

Long-Term Residential Living



Planning for future living arrangements for your loved one with rare epilepsy can be challenging. During the process of evaluating your loved one's needs, some families may consider long-term residential care. With this option comes many questions and details to sort through. The following information can help guide you in asking questions to obtain the information you need to make an informed decision on the type of facility that can best support your vision for the long-term care plan that reflects your future wishes while addressing the needs of your loved one with rare epilepsy. Even if residential living arrangements are not the first choice for your loved one, investigating what options are available may be helpful if future care situations change.

Print and bring this list with you when you visit potential facilities. Space is provided to allow you to capture the information you gather from each facility you may research or visit. Also included is additional space to add your own questions unique to the individual needs of your child. You can use this document as a guide to refer back to later as you consider what options best align with your vision of future long-term care for your loved one with rare epilepsy.^{2,3}

Researching & Touring Facilities for Long-Term Care: Questions & Worksheet/Checklist

Name of Facility Being Evaluated: _____

GENERAL QUESTIONS FOR CAREGIVERS

1. Do you have an advocate that can help you with transition to adult services and benefits that may be available?

☐ YES ☐ NO

Details: _____

2. Is there a day or work program near your residence?

☐ YES ☐ NO

Details: _____

3. Is there medical support close by?

☐ YES ☐ NO

Details: _____

4. How close is the facility to where the family lives?

Number of miles: _____

5. Are staff making eye contact with you, smiling, speaking kindly to the residents—do staff look happy?

Observations: _____

FACILITY CONSIDERATIONS

6. Is the home co-ed?

☐ YES ☐ NO

Details:

7. How is communication between the staff and family handled? How do I keep up with what is going on in my loved one's life?

Details:

8. What level of support do the other residents require?

Details:

9. What kind of activities are offered?

Details:

10. What are the recommendations for transitioning to the home?

Details:

11. What is the staff's experience with rare epilepsy? With developmental delay?

Details:

12. What is the facility's protocol in the event of an emergency? (for example, earthquakes, fires, tornadoes, etc.)

Details:

STAFFING CONSIDERATIONS

13. Is there a place where I can find data about the facility? Ratings, staff retention, previous complaints?

Details:

14. What is staff-to-resident ratio? Does this number change on weekends and holidays? ☐ YES ☐ NO

Details:

15. What is the staff turnover rate? Are you fully staffed or are there openings?

Details:

16. Describe staff training, as well as any ongoing training that they receive.

Details:

TIP: This [website](#) offers ideas for Direct Support Professionals (DSP) training. Some of the trainings to look for in the staff may include CPR, basic first aid, basic nutrition, seizure disorders, safe lifting for DSPs.

17. Are there cameras and/or seizure monitors? If so, how are they monitored/documented?

☐ YES ☐ NO

Details:

18. How would the night staff monitor nocturnal seizures?

Details:

19. Who supervises the staff? Do you have any input in the staff evaluations? Hiring?

Details:

VISITATION CONSIDERATIONS

20. Are there any restrictions on visitation?

☐ YES ☐ NO

Details:

21. Is there an open-door policy for family?

☐ YES ☐ NO

Details:

MEDICAL & ACCESSIBILITY CONSIDERATIONS

22. Do they have a nurse or other medical personnel on staff?

☐ YES ☐ NO

Details:

23. How are medications handled? Where are the medications stored? Is it in a locked cabinet?

Details:

24. How do they handle safety with eating, drinking, locking doors, danger, burns, fires, etc.?

Details:

25. How are meals and meal planning handled? Ask for sample menu. Do they have a nutritionist on staff? ☐ YES ☐ NO

Details:

26. What are the accessibility options in the facility for mobility, bathing, etc.?

Details:

27. Can your loved one get up and go to bed as she/he wishes? Or is there a bedtime and wake up time that is set?

☐ YES ☐ NO

Details:

28. Can your loved one have electronic devices like iPads?

☐ YES ☐ NO

Details:

29. How are challenging behaviors handled? Do they have a behavior specialist available to consult on challenging behaviors?

Details:

30. Are physical restraints ever used? If so, when?

Details:

31. What is in place for fall prevention and to reduce the chance of injury when falls happen?

Details:

32. What is the condition of beds/floor mats, etc?

Observations:

FINANCIAL CONSIDERATIONS

33. How will the money be handled? Cash, debit card?

Details:

34. Can you pay the room and board, or do they require that the agency be the representative payee?

☐ YES ☐ NO

Details:

HYGIENE CONSIDERATIONS

35. Will they shave residents when needed?

☐ YES ☐ NO

Details:

36. Do they bathe and wash residents daily?

☐ YES ☐ NO

Details:

37. How often do they brush residents' teeth?

Details:

38. Do they have standards of care that they follow?

☐ YES ☐ NO

Details:

ADDITIONAL OBSERVATIONS

39. Are there younger residents?

☐ YES ☐ NO

Details:

40. What are residents doing?

Details:

41. Do residents look happy?

☐ YES ☐ NO

Details:

42. Does the food look and smell appetizing?

☐ YES ☐ NO

Details:

43. How is transportation handled? Does the home have its own van/car?

Details:

44. Do they have someone on staff who is able to accompany your loved one to doctor appointments? ☐ YES ☐ NO

If so, will they ensure this person brings with them any appropriate information/documentation required for a successful appointment?

☐ YES ☐ NO

ADDITIONAL QUESTIONS UNIQUE TO MY LOVED ONE WITH RARE EPILEPSY

45.

Details:

46.

Details:

47.

Details:

48.

Details:

49.

Details:

50.

Details:

51.

Details:

52.

Details:

53.

Details:

54.

Details:

55.

Details: