

# **REPORT OF THE BSPGHAN WORKING GROUP TO DEVELOP CRITERIA FOR DGH GASTROENTEROLOGY, HEPATOLOGY AND NUTRITION SERVICES**

## **MEMBERSHIP**

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## **REMIT**

The group looked at the following issues: -

Service provision including support services  
Core conditions and their management  
Links with tertiary services

This document therefore does not consider training issues and specifically doesn't address the training required to be a general paediatrician with a special interest in paediatric gastroenterology.

It is recognised that along with National Guidelines, in particular the proposed implementation of the National specialised services definition set, these guidelines will need to be revised.

**Review Date January 2005**

## **Background:**

The last few years have seen an increased emphasis on the specialisation of paediatric services. This has mostly been looked at in the tertiary setting in specialist units. It is clearly important also to look at these issues in the secondary setting where many of the patients are seen. In paediatric gastroenterology and nutrition in particular many conditions do not fit neatly into a secondary or a tertiary care model and would benefit a great deal from shared care in both settings. Certain core conditions require specialist assessment and other core conditions are most effectively managed in the secondary setting without referral to a specialist centre

In the future configuration of paediatric services, which will probably result in larger district general hospitals with more consultants there will be continued need for paediatricians with a special interest in paediatric gastroenterology, hepatology and nutrition based in the district general setting.

In an ideal health care environment all paediatric units would have within them individuals with specific expertise in specific areas. This in a small DGH may be a paediatrician who in addition to their general role takes on two specific areas of interest. In a larger DGH one paediatrician may in addition to their general role have a specialist interest in paediatric gastroenterology, hepatology and nutrition.

In order to fulfil these roles effectively the individual consultants require: -

Training in the sub speciality

Time designated to the specialist interest (this we would expect to be a minimum of two sessions per week)

Access to support services

Access to tertiary units including shared care

Continuing medical education

### **The scope of Paediatric Gastroenterology and Nutrition: -**

Paediatric gastroenterology is a clinical speciality comprising the investigation and management of disorders of the gastrointestinal tract (the oesophagus, stomach, pancreas, small intestine and colon) in infants and children.

It also encompasses two closely allied specialities, clinical nutrition and hepatology. Clinical nutrition is relevant to gastrointestinal conditions and also much paediatric pathology in other organ systems.

There is a close interface between various specialities:-

General and neonatal paediatrics

Paediatric surgery

Oncology

Infectious disease and immunology/allergy

Adult services

### **Optimising clinical outcomes**

The best clinical outcomes are achieved when the number of patients being treated in a unit is sufficient for a high level of medical and nursing expertise to be maintained. This has been clearly demonstrated, for example, for paediatric oncology and cystic fibrosis. Both specialities having highly organised shared care between secondary and tertiary units.

The NHS management executive in its guidelines on contracting specialist services emphasises that sensible contracting needs to take into account the optimum population size, not only for the stability of contracted referrals but also to give sufficient critical mass for clinical effectiveness.

### **Paediatric gastroenterology and nutrition services**

Gastroenterology is a key component of general paediatrics. There are common conditions, which have traditionally been managed in the district setting, e.g. coeliac disease, food intolerance, chronic constipation and abdominal pain. Many paediatricians in the district setting acquired training and have developed considerable expertise in these areas and there is no evidence that the tertiary care setting is required for the majority of cases. Some specialist areas, e.g. inflammatory bowel disease, complex enteropathies, including intestinal failure and paediatric hepatology lend themselves to a more tertiary setting for the organisation of the care.

Nutritional care underpins general paediatrics and many paediatric specialities. A nutrition team can provide a background resource and where appropriate active involvement in the care of an individual patient. Nutrition teams are ideally placed in loose alignment with a gastroenterology service.

## Specialist centres

Most regions have a tertiary unit with a full range of speciality services for paediatric gastroenterology and nutrition. Paediatric hepatology services are designated supra-regional and based mainly in King's College Hospital, Birmingham and Leeds with effective liaison between the supra-regional and regional units. The British Society of Paediatric Gastroenterology and Nutrition has agreed that in order for a centre to function as a specialist unit, various criteria need to be met.

A population base of 2.5 million

Two to three trained gastroenterologists to provide on call cover

Paediatric endoscopy service in a child friendly setting with at least 75 procedures per consultant per year

Specialist nursing staff

Specialised paediatric dietetic support

Specialist speech and language therapy support

Specialised psychological support

Specialist pharmacy support

A full range of allied services including paediatric and neonatal surgery, neonatal medicine and paediatric intensive care are required.

A full range of diagnostic services including:-

Paediatric radiology/imaging

Endoscopy

pH studies

Paediatric histopathology

A multidisciplinary nutritional care team

Links with the adult services

Links with other centres

Links with the supra-regional hepatology services

A paediatrician in the District General Hospital with a special interest is unlikely to have all these services available and would need to have good links with a tertiary service centre in order to access services (for example endoscopy) which may not be available locally when needed. It may be that in a larger district general hospital there would be a large enough patient base to offer diagnostic and/ or therapeutic endoscopy which provided adequate numbers of cases are done and the support services (including general anaesthesia and histopathology) available would be appropriate. There are no set guidelines on minimum numbers. It is likely in such a setting there would be clear links with the adult service and the regional paediatric gastroenterology unit.

It is also essential that the multidisciplinary support services in the District General Hospitals have full access to tertiary support services in the specialist unit. This can be effectively organised through local and regional networks, e.g. enteral feeding groups, specialist nursing forums and can be helped by national groups such as the Associate Members Division of the British Society of Gastroenterology, Hepatology and Nutrition.

A major issue is that no two regions have the same set up for tertiary paediatric services and as a consequence there is a huge variation in the service model applied. Many regions, for example have just one paediatric gastroenterologist. It is clear that a large District General, if it has the appropriate patient base and support services may function as a specialist centre for particular conditions. It is likely that such a unit would need to establish close contact/managed clinic network with a tertiary unit. This model works effectively in many parts of the country.

The paediatrician with an interest in Gastroenterology, like the paediatric gastroenterologist has responsibilities to promote multidisciplinary management in particularly for children with nutritional problems from any cause. They play a key role in the interface between primary secondary and

tertiary practice with responsibility for guidelines, audit and education. They need access to the full multidisciplinary team, investigations and support services and can play a key role as advocates for children with gastroenterology, nutritional and hepatology problems within their health care environment to both health care and allied professionals.

## **Specific Patient Groups**

### **Paediatric Surgery**

Many paediatric units now refer regionally for paediatric surgery, particularly neonatal and also older children. This means that the paediatric surgical expertise is now concentrated in regional centres. The patients are, however, often transferred after the initial post operative period to the local unit for continuing care. It is essential to have good links with the regional unit. The transfer of patients locally allows effective involvement of the multidisciplinary team for complex cases.

### **Children with feeding problems and disability**

The assessment of a child with cerebral palsy is multidisciplinary and organised locally through the Child Development Unit and community paediatric services. Many such children develop significant feeding problems and require specialist assessment. The assessment of such children is often complex requiring investigations and review within the feeding clinic setting. We anticipate the district and regional services working together would enhance the management of this patient group. However, issues such as preoperative assessment, gastrostomy tube placement with fundoplication, if necessary, would be dealt with either in a large DGH or a tertiary unit (particularly if fundoplication required).

### **Gastroesophageal reflux**

This is a common cause of regurgitation and vomiting in the first twelve months. It usually resolves without investigation or specific management. Indications for referral to a paediatrician with an interest in paediatric gastroenterology are:- Diagnostic doubt, failure to resolve on simple treatments, haematemesis or significant iron deficiency anaemia, feeding problem, respiratory symptoms or significant failure to thrive. The investigation of these children can be quite complex and includes: - pH study, barium radiology, milk scanning and upper GI endoscopy with input from dietetic services, speech and language therapists and skilled paediatric nursing staff.

### **Recurrent abdominal pain**

Ten percent of school aged children experience abdominal pain. Few are associated with organic pathology. Indications for referral to a paediatrician with an interest in paediatric gastroenterology include:- diagnostic uncertainty, night pain, close family history of peptic ulceration, evidence of gastrointestinal bleeding. Additional symptoms, include, weight loss, growth failure, severe psychosocial problems and/or school refusal. Such patients require skilled clinical assessment often with the involvement of a multidisciplinary team. Further investigations include routine bloods, barium radiology and endoscopy.

### **Coeliac disease and other enteropathies including post gastroenteritis syndrome**

There are guidelines produced by the European Society of Paediatric Gastroenterology, Hepatology and Nutrition for the diagnosis of coeliac disease. The widespread use of endomysial antibody testing means that children are presenting with a much more heterogeneous spectrum of symptoms. The diagnosis requires biopsy confirmation which means a service being available either for Crosby capsule or upper GI endoscopic biopsy with skilled histopathological

interpretation. Children with other causes of enteropathy require skilled clinical dietetic, often radiological endoscopic and histological input.

### **Intestinal failure**

This is severe small intestinal disease resulting in an inability to maintain normal nutritional status without parenteral nutrition. Such children are infrequent and often complex. They need access to the full range of paediatric gastroenterology specialist services including skilled dietetic and nutritional nursing input, input from a paediatric pharmacist with experience in parenteral nutrition, access to the full range of investigations in order to achieve diagnosis. It is clear that the critical mass of patients means that such children should only be managed in specialist centres.

## Inflammatory bowel disease

There is an increased prevalence of Crohn's disease, in particular. The DGH Gastroenterologist has a key role in the early detection raising awareness and advising on local referral patterns and screening strategies. Children require access to the full range of investigative services, in particular endoscopy in order that a tissue diagnosis is obtained before embarking on treatment. Access to skilled dietetic support is essential, particularly for the management of Crohn's disease with enteral nutrition. It is generally agreed that all children with inflammatory bowel disease should be managed either by or on a shared care basis with a specialist centre. It would be anticipated within a district that there would be a number of children with inflammatory bowel disease. Their local care would be most effectively coordinated through a single paediatrician at that hospital, taking them on and managing them in conjunction with a specialist centre in order to allow rapid access to the full range of investigations.

A large district General Hospital with a Paediatrician with special training in gastroenterology may function as a specialist centre for the management of IBD in collaboration with a tertiary unit as part of a managed clinical network and it is not necessarily the case that patients in such units should be managed in a tertiary unit.

## Constipation

This is a very common disorder in children. A few children will have to be referred to a specialist centre, the indications being severe intractable constipation with or without major psychological problems or the concern based on the clinical picture that an underlying cause, such as Hirschsprung's disease or intestinal pseudo obstruction is present. Such children require effective tertiary and multidisciplinary local care for effective long term management. The interpretation of biopsies to exclude Hirschsprung's disease the full access to specialist diagnostic services.

## Paediatric Hepatology

Children's liver disorders are rare and in general management of such conditions should be in conjunction with one of the supra-regional hepatology units. Guidelines from such centres on the indications for referral and the shared management of chronic cases *have been* established. Important areas within the district setting include:

**Response to emergencies.** All paediatric units must have the ability to respond appropriately to paracetamol overdose, the septic jaundiced infant who may have galactosaemia, a Reye-like disorder, neonatal hyperammonaemia, *acute liver failure*, variceal haemorrhage.

**Hepatological events in other paediatric specialties.** Depending on the size of the unit, there will be need for consultation about liver abnormalities occurring in other specialties e.g. TPN cholestasis, abnormal LFTs in oncology patients, cystic fibrosis liver disease, metabolic disorders.

**Recognition of newly presenting liver cases.** The following are examples of conditions where there must be sufficient awareness and knowledge if prompt diagnosis (and probably referral) are to occur - vitamin K dependent bleeding in infancy, cholestasis in infancy including biliary atresia and choledochal cyst, autoimmune hepatitis, Wilson's disease.

## References

A Guide for Purchasers of Paediatric Gastroenterology and Nutrition Services, BSPGHAN 1996  
Referral List for Supra-regional Paediatric Liver Services, RCPCH 2002  
National Specialised Services Definition Set for Children (Draft), London Regional Specialised Commissioning Group 2002

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