

MODULE PARENTS

ACTIVITY 4. SHARED-DECISION MAKING

- **TIME:** Periodically.
- **RESOURCES:** Shared decision making methodology.
- **LANGUAGES:** ENG / SPA.

DESCRIPTION:

Stress, uncertainty or lack of sleep can generate tensions in the family environment. There are some methodologies that allow us to manage such situations. In this activity we propose a series of techniques that can help you when making complex decisions for the benefit of your child.

OBJECTIVES:

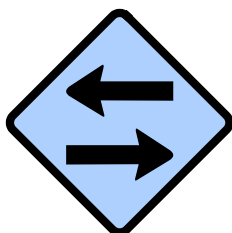
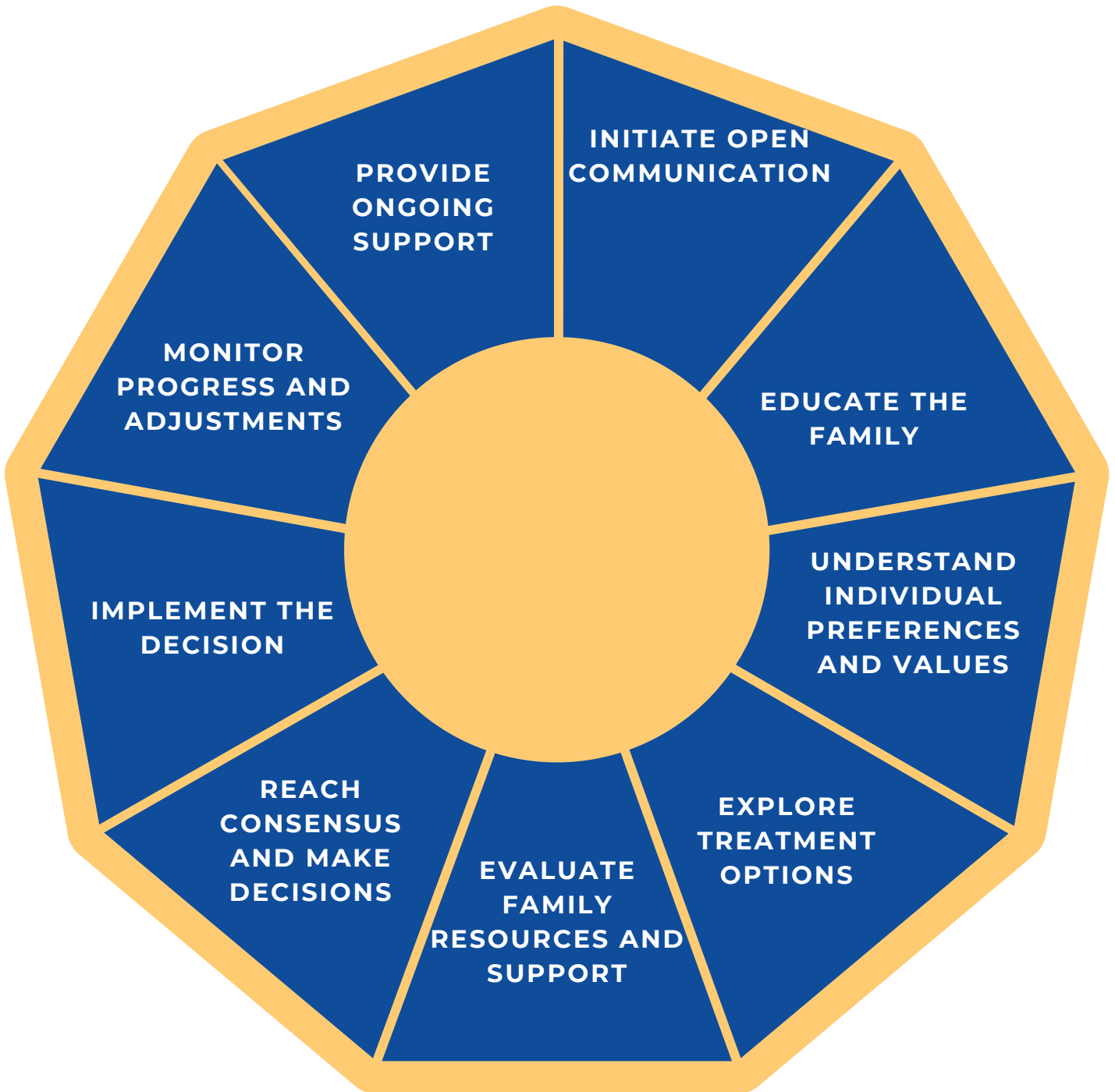
- Create an atmosphere of mutual trust and respect.
- Help parents feel confident and foster team-work.
- Respond to families' concerns about decision-making and fear of regret.

LESSON OVERVIEW:

To implement this type of methodology in your routine, gather all family members involved in the decision-making process, including the individual affected by the rare disease, caregivers, and other relevant stakeholders. Encourage open dialogue and active participation from all family members. Consider each family member's perspective and input when discussing and evaluating treatment options.

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Everyone has opportunities to give and receive information and to honestly and respectfully discuss their thoughts and feelings

INITIATE OPEN COMMUNICATION:

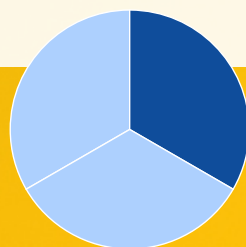
- Start by fostering an environment of open communication within the family.
- Encourage all family members to express their thoughts, concerns, and perspectives regarding the rare disease.
- Create a safe space where everyone feels comfortable sharing their feelings and opinions.

EDUCATE THE FAMILY:

- Provide comprehensive education about the rare disease, including its symptoms, causes, prognosis, and available treatment options.
- Help family members understand the impact of the disease on their loved one's life and the family as a whole.
- Offer resources, such as informational materials, websites, or support groups, to help family members learn more about the disease.

UNDERSTAND INDIVIDUAL PREFERENCES AND VALUES:

- Take the time to understand the preferences, values, and goals of the individual affected by the rare disease.
- Encourage family members to consider the individual's wishes and desires when making decisions about their care and treatment.
- Respect the autonomy of the individual and involve them in the decision-making process to the extent possible.



EXPLORE TREATMENT OPTIONS:

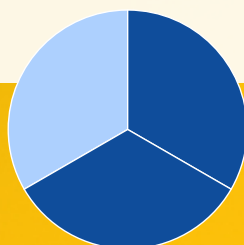
- Discuss the available treatment options for the rare disease, including medical interventions, therapies, and supportive care.
- Consider the potential benefits, risks, and outcomes associated with each treatment option.
- Seek input from healthcare professionals, such as doctors and specialists, to ensure informed decision-making.

EVALUATE FAMILY RESOURCES AND SUPPORT:

- Assess the family's resources, including financial, emotional, and logistical support, available to manage the rare disease.
- Identify potential challenges and barriers that may affect the family's ability to support their loved one's care and treatment.
- Explore available support services, such as counseling, respite care, or community resources, to help alleviate these challenges.

REACH CONSENSUS AND MAKE DECISIONS:

- Work together as a family to reach a consensus on the best course of action for managing the rare disease.
- Take into account the preferences, values, and needs of the individual affected by the disease, as well as the collective agreement of the family.
- Document the decisions made and the rationale behind them to ensure clarity and accountability.



IMPLEMENT THE DECISION:

- Develop a plan of action based on the decisions made, outlining the steps to be taken to manage the rare disease effectively.
- Assign responsibilities to family members and other stakeholders to ensure the smooth implementation of the plan.
- Coordinate with healthcare providers and other relevant professionals to initiate the chosen treatment approach.

MONITOR PROGRESS AND ADJUSTMENTS:

- Regularly monitor the individual's progress and response to treatment.
- Stay in communication with healthcare providers to address any concerns or changes in the individual's condition.
- Be prepared to make adjustments to the treatment plan as needed based on new information or evolving circumstances.

PROVIDE ONGOING SUPPORT:

- Offer continuous support and encouragement to the individual affected by the rare disease and other family members involved in their care.
- Maintain open communication within the family to address any challenges or concerns that arise during the course of treatment.
- Seek additional support from healthcare professionals, support groups, or other resources as needed to navigate the complexities of managing a rare disease within the family.

