

A Role for Local Small Scale IBD Family Education Days

Levi R¹, Green S², Marshall S¹, Greveson K¹, Furman M¹, Crespi D¹,
¹Royal Free Hospital, Pond St, London; ²Royal Free Hospital Children's School, Pond St, London

Introduction:

Patient and family knowledge is crucial in optimising management of IBD and facilitating the partnership between family and the medical team. This need is arguably greatest as the young person passes through adolescence, transition and public examinations. The IBD charities provide a fantastic resource for information and large scale education days. We questioned if there might be an additional useful role for small scale local family days run by local IBD teams.

Aims & Objectives:

- To provide information to better equip families of young people with IBD approaching examinations on their exam entitlements, tools to help manage their IBD during this time, general IBD education and the opportunity to meet their own Multidisciplinary team and ask questions.
- To offer our IBD patients and their families the chance to meet other local families, form links and share experiences

Subjects & Methods:

During the August summer holiday, ten families attended an IBD Education and Information Day, delivered by a multidisciplinary team, to address issues considered relevant to children of examination age and approaching transition (fig 1). The multidisciplinary team included two Consultants, a Senior Pharmacist, the Deputy Headteacher and Examinations Officer of the Royal Free Hospital Children's School, two Specialist IBD Nurses (one Paediatric, one Adult Services), a Consultant Clinical Psychologist, and a representative from the charity Crohn's and Colitis UK. Each speaker was allocated a time slot allowing for questions and discussion at the end. There were talks, a workshop and a chance to put questions anonymously for a Question and Answer session to the panel. The programme of the day is outlined below (fig. 2).

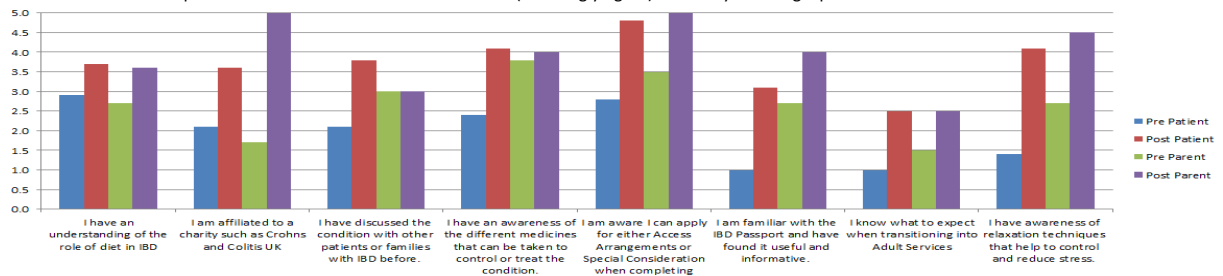
Fig 1. A session in progress



Fig 2. Programme of the Day

Time	Speaker/Activity
10.30 - 10.50	Start and introductions, icebreakers, and an opportunity to leave any questions you may have anonymously in the box provided to be answered during the panel session
10.50 - 11.20	Crohn's and Colitis UK - What they can offer and how they can help? Elliot James, Young People & Families Development Officer at Crohn's and Colitis UK
11.20 - 11.45	Your IBD Medicines - Chloe Benn, Senior Pharmacist at The Royal Free Hospital
11.50 - 12.30	Q&A Specialist IBD Panel - Dr Daniel Crespi, Consultant Paediatric Gastroenterologist, Dr Rachel Levi, Paediatric Gastroenterology, Susan Marshall, IBD Specialist Nurse, Abi Freedman Paediatric Dietician, Chloe Benn, Pharmacist, Elliot James, Crohn's & Colitis UK
12.30 - 1.15	Lunch. An opportunity to meet informally with other patients & families with IBD
1.15 - 1.35	Applying for Access Arrangements and Special Consideration when taking examinations - Steve Green, Deputy Head of the Royal Free Hospital Children's School
1.35 - 2.05	Managing stress and triggers associated with IBD workshop- Deborah Woodman, Lead Child Clinical Psychologist & Consultant Clinical Psychologist
2.05 - 2.35	Travelling with IBD. The IBD Passport - IBD specialist nurse from Adult Services
2.35 - 3.05	IBD & Diet - Abi Freedman, Paediatric Dietician at The Royal Free Hospital
3.05 - 3.10	Evaluation forms
3.15	End

Results: Likert scale from questionnaire converted to numerical value (5=strongly agree) and analysed using a paired t test.



Pre and post session questionnaires showed improved knowledge in both patients and family members (pooled data) p value <0.01. All families gave written feedback which was overall extremely positive. For example:

"Was unaware of the home invigilation or 5% added onto results"

"Good to realise that I'm not alone in my condition"

"This is so useful, particularly for the newly diagnosed. I wish I had done this 3 years ago"

Conclusions:

- Children and their families found the day both interesting and informative. The simultaneous access to such a group of experts was unprecedented, allowing questions to be answered regarding medicines, diet, stress reduction, travelling and reducing the impact of missing school in a single hospital visit.
- The day provided an excellent opportunity for families to share their experiences of IBD in a social, supportive and empowering manner in a non-clinical setting.
- This also led to professionals forming closer relationships with patients and families, promoting greater empathy, compassion and understanding of how IBD impacts individuals and their families.
- The multidisciplinary team reported increased cohesion, improved communication and better awareness of individuals' roles.
- Families with IBD found a small scale education and social day with the team very helpful and expressed interest in further similar days.
- There is a definite role for small scale family IBD education days locally, in addition to the larger ones organised by charities.
- This was also a unique opportunity for families to network, share experiences and provide mutual support.