



## Trainee & Program Details

### Training Program

Neurology (Paediatrics & Child Health) – Advanced Training

### Training Program Phase \*

Specialty Foundation Phase

### Date of Learning\*

28/05/2026

## Learning Capture Details

### Type of Learning \*

Clinical experiences

### Title\*

Coordinating longitudinal care for a child with Duchenne muscular dystrophy

### Select the primary learning goal \*

8: Longitudinal care

## Learning Capture Details

### Description of Activity \*

I participated in the ongoing management of a 9-year-old boy diagnosed with Duchenne muscular dystrophy. This involved reviewing his progress during a scheduled follow-up clinic, assessing functional decline, and coordinating multidisciplinary input from physiotherapy, respiratory medicine, and social work. I also discussed anticipatory guidance with the family regarding future interventions, including cardiac monitoring and transition planning to adolescent services.

### What did you learn? \*

I learned the complexity of providing longitudinal care for children with progressive neurological conditions. This experience highlighted the importance of continuity, proactive planning, and maintaining strong communication across multiple specialties. I gained insight into how regular monitoring and early intervention can significantly impact quality of life and functional outcomes. Additionally, I understood the emotional and psychosocial challenges families face over time, as well as the need for consistent support and clear expectations.

### How will you apply this learning in the future? \*

In future practice, I will ensure that longitudinal care plans are structured, documented, and communicated effectively to all team members. I plan to use care coordination tools and family-centered approaches to anticipate needs and avoid fragmented care. I will also incorporate regular goal-setting with families and provide education about disease progression and available resources. Furthermore, I aim to strengthen collaboration with allied health professionals and community services to deliver holistic, continuous care throughout the child's development stages.

## Assessor Feedback (optional)

### Feedback From \*

Dr John Winchester

### Assessor Role \*

Consultant Paediatric Neurologist

### Personal Message

Dear Dr Winchester, I've uploaded my reflection on the longitudinal care of a child with Duchenne muscular dystrophy.

### Feedback Requested Date

02/06/2026

### Feedback \*

Amara demonstrated a strong understanding of the principles of continuity and proactive planning in the management of chronic neurological conditions. Your approach to involving multidisciplinary teams and providing anticipatory guidance was excellent. For future improvement, consider formalising care plans using structured templates and ensuring clear documentation of transition planning for adolescent services.

Overall, this was a well-managed case, and your reflection shows maturity in recognising the psychosocial aspects of long-term care. Keep building on these skills by leading more follow-up clinics and engaging with community resources.