

Supporting autistic people to get a COVID-19 vaccination

A guide for health professionals

Autistic patients often require person or patient centred health care services. There are several barriers that may prevent autistic people from regularly accessing health care. There are a range of strategies and supports that health care professionals can use to support autistic patients to receive quality health care and have a positive experience with health care providers.

This guide outlines some important adjustments, supports and strategies that health providers – including COVID-19 vaccination clinics – can make to ensure autistic people and their families and carers have positive experiences and outcomes when attending health services.

The guide reflects current good practice and is intended to be updated as our understanding of the challenges and barriers influencing vaccination uptake evolve.

What is autism?

Autism is a lifelong neurodevelopmental disability that affects the way that people communicate and interact with others. All autistic people are unique. However, autistic people may display some of the characteristics in the two main areas:

- Social communication
 - needs support with communication
 - finds two-way conversation difficult
 - needs support to interact with others
 - has difficulty reading social cues or situations

- can seem uninterested in conversations
- Behaviour, interests and activities
 - prefers structure and routine
 - change can be difficult to process and problem solve
 - narrow interests
 - repetitive behaviours and body movements (sometimes called stimming)
 - under- or over-responsive senses.

To read more about autism, visit the [Amaze website](#).

Making the appointment

Many autistic people can experience difficulties with executive functioning. This means activities like planning, making choices, breaking tasks into small steps and problem solving can be challenging.

The amount of information on COVID-19 vaccination websites may be very difficult for autistic people to sift through and decide what to do. This can mean booking an appointment or using an online booking system can be challenging.

Some autistic people feel stressed when asked lots of questions when making an appointment. Having a prompt beforehand can be helpful, such as knowing how long filling out forms will take and what information they will need to complete the forms e.g. your Medicare Card, photographic identification (passport or driver's licence).

Ensuring both the patient and vaccine clinic staff are familiarised with each other is an advantage. This can involve completing a booking form that helps the autistic person or their family outline any relevant sensitivities, interests and helpful strategies to make the appointment successful.

People may need:

- information on local clinics to reduce travel
- a way to compare appointment options, such as a group booking
- text or email appointment reminders
- help booking their second appointment in advance, or the option to book both appointments at the same time
- reminders to bring their mobile phone, Medicare card and photo identification
- in-home vaccination option
- knowing who the nurse or doctor is in advance
- knowing in advance if they can see the same nurse or doctor for their second vaccination.

Clinic adjustments

There are a number of adjustments that can be made at clinic level to assist autistic patients. Some of these adjustments are around communication, processes and environment.

Communication

Autistic people require clear and direct communication. In a medical setting this is especially important. Amaze has a useful information sheet called '[How to communicate effectively with autistic people](#)'.

Some autistic people may become non-speaking when stressed and begin to shut down. Having a range of visual resources available for people to point to or to write down what they need is useful.

Processes

Ensure that the process of booking an appointment and attending the appointment are clear. This process can be shared with autistic people in a number of ways.

This can include:

- written steps, or checklist if appropriate
- steps presented in pictures
- a social script that describes what to expect through each stage and transition of the appointment. Amaze has produced several [social scripts](#) to support autistic people attending vaccination clinics.

Autistic patients may need to know how many staff members they will meet at the clinic, including security staff and marshals. If possible, meeting one person and having them escort the autistic person through from start to finish can help, particularly at busy vaccination centres.

Some autistic patients will find speaking to numerous new people in one day exhausting, particularly if they are already feeling anxious about their vaccination appointment. Autistic people would benefit from knowing what they need to share and do at every step of the vaccination process.

A good way to support clarity in the process is to offer longer appointment times, and where possible, ensure that the set schedule is adhered to. If the clinic is running over time, it is helpful to let patients know that this is the case and provide them with regular updates about when they can expect to proceed to the next stage.

Environment

Autistic people prefer low arousal environments (also known as 'low sensory environments'), particularly during times of stress, like receiving a vaccination. This means providing a calm environment. Reducing light, noise, odours and any other sensory input, contributes to a low arousal environment. If there is an intense sensory experience in the clinic, let autistic patients know in advance. This will allow autistic patients an opportunity to self-manage and bring coping items.

This may include items like:

- hat/sunglasses
- ear defenders
- fidget items
- phone/tablet to watch videos/listen to music.

Some people may need to rest, so providing a quiet space/room can be helpful. This can assist people to recharge before going into their appointment for their vaccination. If the person becomes distressed, this gives them a safe place to go. If this is not possible, some autistic people may prefer the first or last appointment of the day in order to avoid busy times, or to not feel rushed.

After an autistic patient has received their vaccination, they find waiting challenging. Some people will set a timer in their phone. Some autistic people may need a visual timer to show time. This uses colour and not numbers, to count down. [Time Timers](#) and Plastic Hour Glasses can use useful tools for patients. Some patients may need to wait in a quiet space.

Pre-appointment

Autistic people like routine and to know what is expected of them in new environments. This helps with planning and being able to stay calm.

There are several tools that clinics can develop and implement to assist autistic patients. They may include:

- answering questions and filling out paperwork before the appointment
- a script of personal information that may need to be confirmed at the appointment, such as contact details and Medicare information
- offer familiarisation visits, so autistic people can see the vaccination clinic in advance

- if familiarisation visits are not possible, consider making a video tour of the clinic
- some autistic people experience distress with touch, or the feeling of textures on their skins. This may include antiseptic swabs/Band-Aids

detailed information about finding the clinic and wayfinding from the street or carpark to the front door, presented in clear language and with arrows when relevant.

Providing this information in advance is important. It can also be included as a part of your organisation's accessibility information on their website.

Managing stress and anxiety

Some autistic people may require support to manage extreme stress and anxiety. For some, this may be a formal behaviour support plan (BSP) which their support person may be following. The BSP may contain prevention strategies but also reactive strategies. It is important this is discussed before the person attends the appointment.

There are some general tips that can help manage stress and anxiety:

- Give the person space.
- Minimise speech.
- Don't touch the person.
- Offer some water.
- If the person can walk, guide them to a quiet and private place (this could be outside).
- Give the person time to calm down, don't rush them.
- When the person is feeling calm again, don't overwhelm them again with too much. Visual supports can be helpful.
- Avoid involving security, unless the person is harming themselves or others.

Existing programs and useful resources

[Amaze – Going to the GP about your mental health – A guide for autistic women](#)

This resource contains some good communication checklists, such as how to book an appointment.

[Melbourne Vaccine Education Centre – Needle phobia](#)

This is a helpful resource on needle phobia, including some short-term strategies. There are some tips for supporting autistic people who have a needle phobia.

[My Health Passport \(Queensland\)](#)

This is person-centred health care resource is for people with complex support needs. This resource assists health care staff to prepare and effectively support a person, particularly if they use non-speaking communication methods.

[AASPIRE Healthcare Toolkit for Adults](#)

This toolkit provides written resources on accessing health care. While there is no content about vaccinations (blood tests are mentioned), the information would be beneficial for healthcare workers.

[Autism New Zealand](#)

Autism New Zealand have been promoting autism friendly COVID-19 vaccination clinics. They have developed some good resources on the accessibility of the vaccination, such as:

- low-sensory vaccination clinics
- resources to assist with bookings
- social scripts

St Vincent's Private Hospital

St Vincent's have some excellent examples of patient resources for elective day surgery:

- [Parent information sheet](#)
- [My visit to Hospital — social script](#) – written by Amaze

[National Relay Service](#)

The [National Relay Service](#), a service from the Australian Government is available provides options to communicate with people who have trouble hearing or speaking with people over the phone with the help of a relay office.

Need more advice? Contact Autism Connect.

Contact Autism Connect for more advice on how health professionals can support autistic people getting their COVID-19 vaccination.

Autism Connect is a free, national autism helpline, providing independent and expert information over phone, email and webchat.

Call 1300 308 699 or visit the [Autism Connect website](#) speak to an advisor.

References

- [Australian Commission of Safety and Quality in Health Care — Patient \(Person\) centred healthcare](#)
- [Patient-centred care explained — Better Health Channel Factsheet](#)