“My Child’s CF Health Journal” – an educational resource/journal for parents of a newly diagnosed child with CF
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Newborn screening for cystic fibrosis was introduced in Ireland in July 2011. This development provided our CF paediatric centre with an ideal opportunity to design and introduce a comprehensive, combined educational resource/handheld journal for parents following the diagnosis of their asymptomatic infant with CF. This initiative is based on a pilot study carried out by the author in 2008, to then determine parents’/families’ educational needs together with their need for a handheld record/journal of their child’s progress. The design of a diary/journal was met with a positive response and welcomed by all parents. The objective of this resource is to empower parents/families with knowledge on CF and also provide information regarding their child’s progress.”My Child’s CF Health Journal” is in the form of a binder and includes sections on
1. Important Information
2. Clinic Visit Summaries
3. Medications
4. Nutrition
5. Respiratory Care
6. Lab/Radiology Test Results
7. Pulmonary Function Tests
8. Miscellaneous
This binder is provided to each family following diagnosis and additional relevant information sections are added on an incremental basis as parents learn more about the disease/aspects of treatment, or the need arises (CF complications).

Screening for pediatric lung transplantation: the pediatric psychologist’s role
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Objectives: To outline the role pediatric psychologists can play in the decision making process surrounding pediatric lung transplantation.
Methods: Three to four children a year are placed on the Eurotransplant waiting list after screening in the Beatrix Children’s Hospital, University Medical Center Groningen. About half of these children suffer from cystic fibrosis. Of the children on the waiting list a mean of two are transplanted per year. We present a description of the screening process and the role the psychologist is given during screening. The contribution of a systematic interviewing technique to determining the psychosocial status of children and their families is described. Generic cases, in the form of psychosocial vignettes, based on the characteristics of children who have been screened and/or transplanted during the past ten years, will be presented. Psychological consequences of the decision making process will be discussed.

Conclusions: Systematic use of interviewing by a pediatric psychologist during screening helps enable the decision making process. Children with special needs can be identified and help can be organized to optimize (psychological) health in order to promote psychological resilience and motivation.

Patterns of referrals to a psychology service at an adult CF centre: comparison of referred and non referred patients
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Objectives: Previous studies of CF clinical psychology services do not show whether referred patients have more severe physical disease. We wished to look at this and also to devise a robust referred problem coding system for use in future studies.
Methods: Records of all 39 clinical psychology referrals (15% of the clinic) over a 10 month period were examined. Details of clinical state and referred problem were collated and coded by the psychologist (DL) and clinical details compared with the remainder of the clinic population. A subset of 33 referred problems were independently recoded a second investigator (RT).

Conclusions: Referred and non referred patients were similar in terms of demographics (median age for both groups 26 years [IQR 8.6 and 10.9 respectively]; 54% of referred patients male [vs. 58% of non referred]). There was no difference between groups in nutritional state but referred patients had lower %predicted FEV1. This difference was significant using a t-test (Mean[SD] 66%[22.0] vs. 76[24.8], p < 0.05).

Codes for referred problems were found to have good inter-rater agreement (Cohen’s Kappa 0.73), suggesting this is a robust system. The commonest referral reasons were low mood (13), anxiety (6), patient request for confidential assessment (5) and non-CF related problems (4). This is consistent with previous studies and shows the importance of considering a wide range of psychological issues in the CF population. Further work is needed to examine the potential link between respiratory function and psychological distress, including implications for targeting psychological resources and screening.