

Matthew Wardle (date of birth)

Family Mum –, Dad – Jol, Brother (identical twin) Jack

History – twin 1. Born 27 weeks gestation (twin to twin transfusion – Matthew was recipient twin). Quadriplegic cerebral palsy, gastrostomy (no fundus), registered blind (some vision – can see bright colours, faces, movement. Sees better in upper field so hold things above him).

Epilepsy – mainly absences (few seconds to 1 minute in duration, more common when tired) does a big blink and grin when comes out of them. Not action needed. Very occasional tonic/clonic seizures. As these are so rare (4 in lifetime) epistatus given as soon as possible. Have all occurred when ill. Both hips now subluxed.

Medication (all given via tube – bolus delivery. Meds squirted into 60mls syringe with water)

Before breakfast – 1 zoton fast tab (15mg)

5mls sodium valproate (Orlept) (200mg/5ml)

6mls baclofen (squirt in slowly or settles at bottom syringe) (5mg/5ml)

1 capsule gabapentin (opened and granules sprinkled into water given via tube) (100mg)

1 tablet glycopyrrulate bromide (robinul) dissolved in small amount of warm water

2pm – 6mls baclofen

1 capsule gabapentin

1 tablet glycopyrrulate bromide (robinul) dissolved in small amount of warm water

6pm - 10mls baclofen

5mls chloral hydrate (145/5mg) can have additional 5ml if wakes in night – 2mls is normally adequate to get him back to sleep

5mls sodium valproate

1 capsule gabapentin

2.5mls codeine (15mg/5ml) if necessary for hip pain – very unsettled, right leg very tight and is pulled across to left, calf muscles also feel tight. One dose normally adequate for whole day.

Midazolam (epistatus) 0.5ml (buccally) in the (rare) event of seizure

Mickey button. 7ml saline. Checked Tuesdays

No allergies but sensitive skin. Use Antifungal/mild steroid cream if face/stoma flair up.

Food : Needs to be pureed. Weetabix with warm milk and sugar for breakfast. Eats most things enjoys lamb casserole, fish fingers, petit filou yoghurts and white chocolate (mind your fingers he has a strong bite reflex!) Tilt chair back (pedal on foot bar at back). Sees food coming from above and to his left best. Tell Matthew food is coming and say 'big mouth' to get him to open his mouth. Head sometimes flops so say 'head up!' Not very good at eating for unfamiliar people. If not eating very well try feeding on your lap. Otherwise 200ml bottle of Nutrini Energy Extra with fibre. Does not tolerate this very well (ie brings it back very easily) so give slowly or via pump.

N.B. Needs plenty of winding after liquids

150mls water (via tube) mid morning/afternoon.

150mls water with meds ie after meals (before breakfast)

Tendency to be constipated. 4mls syrup of figs given if no bowel movement for 3 days or if appears distressed when straining. If still no bowel movement 2g glycerol suppository given. Less of a problem now gabapentin is helping with hip pain so codeine not needed as often.

Chair: Panther by R82. Tilt in space – central pedal on foot bar at back. Recline – pull up on loop just above rucksack, needs pulling twice as on ratchet. Needs ankles straps on otherwise scissors over pommel. Loosen straps via clips at back (badge kept on ends to stop them coming through). Also has lap strap.

If upset calms if you count to 10 slowly or sing ‘wheels on the bus’ (but include silly phrases eg the snakes on the bus etc). Also like ‘s’ and ‘z’ sounds especially ‘pssst’, ‘wizard’ and ‘sssssnake’. Other favourite words, ‘trolley’, ‘cooioie’ ‘juice’.

Likes - silver foil/space blankets, helium balloons tied to arm of chair so can hit them, being held (upright) **Dislikes** - being left alone (gets panicky) noise of hairdryer.

Wears splints (AFOs) padded edge on inside of leg

Wears glasses – has strap to help keep in place. Sometimes knocks them with hand

Bedtime Routine (7pm)

Usually enjoys having a bath/hair wash. Sleeps in symetrik sleep system at school. At home still sleeps on front (recovery position), arms either side of head, head to left (ie lies on right cheek), red heart-shaped cushion between knees. No pillow. Has dummy. Need to hold dummy in place and/or use cloth and purple bear to help keep it in. Can take a while to latch on and settle. Will yell if loses dummy. Light sleeper but usually stays asleep unless woken by hip pain, wind or outside noise.

N.B. Cannot be left on front if yelling as everts upper eyelid. If this happens hold Matthew upright as gravity is normally enough to make it drop down again. Eye may become gungy and need bathing and antibiotic cream if very red and swollen. If his eye everts it may happen again as tissue gets stretched and so is easier to ‘flip’ again

Contacts

Home (address land line phone number and both parent’s mobile numbers)

School: (name address and phone number)

(updated 11/11/09)