Individual management plan

Patient: **Address:** **GP details:**

Should be seen by a middle-grade doctor or consultant if possible

Mechanism for admission

Within hours: Contact GP will contact the GP admissions centre: 8am–8pm
Weekends: Via acute medical unit (AMU) coordinator: bleep XXXX
Out of hours/acutely unwell: Emergency services

Location of individualised care plans: electronic patient-reported outcome (EPRO), patient administration system (PAS) alert (second PAS screen) or Oceano (it will differ between organisations); GP; parents; AMU folder; responsible consultants: Dr A, Dr B, Dr C (Ward A)

Ideal placement:
Side room with space for resident parent/carer.
Consider direct admission to be Ward A if clinical situation is stable.
Discuss with AMU consultant on call.

Diagnoses

1 cerebral palsy with four limb involvement
2 focal epilepsy with secondary generalisation
3 gastro-oesophageal reflux with gastrojejunostomy
4 renal and bladder calculi
5 ileostomy
6 central line *in situ* for emergency use.

Current medication

- lamotrigine 100 mg twice daily
- levetiracetam 1,500 mg twice daily
- midazolam PRN (home protocol: 10 mg after 2.5 minutes, further 10 mg after further 2.5 minutes – call paramedics)
- clobazam 10 mg, use as required (for increasingly severe absence seizures)
- diazepam 10 mg twice daily
- lansoprazole 30 mg twice daily
- baclofen 20 mg twice daily
- oxybutynin 10 mg once daily.

Likely causes for admission

1 seizures
2 gastrointestinal (GI) failure – abdominal pain/oesophageal spasm/not tolerating feeds
3 feeding tube issues – tube blocked or out
4 urinary tract infection (UTI).

Resuscitation status

Due to excellent quality of life, is for **full escalation including intubation and ventilation**: should be discussed at consultant-to-consultant level.

Medical management

Problem – tonic clonic seizures in hospital:

- Give oxygen, ensure safe, call a doctor.
- If not self terminating after 5 minutes, give 2 mg IV lorazepam or buccal midazolam – Buccolam 10 mg/2 ml.
- Repeat after 3 minutes. Escalate as required.

Search for possible precipitants.

Consider: (1) UTI (2) chest infection (3) pain

Investigations: full blood count (FBC), urea and electrolytes (U&Es), C-reactive protein (CRP), liver function test (LFT), blood cultures, chest X-ray (CXR) / abdominal X-ray (AXR), urine dip / midstream specimen of urine (MSU)

Full physical examination

Problem – feeding tube issues, within hours:

- Patient has balloon held fluoroscopy placed 16 fg gastrojejunal tube (G-tube).
- If the balloon fails and the tube falls out, tract can close within hours.
- Patient's mum will contact the nutrition nurses on Ext YYYY.
- Nutrition nurse will see the patient in the nutrition nurse led clinic.

Problem – feeding tube issues, out of hours:

- May present with a 16 fg G-tube in the tract, patient's mum able to place. **Do not use for feeding**, due to risk of aspiration.
- If mum unable to place 16 fg G-tube, try to salvage tract.
- Insert Ryles tube 16 fg, ideally salvage the tract.
- A smaller gauge can be used if 16 fg is hard to pass.
- Contact nutrition nurses to organise tube replacement.
- Consider IV fluids. Able to tolerate small amounts of oral fluid but unlikely to meet needs.

Problem – vomiting

- Enteral feed present in vomit? Tail of the G-tube may be malplaced in the stomach. **Do not use for feeding**, due to risk of aspiration.
- Liaise with radiology: contrast the jejunal port on the G-tube to confirm the position of the tail. Ask if they can reposition the tail of the tube. If not, a new tube will be required.

- Contact the nutrition nurses to organise tube replacement.
- Consider IV fluids.

Feeding regime:
On overnight feed for 11 hours through percutaneous endoscopic gastrostomy (PEG) rate 75 ml/hr
Elemental 028 Extra
Lactose- and dairy-free diet in the day, 'little and often'.

Fluids
Needs encouragement – 400 ml daily cooled boiled water.

If admitted to a hospital ward, please inform nutrition nurses: wards will be unfamiliar with the feeding tube.

Home environment, transition issues and general information

- keen supporter of Manchester City Football Club
- formalised package of care via NHS continuing healthcare agreements
- regular respite in place: Apple Tree House, West Sussex
- lives at home with parents and younger sister
- attends college, on a bridging course, will stay at college until the age of 25
- attends day services, 3 days a week.

Multidisciplinary team (MDT) involvement

- Mr and Mrs C (mother and step-father)
- Dr A: rehabilitation consultant — Mobile via switchboard or Ext YYYY
- Dr B: consultant neurologist — Mobile via switchboard or Ext YYYY
- Dr C: consultant physician — Mobile via switchboard or Ext YYYY
- Dr D: chief of service ED — Mobile via switchboard or Ext YYYY
- Miss E: consultant urologist — Mobile via switchboard or Ext YYYY
- Learning disability liaison — Bleep 0000
- Mr F: epilepsy nurse specialist (adult) — Mobile via switchboard or Ext YYYY
- Miss G: clinical nutrition nurse specialist (adult) — Ext YYYY

DATE: