

The experiences of parents of children diagnosed with cerebral adrenoleukodystrophy

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The psychosocial impact on parents of having a child diagnosed with cerebral ALD

Interview topic guide.

1. Introductions and ground rules

Check connectivity, time available, privacy, pseudonym etc.

Review PIS and take informed consent (recorded – take consent, stop recording and then restart for the interview).

2. Can you tell me about your family...
Can you tell me how you came to know that you had a child with cerebral ALD?
 - a. Family background and structure
 - b. Children
 - c. Affected child (ren)
 - d. Early signs of disease
 - e. Route to diagnosis
 - f. Initial responses to the rare diagnosis
 - g. what helped you to understand the condition early on
3. Can you tell me about the day-to-day realities of caring for xxxx?
 - a. Physical aspects
 - b. Psychological effects
 - c. Social aspects
 - d. Engagement with health and social care services
 - e. Treatment and care
 - f. Impact on you and your family?
1. What about support – where did that come from?
 - a. Formal support sources
 - i. How did you find out what support was available?
 - ii. Role and function and scope of support accessed
 - iii. Accessibility
 - iv. Usefulness
 - v. Unmet need - What else would have helped?
 - b. Informal support sources
 - i. Role and function and scope
 - ii. Ease of access
 - iii. Usefulness
 - iv. Would anything else help?
4. What has the genetic aspects of ALD meant for your family (immediate and wider family members)?
 - a. Options and decisions around testing
 - b. Involvement of genetic counselling services
 - c. Communications and information sharing within the family.
 - d. Difficulties and areas of uncertainty related to testing options
 - e. Thoughts on newborn screening
5. Anything else you would like to share with us?

Thanks and check understanding about next steps with the project.

Would you like to choose a pseudonym?