination visits
- Sedation services

See the [Victorian Government's information sheet](#) on COVID-19 vaccination planning for young children for details on some of these supports and services and how to access them:

If you require further information about these support and services, consult your GP or a Disability Liaison Officer.

To receive support from a Disability Support Officer, [fill in the form on their website](#).

Reach out to peers and the autism community

Consider joining a peer support group if you aren't already a member of one. Many parents and carers are facing similar challenges surrounding vaccine aversion in their children. Other parents and carers may be able to share their ideas and experiences with you. They may also provide you with moral support.

Go to [Autism Connect: Search](#) on the Amaze website to find a peer support group in your local area.

Call the Amaze helpline on [1300 308 699](tel:1300308699) or use the webchat on the [Amaze website](#) to receive advice on engaging with vaccine aversion as well as resources and services to help you with this.

Tell us your stories

We are collecting stories of positive vaccination experiences amongst Autistic children so that our community knows what supports are available.

Let us know if the supports you and your child put in place helped them, or let us know if there is a child or young person in your life who is willing to share their vaccination story by emailing us at communications@amaze.org.au.

