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Caregivers of Children with Cerebral Palsy

How to Provide Comfortable Care to: Maya Shusterman

Please read this informational sheet to learn more about interacting with Maya Shusterman and making her feel more at ease during her visits.

I have cerebral palsy. In my particular case this means it is difficult for me to control my muscles particularly in my hands, arms, trunk, and legs. I am not able to stand on my own and rely upon my wheelchair to sit comfortably without assistance.

It makes me feel excited and nervous to visit Dr. Smiley.

There are some things that my body does or is sensitive too that I don't have control over and I would like for you to be aware of:

- 1. I have a strong startle reflex** triggered by fear of noises and anticipation of a noise or something I find threatening. My muscles become very tense.
- 2. When my muscles are stiff please do not force them to move.** You can ask my mom or dad for assistance or ask me to take a few deep breaths to try and relax my muscles.
- 3. When you ask me a question please give me extra time to respond.** I am very in tune with my surroundings and I listen carefully when people speak to me (unless I have asked a question and am waiting for an answer). I do sometimes need extra time to respond.
- 4. I have facial blindness.** Although I may know you very well and have seen you before, **please tell me your name** since I cannot recognize faces.

5. I feel uncomfortable having my head touched.

I worry most about getting shots/needles and suppositories.
Even though I don't complain when I get shots, the anticipation makes me very anxious.

You can help me to relax by letting me know what will be happening during my visit and before you approach me i.e. take my temperature, check my ears, check my reflexes etc. Whenever possible please explain what you are doing and why you are doing it.

Some things I find comforting are when I am able to hold something in my hands. I also love music and I like to play with the latex gloves in the patient rooms.

It's very important to me to have the opportunity to communicate my feelings, ideas, and concerns.

The "Comfortable Care Template" is intended to be used as non-medical educational reference guide that families complete and present to their child's support team. It is intended to encourage greater understanding, comfort and connection between the child and professional.

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