

Emergency Information Card

For Parents of Boys and rare Girls with Duchenne



LEG FRACTURE TREATMENT:

- If your child was able to walk well before their leg fracture, ask the doctor: “Can my child have surgery (internal fixation) rather than casting external fixation)?” Surgery should help preserve muscle and allow your child to walk sooner than casting.
- If your child is breathing rapidly and/or if they have neurological deterioration (like confusion) after a fracture or body trauma, doctors should consider **fat embolism syndrome**.

RECOMENDATIONS AND PRECAUTIONS:

- Keep all of your child’s immunisations up to date.
- Do not use live vaccines if your child is taking corticosteroids.
- Always wear seat belts!

ANAESTHETIC PRECAUTIONS:

- All general anaesthetics should be given by intravenous route (IV) only. Do not allow the use of inhaled anaesthetics.
- Local anaesthetics and Nitrous Oxide are safe for minor dental procedures.

IF YOUR CHILD IS VOMITING AND/OR UNABLE TO TAKE CORTICOSTEROIDS FOR 24 HOURS:

- Take them to a hospital emergency department.
- Tell staff that they need a substitute corticosteroid by IV until able to take their pills by mouth again. This will help avoid adrenal crisis. Show hospital staff this conversion:
6 mg of deflazacort equals 5 mg of prednisone.
- Remind hospital staff: “If my child has blood tests, AST/ALT (liver enzymes) will be high. That is normal for boys and rare girls with Duchenne.”

RESPIRATORY CARE:

Risk: Respiratory failure.

- **Do not give oxygen** without checking end-tidal or blood CO₂ level. A low haemoglobin saturation may indicate CO₂ retention and a need for positive pressure ventilation. IF supplemental oxygen is given, please monitor CO₂. Non-invasive ventilation may be required.
- Assisted coughing helps to clear sputum & mucus plugs. Use the Cough Assist machine if available. If not available, an AMBU bag may be used.

CHILD’S MAIN DOCTOR / PHONE NUMBER



With thanks to

**Parent Project
Muscular Dystrophy**
LEADING THE FIGHT TO END DUCHENNE