



A Patient and Family Guide to Shared Decision Making

Taking care of special health care needs – for yourself or for a child – is a big job. For many patients and family members, it can feel new and overwhelming. You may feel very alone.

It doesn't have to be that way. Research has shown that the best health care outcomes happen when patients, their family members, and their providers work together to understand a patient's needs, consider what works best for each family situation, and make decisions together about treatment plans. This is called Shared Decision Making.



The Agency for Healthcare Research and Quality created the **SHARE approach** to describe the provider role in Shared Decision Making. A group of parents and family members who have faced challenges dealing with special health care needs have modified the **SHARE approach** to describe the role that patients and families play in Shared Decision Making.

The patients and family members who helped create this document want you to know that you don't need to have all of the answers right now; you just need to know how to find the answers. Shared Decision Making means that health care providers, patients and families work together to choose the best treatment options, based on the provider's knowledge and experience, and the patient's and family's values and preferences. The role of patients and families might be the most important because, in the end, most health care happens at home and in communities.

This guide describes how you can use the **SHARE approach** to improve communication with health care providers and make decisions that are best for you and your family. With Shared Decision Making, you are not alone.

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S

Seek Participation

Tell your provider you want to be involved in making decisions that are best for you and your family.

Introduce yourself to a new provider by telling them what things you like to do and what is important to you. This will help your provider avoid making assumptions about you.



Tips for seeking participation:

- Let your provider know you want to participate in making health care decisions. Say, "I want to work with you on this."
- Share how you prefer to participate: Do you want paper or electronic copies of information? Do you use the patient portal or phone calls when you need advice?
- Tell your provider which family members you would like to include in decision making.
- Before your first appointment, send your provider a document that introduces yourself.



Elizabeth is a dynamic, 21-year-old, patient advocate. At age 9, she received a diagnosis of temporal lobe epilepsy. At age 18, she had a responsive neuro stimulation device implant, with a very positive outcome and significant reduction in her seizure activity.

Elizabeth is very proactive and engaged in managing her health. She developed her own transition plan to move from pediatric to adult care providers and made an appointment with a local Family Practice physician.

At Elizabeth's first visit with her new Family Practice physician, the physician made some unfortunate assumptions. She asked if Elizabeth needed extra help in school, if she had an IEP or other special classes. Elizabeth explained that she was in the Honors program at a very competitive college with dual majors in Biology and Music, on track to enter a graduate program in public health.

Elizabeth felt the physician was questioning her capabilities based on her condition. It was the first time she felt judged by her diagnosis. Her family has always believed that Elizabeth may have epilepsy, but she is not defined by it.

She felt labeled by the physician's assumptions. Being proactive, she completed a patient satisfaction survey and made her point to the health system.

When Elizabeth was diagnosed with a new condition, she decided to find a different primary care physician who will be a partner with her, listen to her, and consider her wants, needs, and priorities. To make sure her visits start off well, Elizabeth helped create the **"Meet Me" document**.

Meet Me

Shared Decision Making relies on mutual trust and understanding. The Patient and Family Advisors to Michigan's Pediatric Epilepsy Project recommend patients and families set the stage for partnership before the first visit by sharing key information with your health care provider. This tool can be used with pediatric or adult patients.

All about me

My school or work:

I feel most confident about:

I'm really proud of:

My goals for the future:



Place your photo here

My Health

Type(s) of seizures I have:

How long I have had seizures:



Scan code for Meet Me document



Help to Compare Treatment Options

Many health care decisions have multiple treatment options, including the option of no treatment. Often there is no single option that is clearly better than the others.

Ask your provider to explain the pros and cons of each treatment option, including what information is unknown and what would happen with no treatment.

Repeat back to your provider what you heard about each treatment option, and ask if what you heard is correct.



Tips to help compare treatment options:

- Ask for information in plain language.
- Keep a running list of questions. Ask as many questions as needed for you to feel like you fully understand the options.
- Ask your provider, “What evidence do you have that this treatment will help?”
- Ask if there are visual aids or decision tools to help compare the options.



A

Assess Your Values and Preferences

Take time to think about what matters most to you: Keeping pain under control? Being able to participate in a favorite activity or attend an upcoming event?

Be honest about what will work for your family. Are family members willing and able to carry out the treatment? Will medical equipment fit in the family home and vehicle? How will treatment options affect the day-to-day life of family members?

Consider how each treatment option best matches your ability and what you prefer. Create a checklist to help identify which option comes closest to what you prefer.



Tips for assessing values and preferences:

- Be honest with your provider about what matters most to you in choosing the best treatment option.
- Be open about what can and cannot work in your family or home.
- Check with your insurance plan about possible out-of-pocket costs.
- If needed, check with school officials to make sure they are able to give medication or carry out other aspects of treatment.

Think about aspects of day-to-day life that may be hard, such as childcare, shared custody, physical space at home and school, and parent work schedules.

Elysianna was born with a syndrome that challenges several body systems. As an infant, she had many hospitalizations, surgeries, and medical appointments. Through all of this, her family tried to keep as much balance in her life as possible and worked hard to give her opportunities that other girls her age enjoyed.

When they enrolled her in a dance class, Elysianna loved being able to dance, and her parents were thrilled to see her having so much fun. Dance was also great for her movement and coordination.

When Elysianna's providers recommended more intensive speech therapy which was not covered by her insurance, the family had to think about what was most important: paying for dance classes or paying for the extra therapy. They asked for help, and the dance studio found a scholarship which allowed Elysianna to do both.



R

Reach a Decision

Colin was diagnosed with epilepsy at age 9. He had multiple, varied seizures every day. Over the course of one year and many tests, he finally was diagnosed with Lennox-Gastaut Syndrome.

Colin's drop seizures were frequent and dangerous. His parents consulted many doctors in multiple states trying to find the right answers for Colin. Many of the recommendations were difficult to hear, and Colin's parents faced tough, personal decisions in trying to identify the best treatment options.

Colin has had several surgeries, including a complete corpus callosotomy. The success rate for this surgery is typically 85%. Colin's parents had to weigh the chance of success with the risks of the surgery.

The surgery did not eliminate Colin's seizures, but they did slow them down. Colin continues to have daily seizures. He will never be seizure free, and his parents will continue to make health care decisions for him based not on a cure, but on his quality of life.

Colin's parents enjoy a good relationship with his medical team. They are always able to come to an agreement on the best course of action and appreciate that they can be on the same page when it comes to what is best for Colin.

Find out the timeframe for making a decision. If possible, talk over your decision with trusted family and friends.

Decide together on the treatment option that best meets your values and what you prefer.

Confirm your decision with your provider. Explain what you hope to gain from this treatment and why you think it's the best option. Ask your provider if what you understand is correct.



Tips for reaching a decision:

- Remember that patients and families have an important role in decision making. A recommendation is just that.
- Ask for extra educational materials or decision tools.
- Remind yourself that choices can be tough. Be open about your goals: Are you hoping for better quality of life or removing a problem?
- Ask your provider what happens next: When will treatment begin? How long until benefits are seen? What is the timeframe for follow-up visits?



E

Evaluate Your Decision

Agree on a “trial period” to see the impact of your treatment decision; at the end of that trial period, talk with your provider about whether to continue with that treatment option.

Take notes on how well the treatment is working, including both medical and quality-of-life factors. Share this information with your provider at follow-up visits.

Let your provider know if you have any problems with implementing your treatment decision.



Tips for evaluating the decision:

- Ask about resources to support your treatment choices. Resources could include scholarships for activities, referrals to community agencies, mental health support, or connections to other families facing similar challenges.
- Remember that mutual trust between patients, parents, and providers is the basis of a good working relationship. Be honest with your provider about what is and is not working.
- In many cases, particularly for the management of a chronic illness, treatment decisions can and should be revisited after a trial period.



Consider factors that might change a treatment decision:

- School year vs. summer vacation
- Social or educational situations
- Unexpected side effects
- Family circumstances



Contact:
Family Center: 517-241-7630
CSHCS Family Phone Line: 800-359-3722
Email: cshcsfc@michigan.gov

**Scan for
website:**



<https://www.michigan.gov/mdhhs/assistance-programs/cshcs/the-family-center-for-children-and-youth-with-special-health-care-needs-family-center>



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