



British Society of Paediatric Gastroenterology Hepatology and Nutrition

Exit strategy from the Coronavirus (Covid 19) lockdown and 'enhanced social distancing' (shielding) for children and young people receiving home parenteral nutrition (HPN); a decision making framework from the BSPGHAN Nutrition and Intestinal Failure working group.

Bullet Points

- children and young people receiving HPN were advised to 'shield' when lockdown commenced in March 2020
- it is now apparent that gastrointestinal manifestations of Covid19 in children are mild and self limiting
- we have not identified any reports of severe complications of covid19 in short bowel syndrome (SBS), intestinal failure (IF) or HPN from Covid19, in the adult and paediatric medical literature
- mental health of children required to take quarantine measures is well described with anxiety, distress and increased risk of major mental health disorders
- HPN children should no longer be considered 'extremely vulnerable' since negative social and developmental effects would appear to outweigh protection
- Shielding is due to end June 12th when the majority* of families can transition to the current local social distancing protocols
- if there is resumption of lockdown due to a second virus peak, we propose that the majority* of families only follow social distancing policy and do not resume 'shielding' again, even if adult HPN populations do so
- patients* and families should have a balanced conversation about returning to school. They may wish to take a tailored approach, such as following in two weeks behind their peers to assure that initial logistics of social distancing are being followed

*If a child has coexisting disease, e.g. cardio-respiratory, neurodisability, immunodeficiency, inflammatory bowel disease (IBD) or is on certain immunosuppressive treatment that would not in itself be severe enough to warrant shielding, clinicians may wish, in conjunction with other speciality teams and families consider that the patient should continue shielding from cumulative multi-organ risk.

Background

In response to the novel Coronavirus (COVID-19) pandemic, rapid and unprecedented public infection control measures have been undertaken by all four devolved of the UK. These have included the cessation of public gatherings, schooling, social distancing and finally 'lockdown' with the majority of the population being asked to stay at home other than for a few designated essential activities. In addition, identified vulnerable members of the population, have been required to participate in 'enhanced social distancing' or 'shielding'; remaining strictly housebound, dependant on outside assistance for essential items, and isolating from members within their household. This was proposed to be for 12 weeks in the first instance (1-4).

Necessity for shielding was considered on basis of relative burden of chronic disease and known risk factors for severe COVID-19 infection. The limited data, all from out-with the UK did demonstrate

chronic disease as a risk factor for severe infection, but that young age conferred a protective association with infection (5). Although central government described the principles of enhanced distancing measures, the framework for the degree of measures employed and to which distinct patient groups was largely devolved to national expert bodies. As such multiple national expert bodies considered adults with long term intestinal failure (IF) with an ongoing need for home parenteral nutrition (HPN), as significantly vulnerable enough to warrant 'shielding' (6,7).

The RCPCH, in consultation with multiple paediatric speciality groups published advice on the principles of 'shielding' for children; with reference to the unique challenges for families and carers to deliver socially distanced cares to dependent children and the specific pathology's and their impact on children(8). As such the RCPCH and BSPGHAN endorsed 'shielding' for a number of key chronic gastrointestinal conditions, although with a stratified approach in some conditions such as inflammatory bowel disease. However, it was agreed in consultation with the BSPGHAN Nutrition working group, that children and young people receiving HPN should participate in shielding (8). This was largely on the basis for the need to keep crucial carers well and the desire to keep these children safe, well and out of hospital (given that this population are required to present to hospital with all significant fever). As this time period comes to an end and lockdown exit strategy is described, it is important to consider what social distancing policies this patient groups should now follow.

The purpose of this document is to describe the developments in our understanding of the Coronavirus in the context of children with chronic health conditions, the effects of 'shielding ' on young people. We describe a proposed strategy to end shielding measures for children receiving HPN for them to participate in standard social distancing with their age group peers and any additional considerations that may modify this approach.

What is now known about Coronavirus and Children

Whilst the initial information from China on Covid-19 did appear to suggest a significant protection from severe infection by young age, what was not immediately clear was the dramatically smaller proportional need for hospitalisation or mildly symptomatic infection. Asymptomatic carriage, although harder to quantify, also appears less. The gastrointestinal manifestations of Coronavirus in children are only apparent after respiratory symptoms, and are mild and self limiting and do not contribute significantly to COVID-19 morbidity in children (9-20). Transmission rates of Coronavirus are very low and countries that have re-opened nurseries and schools have not experienced institution related outbreaks. The data for Coronavirus infection in children with chronic gastrointestinal conditions, although limited, are reassuring in terms of relative incidence and severity (21, 22). Data from severely immunosuppressed children, even in high level pandemic areas, are that of low overall infection rate with low level need for hospitalisation (23). To date significant morbidity and mortality from COVID-19 in children appears limited to the idiopathic paediatric multisystem inflammatory for which pre-existing chronic disease does not appear a risk factor (24, 25).

We have been unable to identify any data identifying severe complications of short bowel syndrome, IF or HPN from Coronavirus, both in the adult and paediatric literature. Also, of note, to date, none of the ≈400 patients <16yrs receiving HPN in the UK have knowingly contracted Coronavirus.

What is now known about children and ‘shielding’

The consequences on the mental health of children required to take quarantine measures is well described already with anxiety, distress and increase risk of major mental health disorder (26). The effects of the cessation of formal education on such a prolonged and large scale, for a population already at significant risk of poorer social and educational attainment are not, but need to be considered in ongoing risk assessment. It is clear that there has been a significant reduction in children’s presentation to accident and emergency departments and face to face paediatric consultations. Children’s presence in society has declined in general and particularly with chronic health conditions. These children as such are ‘vulnerable’ and the risks of this ongoing social invisibility need to be considered when weighing up the potential benefits of social distancing measures (27).

Leaving lockdown and shielding

This initial period of shielding will end for many vulnerable patients. What happens thereafter is determined by the individual condition, and local protocol on social distancing across the four nations. We outline a new strategy for children receiving HPN based on the available evidence and our cumulative experience which advocates a tailored case by case approach but with the general principle that the majority of these children will be coming out of shielding.

We recognise that these children have chronic health needs but we propose that, in general, they should no longer be considered ‘extremely vulnerable’ en masse and that to do so maybe more to their social and developmental detriment than their protection.

Initial emergence 'shielding'

Shielding is due to end June 12th. Depending on geographic location in the UK, the social distancing status of the general population may vary from 'ongoing lockdown' to primary or secondary phased relaxation of lockdown measures (1-4). An understanding of your local (national) emergence from lockdown framework is essential to inform decision making for emergence from lockdown. (UK variations in phase re-emergence are summarized in **Table 1**).

Ideally the MDT should conduct a face to face or virtual consultation with each family ahead of June 12th to discuss the family's current enactment of 'shielding' (as this may already have involved a degree of personal interpretation out of necessity) and then a strategy for lockdown re-emergence. The following principles should inform this discussion;

1. The majority of families can discontinue shielding as of June 12th and transition to the current local social distancing protocols. Only patients that are the highest risk (now defined as Group A) should continue shielding until June 30th and instructions for enactment of 'shielding' may change going forward.
2. In Group B patients who have some risk factors additional to IF, but it is agreed these are insufficient to warrant placing in 'Group A', then families and MDTs may wish to agree some enhanced distancing measures above whatever the current local protocols (such as remaining a step behind).
3. Where the general population are several steps ahead of shielding patients (on phase 2 or beyond of emergence), families may want to consider a phased transition (such as 2 weeks in phase 1 before progression).
4. The MDT and the family may wish to consider circumstances for a more cautious approach to initial emergence, such as; remaining 1 phase behind the general population; remaining in lockdown but not shielding, or in exceptional cases to continuing shielding. If there is a regression in local emergence protocol, e.g. the resumption of lockdown due to second virus peak, we propose that the majority of families only follow social distancing policy and that patients and families do not resume 'shielding' again, even if adult HPN populations do so; unless this has been pre agreed by the 'special circumstances' of an individual case.
5. If an MDT considers that the mental health risks to the individual or family OR the if potential safeguarding risks for the child are significantly high enough, they may wish, in conjunction with the families or social services to make a case for ongoing nursery or school placement even with lockdown resumption. However, we recommend some form of peer review for this extraordinary decision.

A summary of potential strategies for emergence from lockdown are summarised in **Table 2**.

Resumption of face to face education

The plans for resumption of school education is complex and diverse across the 4 UK nations at time of writing

- Some school education has resumed in part England on June 1st
- No plans for schools to open prior to term-time in mid-August in Scotland
- Wales has detailed no plans to open en masse before summer recess
- North Ireland has confirmed no schools will be opening before September
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However, again, an initial discussion will aid in making individual decisions on re-engagement with education. As per the RCPCH guidance the following principles should guide discussions;

1. Children should only not engage with schooling if they are considered as part of 'ongoing shielding'
2. The majority of patients should be having a balanced conversation about returning to school, many families will be understandably anxious about this and may wish to take a tailored approach (such as following in two weeks behind their peers to assure that initial logistics of social distancing are being followed well, or initially following a reduced timetable).
3. Where there is reluctance to re-engage with face to face education, the MDT may need to consider what impact this may have on a Childs social invisibility and resultant vulnerability.
4. Siblings of extremely vulnerable children should attend school as per local social distancing protocols.

Outcome of discussion about lockdown emergence strategy and educational re-engagement should be documented and ideally summarised with a letter sent to families. A template of lockdown emergence strategy family letter is enclosed (Appendix 1) and can be adapted for local use.

BSPGHAN NIFWG May 2020

Table 1				
Nation	England¹	Scotland²	Wales³	Northern Ireland⁴
Lockdown	Commenced March 23 rd	(Phase 0) commenced March 23 rd	Lockdown commence March 23 rd	Commenced 17 th March
Step 1	Commenced May 16 th <ul style="list-style-type: none"> Workers who cannot work from home now travel to work Unlimited exercise outdoors Non household meetings one on one outdoors Travel to outdoor spaces Vulnerable limit contact outside household Continue 'shielding' 	Commencement May 28 th <ul style="list-style-type: none"> Unlimited local outdoor exercise contact with other household outdoors Re-opening of workplaces for work that cannot be performed at home Outdoor limited retail 	'Red' Possible May 31 st <ul style="list-style-type: none"> School remains for key workers and vulnerable Seeing one member out-with household for care only Unlimited local outdoor exercise 	<ul style="list-style-type: none"> Schools remain for key workers and vulnerable Workers who cannot work at home travel to work Outdoor non contact sports activities Groups of 4-6 non household members can gather outdoor
Step 2	Planned June 1 st <ul style="list-style-type: none"> Phased reopening schools Other households contact 'bubbles' to be announced Shared childcare in two households 	No time-frame set <ul style="list-style-type: none"> Larger outdoor gatherings Indoor meeting of other one household On campus lab work Playgroups and sport courts re-open Registration offices for high priority 	'Amber' No time frame set <ul style="list-style-type: none"> Schools open for priority groups Exercise with other individual or group, non contact team sports Travel for leisure and non essential retail Museums and galleries open Limited cultural events 	<ul style="list-style-type: none"> Schools open to wider definition of key workers Non food retail resumes Gatherings of up to 10 individuals outdoors Resumption of team sports training

Step 3	Planned July 4 th at earliest <ul style="list-style-type: none"> Opening of hospitality, public worship and self-care retail 	No time frame set <ul style="list-style-type: none"> Indoor meeting multiple households Longer distance travel School re-open for part time face to face August 11th Museums galleries, indoor gyms and cinema open 	‘Green’ <ul style="list-style-type: none"> All children and students access education Meeting small groups for socialisation outdoors Unrestricted travel All sports and cultural leisure open Pubs restaurants non essential indoor retail open 	<ul style="list-style-type: none"> School open to priority cohorts Phased return office work Gatherings of up to 30 people Resumption non contact sports Museums and galleries open
Step 4		No time frame set <ul style="list-style-type: none"> Further relaxation of face to face gatherings Full opening of childcare, schools and universities Resumption of sport and mass gatherings 		<ul style="list-style-type: none"> Schools open for all pupils part-time Competitive sports resume behind closed doors leisure centres open Wider range of social gatherings
Step 5				<ul style="list-style-type: none"> School extended to full time for early years Extended social groups gather Resumption of contact sports Spectators attend live sports and concerts

Table 1: Summary of four nation approach to exit from lockdown

*Circumstances that MDTs and families may need to consider moving to Group A ‘continue shielding’	+Circumstances for Group B patients that may recommend enhanced or temporal distancing measures short of ‘shielding’	Circumstances that would recommend patients to Group C
<ul style="list-style-type: none"> • Concomitant immunosuppression • Mod/severe neurodevelopment delay • Concomitant moderate lung disease • Sever Cardiac disease • End stage liver disease • Solid organ transplantation 	<ul style="list-style-type: none"> • Any of first column factors not severe enough to merit ‘Group A’ • 7/7 PN • 1yr age • Difficult contingency arrangements for primary carer illness • High out-put ileostomy • Parental anxiety 	<ul style="list-style-type: none"> • No immunosuppression • <7 nights PN • Normal neurodevelopment • Easy contingency arrangements for primary carer illness

Table 2: BSPGHAN NIFWG framework for considering individualised Lock-down exit strategy for children receiving HPN

*These families will represent a small minority of the total PN population and likely most risk factors will emerge from other organ dysfunction. However, it maybe that cardio-respiratory or neurodisability in combination with IF may lead to a decision of ‘continue shielding’ with less severe disease than would indicate shielding in isolation, discussion with relevant other specialist team may assist with decision making.

*Potential strategies;

1. Transition to local social distancing protocol with other age group peers.
2. Temporal transition to local social distancing protocol, such as 2 weeks behind age group peers.
3. Remain a ‘step’ behind age group peers.
4. Remain in lock-down but not ‘shielding’.

If an MDT considers that the mental health risks to the individual or family OR if the potential safeguarding risks for the child are significantly high enough, they may wish, in conjunction with the families or social services, to make a case for ongoing nursery or school placement even with lockdown resumption. However, we recommend some form of peer review for this extraordinary decision.

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.

APPENDIX 1

Dear Parent

The team were pleased to meet with you all today to discuss plans for social distancing for _____ today. As of 12th of June the initial stage of 'shielding' will end and the Royal College of Paediatrics has advised that beyond this, most patients on home parenteral nutrition will come out of shielding and move to the same measures as children their own age. We met to discuss what this would mean for _____

We discussed that currently that shielding has meant for (family members/employment status/ who has had to isolate from patient).

We discussed risk factors for _____ and factors demonstrate 'lower risk'

We therefore all agreed together that from June 12th _____ will

- Continue to 'shield', but discuss what enacting 'shielding' will now involve
- A plan to transition over __ weeks to match the rest of the country
- To remain 'a step behind' until further review
- To immediately move to the local protocol

This plan is in-line with advice from the British Society of Paediatric Gastroenterology Hepatology and Nutrition Intestinal Failure working group and we will keep you up to date on any planned changes as they develop.

Yours

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