

Supporting an Autistic Adult in Medical Advocacy

A Guide for Parents & Care Partners

Why Medical Advocacy Matters

Medical visits can be overwhelming for Autistic individuals due to sensory sensitivities, communication barriers, and systemic challenges. Care partners play a vital role in ensuring healthcare providers respect the Autistic person's needs while supporting their self-advocacy. However, privacy and autonomy are essential—your presence should always be based on their preferences and comfort level.

Encouraging Self-Advocacy at Any Age

Advocacy skills look different for everyone. Some may confidently speak to providers, while others may prefer alternative communication methods. Honor their autonomy and involve them as much as possible.



Ways to Encourage Self-Advocacy

Before the Appointment:

- Ask how they would like you to be involved. Respect their preference.
- Discuss the visit's purpose and what to expect.
- Practice key phrases they may use. (ex., "I need extra time to process").
- Use role-play or social stories to prepare.
- Create a written or visual aid (like an "All About Me" document).

During the Appointment:

- Ensure the provider speaks to them first and allows extra time for responses.
- Respect their communication style. (AAC, writing, gestures).
- Advocate when needed—but avoid speaking over them.
- Request breaks if needed.

After the Appointment:

- Debrief about what went well and what was difficult. Write down follow-up questions. Help request future accommodations if needed.



Preparing for a Medical Visit Together

Use this checklist to help them feel prepared and in control:

- Review the visit's purpose in simple, clear terms.
- Write down concerns, symptoms, or questions in advance.
- Check for sensory accommodations (ex., dim lighting, headphones).
- Bring comfort items (ex., fidget tools, sunglasses).
- Ensure the provider understands their preferred communication methods.
- Encourage providers to direct questions to them first.



Supporting Communication with Healthcare Providers

Many medical professionals are unfamiliar with Autism-specific needs. Bridge the communication gap while ensuring direct provider engagement.

How to Support Without Speaking Over Them:

- Ensure the provider talks to them first. Redirect if necessary: "That's a great question. I'll let them answer first."
- Reinforce their requests by rephrasing or adding details if needed.
- Ensure providers allow extra time for AAC or other nonverbal communications.
- Advocate respectfully if concerns are dismissed; seek a second opinion if necessary.



Knowing Their Rights in Healthcare:

Under the Americans with Disabilities Act (ADA), Autistic individuals have the right to:

- Request accommodations (ex., extra time, sensory supports).
- Use alternative communication methods (AAC devices, writing, pictures).
- Have a support person present - only if they choose.
- Request a provider trained in disability-inclusive care.
- Refuse treatment they are uncomfortable with.



Handling Medical Anxiety & Sensory Overload

Help manage stress by:

- Offering choices (ex., "Would you rather sit in the waiting room or wait outside?").
- Using distractions (ex., headphones, stim toys, podcasts).
- Requesting step-by-step explanations of procedures.
- Ask for breaks during long visits or stressful procedures.
- Recognizing early distress signs and adjusting the visit accordingly.

Supporting an Autistic adult in medical settings is about balance—helping when needed while respecting their independence.

When caregivers and providers work together, medical visits become less stressful, more accessible, and empowering.