

Navigating rare obesity care conversations

A doctor discussion guide for parents and caregivers of children living with rare obesity.

1 How is your child feeling physically and emotionally?

Have you noticed any changes in your child's appetite, energy levels, mood, or daily routines? Check any areas you want to discuss with the care team:

- | | |
|---|---|
| ☐ Constant hunger or distress around food | ☐ Challenges at school or with social interactions |
| ☐ Rapid weight gain or changes in growth patterns | ☐ Difficulty participating in physical activity |
| ☐ Trouble sleeping or daytime fatigue | ☐ Concerns about independence or daily functioning |
| ☐ Emotional or behavioral changes (anxiety, frustration, withdrawal) | |
| ☐ Other _____ | |

Note any specific examples or concerns here:

2 How are they adjusting to treatments and routines?

Track how your child is responding to medications, nutrition plans, therapies, or lifestyle supports. Use it to note successes, side effects, or ongoing challenges.

Things to observe

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|--|---|
| ☐ Changes in appetite, eating behaviors, or food-related distress | ☐ Side effects from medications or treatments |
| ☐ Energy levels throughout the day | ☐ School, social, or family challenges connected to rare obesity |
| ☐ Sleep quality or nighttime waking | ☐ Benefits noticed (improved mood, stable routines, more activity) |
| ☐ Emotional responses related to food restrictions or routines | ☐ Challenges keeping up with appointments, therapies, or care plan |

Questions to ask your child's doctor

- Are the symptoms we're seeing expected or concerning?
- How can we better support hunger management and emotional well-being?
- Are there additional specialists or support services we should consider?
- What signs should we monitor between visits?
- Are there school or community accommodations that may help?

Notes:

3 Supporting daily life and independence

Use this space to discuss the routines, accommodations, and supports that help your child feel safe, included, and successful in daily life.

Consider discussing

- How does hunger affect your child's daily routines, emotions, or participation in activities?
- What environments or routines help your child feel more comfortable and confident?
- Are there situations where your child feels isolated, misunderstood, or unsupported?
- Are there school, home, or community supports that could improve their quality of life?

Note any specific examples or concerns here:

Supports or accommodations to explore with the care team

- | | |
|---|--|
| ☐ Nutrition or behavioral counseling | ☐ Mental health support or therapy |
| ☐ School accommodations or 504 planning | ☐ Support groups or peer communities |
| ☐ Physical activity programs adapted to your child's needs | ☐ Sleep evaluations or support services |
| ☐ Family counseling or caregiver support resources | |
| ☐ Other _____ | |

4 Other notes

Use this space to jot down questions, observations, or concerns you want to remember for your next appointment.
