

386* Providing inpatient education on a segregated ward

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Background: The hospital school provides education at the Royal Brompton Hospital. During 2007–8, 226 different pupils were educated, children with Cystic Fibrosis (CF) are the most frequent attendees: average access=14.3 school days/child/year. In 2006 a segregation policy was introduced to the ward following a survey of opinions from patients with CF and their families – 55% were in favour of segregation. Following introduction patients and families report difficulty in adhering to issues of segregation, particularly less classroom time.

Aim: To discover the impact of segregation on education provision.

Methods: Information was sought from two groups; teachers and clinicians, and patients and families. Meetings were held with school staff, ward staff and the CF Team to examine support options. Patients and families were interviewed to elicit their understanding of segregation.

Results 1: Patients and families reported isolation and loneliness, concerns over a reduction in education provision and a lack of knowledge regarding segregation. Staff described frustration and difficulty in maintaining the policy.

Results 2: The hospital school have introduced measures to maximise access to education: laptop computers, personalised learning timetables and video conferencing. Teaching staff numbers have increased including an art therapist, plus extended access to a drama therapist, story-teller, animations expert and artist. Additionally, a DVD about segregation has been written, produced, and directed by children with CF with support from the CF Team and the hospital school.

Conclusions: The hospital school regularly reviews the segregation policy with the CF Team. Ongoing education of patients and families continues and it is hoped that the DVD will enhance awareness of issues with both the children with CF and their families.

388* Experience of parents of CF pre-teenagers participating in a therapeutic education program

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Introduction: We report our experience after including our children in a therapeutic education program.

Materials: Necker Pediatric CF center and “Etoile des Neiges” Association set up a 1-year therapeutic education program aiming at explaining the CF disease to 11 to 13 year old children. The program was divided in 5 sessions and WE meetings to practice sports. The possibility of cross-infection was minimized by a strict policy: all our children had the same sputum colonization, and this was checked before each meeting; masks were worn during indoor meetings.

Results: For our children, this experience was clearly associated with positive changes. Compliance to treatment was improved because of a better understanding of the disease mechanisms. Our children now feel less isolated because they have shared their difficulties and have learned together how to deal with them. They have a better confidence in their future adult life. Most of our children have initiated or increased a regular sport practice.

We met with the other parents and the nursing staff during the WE meetings. This allowed us to partake our experience, our difficulties in coping with daily care and to share our tricks to improve it. We still keep communicating together and feel less isolated.

The siblings also participated in the WE meetings. They have better understood the burden of the treatment and now increase their participation to the CF-related family daily life.

Conclusion: This education program clearly has improved the daily life of our children and family. We hope that it will have a positive effect in the future years and in the adult life of our children.

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387 Camille and the Dragon. A magic story to explain CF disease to 3–5 year old children

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Introduction: Camille, a 18 year old patient, wanted to write a book to explain the disease to the 3–5 years old CF Children

Materials: The mum of a patient imagined the story of Camille and the Dragon. The nursing staff of Necker Pediatric CF center worked with her.

Results: Camille is a very cute and clever 4–5 years old boy who succeeds to save his people from a terrifying dragon. To be able to do that, he has to take his pancreatic extracts, and make physio. Camille has CF but this does not stop him to be the hero of the story. He does not kill the dragon but he is so clever that he convinces the dragon, which is in fact the symbol of CF, to go away.

After the story for the children, a part “ questions and answers” gives explanations to the main questions that the parents ask.

Conclusion: We hope that this book will be a good therapeutic education tool, which can be used by the parents, nursing staff and teachers.

389 The introduction of a new patient ‘welcome pack’

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The need to implement a more welcoming and educational approach for new patients to our centre was highlighted during paediatric transition clinics.

Aim: To develop a comprehensive guide to our centre which was welcoming, friendly and at the same time educational.

Methods: This ‘welcome pack’ needed to be suitable not only for those transferring from the paediatric services, but also for those transferring from other centres and those newly diagnosed.

Current patient opinion was sought to assess what they thought should be included in the pack. Ultimately, an approach similar to that adopted by many institutions such as schools, whereby children transferring from primary to secondary establishments would be suitably equipped with all the information required to ensure they settled well into their new surroundings.

Results: The ‘welcome pack’ was published as a printed folder outlining our ethos, welcome information and our code of conduct for both patients and staff. Inside the folder is placed a variety of information, such as maps, a leaflet outlining team members, clinic times etc, the CF Trust handbook ‘growing older with CF’, patient newsletters, useful leaflets and a hand cleanser to encourage infection control.

Conclusion: Following the introduction of the new patient welcome pack, feedback has been very positive. The pack is now taken to all paediatric transition clinics and sent in the post to those transferring from other centres. This enables familiarisation with multidisciplinary team members and our centre prior to a first appointment. All patient responses about the welcome pack were positive. One commented that they would like to see ‘pen pictures’ of MDT members and a small write up about each team member added, which will be addressed at the next opportunity.