

Case Study

Emergency Homecare
Provision for a Child with
Adrenoleukodystrophy (ALD)



Inspected and rated

Good



Snapshot

- Child A has ALD, a rare degenerative neurological condition
- Requires full respiratory, mobility, seizure and PEG support
- NLG began crisis intervention in June 2023 and now provides 172 hours of care per week

“Caring for a child with ALD takes consistency, compassion, and clinical skill, and that’s exactly what we bring to every shift.”

— NLG Paediatric Care Worker ”

Case Introduction

Child A lives at home with their family and has a diagnosis of ALD, a rare and progressive condition that affects the myelin sheath of nerve cells in the brain.

As a result, the child experiences significant neurological decline, including loss of mobility, communication, and swallowing function.

After two previous care providers were unable to maintain consistent staffing, NLG was approached to deliver immediate support in June 2023.



Challenge: Service User Needs

- The child requires complex respiratory care, including airway management, PEG care, and occasional nasopharyngeal suction
- Regular episodes of dystonia and seizures require carer oversight, including administration of rescue medication when needed
- The child is doubly incontinent and fully dependent on carers for bathroom assistance, mobility and postural management
- Previous care packages failed due to staffing shortages and lack of continuity in support
- Communication and social interaction are limited due to neurological decline, requiring attentive and emotionally supportive care

Solution: NLG Intervention

- NLG provided emergency care from June 2023, delivering 30 hours per week to cover urgent needs
- Worked with the commissioning authority to reassess and review Child A's ongoing care needs
- Designed a full care plan based on clinical input, expanding to 172 hours weekly by August 2023
- Deployed a skilled paediatric team trained in PEG, seizure, respiratory and neurological care
- Maintains close collaboration with family and health teams to ensure consistent, compassionate care

“NLG has brought reassurance and routine into our home, they really understand our child's needs.”

— Parent of Child A



NLG is a key provider of complex home care in Yorkshire and N.E. Lincolnshire.

Ability to support people with complex needs

“NLG generally manage their care packages very well. They have taken a client that I previously had placed with another agency that was having a lot of issues fulfilling the package requirement. NLG took over and there has been no issue with them.”

— Anita Broadwell, CHC Senior Clinician, East Riding of Yorkshire CCG

“For the more complex service users, NLG is the main provider we use in this area.”

— Diane Murray, Home Ventilation Service Lead, Hull University Teaching Hospitals NHS Trust

NLG's local reputation

“We have a good working relationship with NLG. Whenever we need to raise any issues, they are dealt with efficiently and are easily managed.”

— Hull CCG

“I have worked with NLG in both North Lincolnshire and East Riding. They are good at managing their packages, and we don't get contacted with issues.”

— East Riding CCG

Staff are well trained

“We often use NLG when our packages are in crisis; NLG will stabilise the packages and return them to order. NLG definitely provide well trained staff.”

— Head of NHS Funded Care, North Lincolnshire CCG

“NLG is a 'go to' provider for us when we need to get complex service users out of hospital quickly and into specialist packages of care.”

— Jeanette Johnson Ross, Brokerage Officer, Hull City Council

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