

Supporting Patients with High Support Needs



A Guide for Dental Teams, Guardians, and Decision-Makers

About This Tool

This tool is designed to support the dental care of individuals with high support needs, including those with complex multiple disabilities, profound intellectual disability, or significant communication differences who may not be able to express their preferences in ways that are easily understood.

- It is intended for use by both the dental team and those who accompany and advocate for the person receiving care, such as guardians, family members, direct support workers, and supportive decision-makers.

A note on language:

- This tool uses the term "person with high support needs" to be inclusive of a wide range of individuals who require substantial, ongoing support.
- You may also see terms like "complex multiple disabilities" or "profound disability" used in the field. What matters most is that every person, regardless of how they communicate or what support they need, deserves dignified, person-centered dental care.

Centering the Person: Agency and Choice

Everyone has a right to experience a sense of choice, predictability, and dignity at the Dentist office, even when a person cannot communicate in conventional ways.

- Research and the lived experience of families tell us that many behaviors that appear to be "non-compliance" are responses to uncertainty, anxiety, or lack of information.
- Providing clear, consistent cues, and offering meaningful choices within the structure of care, can reduce distress and support cooperation.

What this looks like in practice:

- **Use the person's preferred communication method** (picture symbols, simple objects, gestures, facial expressions) to check in during the visit.
- **Narrate what you are doing, step by step.** This is a helpful approach for people to understand what is happening to them and around them. Use plain language and succinct descriptions whenever possible.
- **Offer opportunities for control** by providing real choices wherever possible: Which side do we start on? Would you like to hold this mirror? Do you want the light on first?
- **Share information** about what to expect, taste, sensation, sound, length of visit, before it happens.
- **Behavior is communication.** Pause. Watch. Check-in. A change in body tension, eye contact, or breathing can communicate a great deal.

For dental teams and support persons accompanying the patient:

You know this person best. Before the appointment, consider sharing with the dental team these questions, or the dental team may ask you:

- What tends to calm or regulate this person (a favorite object, a specific song, weighted pressure, familiar routines)?
- What sensory experiences are especially difficult (bright lights, unexpected touch, noise, certain tastes)?
- How does this person typically show discomfort, distress, or refusal?
- What choices does this person usually have in their daily routine that we could mirror here?

Tip for Support Team:

- As much as possible, review the appointment steps with your family member or the person you support beforehand, even briefly.
- Using pictures, showing them the tools, or visiting the office before the appointment day can make a meaningful difference.
- They will likely understand something, and that something matters.

Protective Stabilization and Other Supportive Techniques

Some individuals with high support needs require physical support or specialized equipment during dental care to receive treatment safely. Your dental team can discuss which approaches are available for each person. Below are some options that may be explored:

Technique	What it is	When it may be used
Weighted or lead apron	A heavy apron placed on the chest and lap during x-rays. Many patients with sensory sensitivities find deep pressure calming.	Standard for all x-rays; can also be offered as a comfort measure throughout the visit for individuals who benefit from deep pressure input.

Medically Supported Options — These options require additional medical coordination and may only be available at specialized clinics or centers.

Technique	What it is	When it may be used
Nitrous oxide (laughing gas)	A mild sedative gas inhaled through a small nose mask that reduces anxiety and increases comfort. The patient remains awake and responsive.	For patients with significant anxiety or difficulty cooperating with care. Discussed and consented to in advance.
Protective stabilization	Gentle, supportive positioning of the patient's body, sometimes using a padded board or wrap (often called a papoose board), to allow care to be provided safely when a person's movement cannot otherwise be managed.	When involuntary movement poses a safety risk, or when it is not otherwise possible to provide necessary dental care. Always discuss with the patient and guardian and then documented.
Oral sedation or IV sedation / general anesthesia	Medications that cause deeper relaxation or unconsciousness, allowing more extensive treatment to be completed in a single visit.	When other approaches are insufficient and the dental needs are significant. Requires medical evaluation, informed consent, and appropriate facility. May be performed at a hospital or surgical center.

Important:

- The goal is always to provide care that is both effective and as comfortable as possible for the person receiving it.
- Decisions about which techniques to use are made collaboratively between the dental team, the patient, and their decision-making team.
- If you have questions or concerns about any of these approaches, please speak with your dental team.

Scenario Guide: Working Together

The following scenarios reflect real situations that come up in dental care for people with high support needs. They are offered as a starting point for conversation, not as rules, and are meant to help both dental patients, dental teams, and support persons navigate difficult moments together.

A note on co-regulation:

- Co-regulation is the process by which a calm, regulated adult helps create the conditions for a dysregulated person to settle.
- In all of these scenarios, everyone in the room who is not the patient should prioritize regulating themselves first, speaking calmly, slowing down, and maintaining steady energy.

SCENARIO 1: *The person becomes very distressed as the appointment begins — crying, resisting, or attempting to leave the chair.*

For the Dental Team

- Pause and reassess. Validate the patient's feelings and concerns. Check in with the support team:
 - Are there suggestions you have for how to best support the patient at this time?
- Ensure the patient they are safe, and work with the support team to find an approach that balances necessity, safety and wellbeing.
- Integrate the tools and tips you learned from the intake paperwork and tools such as *How to Avoid Misunderstandings in Healthcare Conversations*, and *Patient Accessibility Needs Form*.
- In the absence of support information, try the following:
 - Try offering a short break,
 - a preferred sensory item, visuals,
 - or narrating the next step calmly.
- It may be appropriate to stop and reschedule if meaningful care cannot be provided safely that day.

For the Support Team

- Encourage everyone in the environment to remain calm.
- Provide support in assessing what the patients needs are and communicating that to the dental team.
- Directly provide support for the patient
- Support the patient through problem solving and next steps with the dental team.
- Let the team know what usually helps this person de-escalate.
- If you know that waiting and talking makes things worse, share that. You have important information about this person's patterns.
- Always prioritize being an advocate for the patients and ensuring their needs and wants are prioritized.

SCENARIO 2: *The guardian requests that the team 'just get it done' and proceed despite the person's visible distress.*

For the Dental Team

- Affirming fear/ discomfort and acknowledge overall safety for the patient
- Respect the support team and patients perspective, dental care is genuinely important, and delaying care has real consequences.
- Work together to find the least distressing path forward.
- If protective stabilization is used, document it and ensure the guardian has a written record.

For the Support Team

- Your instinct to ensure care gets done is valid. Seeing a loved one in distress is difficult. It is important to self-reflect on how you can guide the person you support through the distress.
- The dental team is your partner in finding an approach that balances necessity and wellbeing. The conversation about how, not just whether, to proceed is an important one.
- Follow-up with the patients broader support team to find tools and resources that can be learned and used in appointments moving forward.

Notes:

SCENARIO 3: *A newly appointed guardian arrives for the appointment with little knowledge of the person's preferences, history, or communication style.*

For the Dental Team

- Welcome them. Offer the person's support file or health passport if available.
- Ask the patient/support team open questions: What do you know about how this person communicates comfort or distress?
- Is there anyone else who knows this person well? Proceed gently and observe carefully.
- Use the *Dental Visit Story Guide*, *Patient Comfort & Communication Checklist*, and *What to Expect at Your Dental Visit*, to develop strategies to have a successful appointment.

For the Support Team

- It is okay to say 'I don't know yet.'
 - The dental team can help you observe and learn.
- If possible, before the appointment, contact the person's prior caregivers, agency, or service coordinator to gather background information.
- Use the opportunity to create some basic strategies for communicating with the patient
 - For example, thumbs up/thumbs down, or sign language for yes and no, ways to create decision-making tools in the moment so the patient has a sense of control over when to consent or stop.

Notes:

Preparation Checklist

Use this checklist to prepare for a dental visit for a person with high support needs.

- ☐ **Review past dental history:** Use My Dental Appointment Reflection to document what worked or didn't work in previous visits.
- ☐ **Complete or update the person's support profile:** Use the Patient Accessibility Needs Form to document updates on Communication style, sensory preferences, calming strategies, triggers.
- ☐ **Preview the appointment with the person:** Using pictures, plain language, a visit to the office, or a social story. Create a safety plan for the meeting (start/stop procedures and how to work through more challenging situations). Use the Dental Visit Story Guide and What to Expect at Your Appointment as starting points.
- ☐ **Identify and bring comfort items:** Use the Patient Accessibility Needs Form to identify a familiar object, fidget tool, weighted item, or preferred music.
- ☐ **Share ALL medical information with the team:** Medications, health conditions, and any changes in behavior or routine.
- ☐ **Confirm and share who will be present at the appointment and their role:** Guardian, direct support worker, family member, and identify who is authorized to consent.
- ☐ **Discuss the plan with the dental team before the appointment begins:** What to expect, what the team will try first, and when to stop if needed. Use the Patient Accessibility Needs Form to guide this conversation.
- ☐ **Complete an end-of-visit action plan:** Who is picking up prescriptions? Who is documenting how the appointment went (what worked, what didn't)? Who is communicating next steps and follow-up dental care to ensure continuity of care?
- ☐ **Document any use of higher-level techniques:** If protective stabilization, sedation, or other higher-level supports were used, ensure this is documented and a written record is provided. This protects the patient and the team if any concerns (e.g., unexplained bruising) arise afterward.

Notes:

Safeguarding and Wellbeing

Dental and medical appointments can sometimes be the primary time a person with high support needs is seen by professionals outside of their home or day program setting. This is an important opportunity to observe and, if necessary, act.

For the dental team:

- Dentists and dental hygienists are mandated reporters. If you observe signs of abuse, neglect, or unexplained injury, you are legally required to report.
- People with disabilities, particularly those who cannot communicate in conventional ways, may not be able to tell someone if they are being harmed. Your observation matters.
- Document any use of higher-level techniques: If protective stabilization, sedation, or other higher-level supports were used, ensure this is documented and a written record is provided. This protects the patient and the team if any concerns (e.g., unexplained bruising) arise afterward.

For guardians and support persons:

- Dental and healthcare professionals are here to support the person's health and safety, including making sure they are safe at home and in the community.
- If you are concerned about the well-being of someone you support, you can reach out to your county's Developmental Disabilities Board, Adult Protective Services, or the Arc of your region for guidance.

Trusted Partners and Further Resources

Organization	How they can help
The Arc	Advocacy and support services for people with intellectual and developmental disabilities and their families. Find your local chapter at thearc.org .
Profound Autism Alliance	Advocacy, resources, and community for individuals with profound autism and those who support them. profoundautismalliance.org
Disability Network / Centers for Independent Living	Local support for people with disabilities across all aspects of life, including healthcare navigation. Find your local center at ilru.org .
County Developmental Disabilities Board	Your county's DD board can connect you to services, funding, and support resources in your area.
Adult Protective Services (APS)	If you are concerned about the safety or wellbeing of an adult with a disability, APS can investigate and connect to services.
Special Olympics Healthy Athletes	Free health screenings and health education for athletes with intellectual disabilities, including dental health. specialolympics.org/our-work/health