

## **The experiences of parents of children diagnosed with cerebral adrenoleukodystrophy**

PIERCY, Hilary and NUTTING, Charlotte

Available from Sheffield Hallam University Research Archive (SHURA) at:

<https://shura.shu.ac.uk/32572/>

---

This document is the Supplemental Material

### **Citation:**

PIERCY, Hilary and NUTTING, Charlotte (2023). The experiences of parents of children diagnosed with cerebral adrenoleukodystrophy. *Child: Care, Health and Development*. [Article]

---

### **Copyright and re-use policy**

See <http://shura.shu.ac.uk/information.html>

# 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?