

Vignettes

1.

Millie, a 10-year-old girl, has intractable diarrhoea due to Tricho-hepato-enteric syndrome, caused by a mutation in the gene TTC37. She receives Home parenteral nutrition 4 nights per week, and takes a milk free diet supplemented by oral nutritional supplements. She has a cardiac anomaly, (aortic insufficiency) and mild bilateral hydronephrosis.

In infancy she had recurrent otitis media and has immunodeficiency, with low serum concentrations of immunoglobulins in infancy which improved with age and has had a poor immunological response to childhood vaccination (Hib and pneumococcal titres remain low). She developed bloody diarrhoea in later childhood and at colonoscopy, histology shows an IBD-like distal colitis, currently treated with prednisolone 5mg alternate days.

The clinician, MDT and parents discuss the child's situation. She has major organ failure (Intestinal Failure) in combination with additional risk factors (immune dysregulation, cardiac anomaly, renal anomaly, IBD-like illness). Although she hasn't had a severe infection for a number of years, her cardiac and renal anomaly are stable, and her rectal bleeding appears to be in remission on treatment with low dose steroids, it is agreed that it would be prudent to continue to '**continue shielding**' (move to Group A) at home.

The team also advised that her sibling age 15 attends school (as her local school in England has re-opened) as stringent social distancing can be offered at his school, however, her younger sister will stay at home as is unable to understand and follow instructions on social distancing and is supported to learn at home. Millie's parents elected to stay at home as can work in the home.

2.

Stephen is a 3½ year old only child. He was born prematurely at 28 weeks and had severe NEC resulting in resection of significant amounts of small bowel and colon, he has an ileostomy and is on 5 nights a week PN. In addition he had chronic lung disease of prematurity and only came out of oxygen over-night 6 months ago. He also had IVHs and has some periventricular leukomalacia and cystic changes, he is ambulant but walks with a supportive frame and has a marked left hemiplegia. Dad has to work out of the house hold, he assists with hanging his PN.

The clinician, MDT and the family had a long discussion about the next move; Stephen has a few risk factors that don't fulfil 'shielding' individually. However his mum and dad were keen to get back to normality as much as possible and go back to nursery. They agreed to '**remain a step behind**' and they first would take Stephen into 'lockdown' measures, and then (as per Scotland moving into step 2) allow Stephen and family to meet up with 1 other-house hold after 2 weeks.

Dad will continue to go out and work but the MDT emphasised to continue change clothes and shower before engaging with the rest of the household when they get in. They agreed they would hold another consultation before discussing Stephen's nursery placement and that if it did open, they would at let the nursery be open for 2 weeks to check the logistics of social distancing were being enforced well practically.

3.

Ella is 14. She had congenital gastroschisis as an infant and has an ileocolonic anastomosis with continuity. She eats on top of enteral feeds but still requires 3 nights PN a week. She has no neurological impairment and, prior to lockdown, was starting to socialise a lot with her peers in the evenings she was off PN, including being a keen footballer with a local team. She has had no central line infections for several years and is growing well. She has 3 siblings all are well

The clinician, the MDT and the family discussed. Mum was very anxious about coming out of lockdown, and always engaged in extended hygiene measures within the house and for visitors prior to lockdown. Despite their hometown in Northern Ireland soon moving to step 2 (groups of up to 10 individuals meeting outdoors) mum has kept Ella inside. There was clearly tension between mum and Ella in the consultation although she is always quite when mum speaks.

After a long consultation agreement was made that Ella would engage in a **'temporal transition'** with 2 weeks between lock-down, Step 1 and then step 2. The Clinical Nurse specialist was going to keep in close touch to encourage the family to engage in emergence for Ella, getting to meet friends in groups and re-integrate with her outdoor sports when it becomes possible.

Ella and her siblings should return to school when it starts for Northern Ireland in September, although it may be reasonable for Ella to wait out the first week to check that the local High school is coping with social distancing protocols.

4.

Marcus is 2 years old, he has intestinal aganglionosis. He has a high ileostomy which can put out >1litre some days and he's on minimal feeds with 7 nights of PN a week. Marcus's mum Alicia is a single parent as there was domestic violence within the household and Marcus's dad has no contact with the family anymore. Alicia has a history of major mental health problems and has follow up regularly with a CPN. Alicia has assistance from her own mother for PN hanging and to help with Marcus's older sister who is 4, but she also has to work during the day. Marcus has had 3 central line infections in the past 18 months but is quite well currently

The Clinician, the MDT and Mum had a discussion about coming out of lockdown. Alicia became tearful very quickly as under the current plans, in Wales, nursery places will not to open up again as yet. Her CPN who had joined the call stated that he was concerned about how exhausted is with having the children at home all the time and that she hasn't been sleeping well.

After a discussion everyone agreed that the team would try to make a case for Marcus to be considering a 'priority group' for returning to nursery as his additional needs during shielding were starting to take a strain on mum. Alicia was very grateful when the IF team social worker suggested she make contact with the local education authority to see what could be arranged.