

**441 Cystic fibrosis (CF) annual review documentation ... from paper to the web**

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Annual reviews are regarded as useful in achieving the best care in a changing complex disorder like CF. [1]

At our centre annual reviews are coordinated by a CF clinical nurse specialist. Initially the review process was recorded in paper format. This became inadequate due to insufficient space to record findings also it was often disjointed and could not be accessed by more than one person at a time.

The annual review document was reviewed by team members (nurse, dietitian, physiotherapist, consultant) and adapted to incorporate more detailed assessments. Additional information included detailed clinical assessment, current medications, psycho-social issues and the consultant's summary of proposed treatment recommendations. The document was then integrated into the electronic patient record (EPR) which is accessible to all members of the CF team on any computer within the department. From this portal it was possible to create a web page to store information on all patients undergoing the transplant referral process and commencing new treatments which required monitoring. The document site also incorporates the facility for audit and research. During 2005, 220 patients were invited for annual review and 142 attended.

This electronic annual review has been beneficial to patients and staff. Patients' report that the document is clear and easy to read. Staff report that completing it is quicker than the previous paper version. Hard copies are sent to the patient, general practitioner, and shared care centre.

**References**

- [1] Standards for the clinical care of children and adults with cystic fibrosis in the UK 2001. CF Trust. May 2001.

**443 How easy is it to track the CF patients' lung transplant journey through their health records?**

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**Aims:** As life expectancy of CF patients increases, so the numbers of adult patients referred for transplant assessment is rising, as are the numbers of CF staff caring for them. 10% of patients at the Scottish Adult CF Service have undergone transplant. Communication between staff and patients must be transparent and robust in order to achieve consistently high standards of care. Anecdotally we felt that there were gaps in the audit trail of the patients' transplant journey, which could result in failures of communication. The aim of this study was to develop a robust system to track the patient's transplant journey.

**Methods:** We performed a retrospective audit, of potential transplant patients' health records, over a 15-year period. An Audit tool was developed to collect evidence of the transplant journey. We also reviewed 3 case studies in detail.

**Results:** 27 sets of records were reviewed. 11 patients have been transplanted, 5 are currently listed. 96% of this group did not have initial transplant discussion followed up with written information. Nursing notes revealed more about psychological adjustment, emotional and ongoing support than medical notes. All records documented medical outcome from the transplant centre but 41% of these records did not evidence the psychological/emotional impact on the patient.

**Conclusion:** Information was difficult to access and fragmented across different sets of notes. The system currently relies on team members' inherent patient knowledge, rather than written documentation, to retrieve information. We need to develop a more transparent and integrated system of the patients' transplant journey in order to ensure good communication between staff and patient. A new system of patient held records is being developed to address these issues.

**442 Building a bridge between primary and secondary CF care**

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**Aim:** Home IV therapy is common practice for many CF patients. When problems occur patients in Belgium may seek help from private nurses or private organizations. Over the past few years it became clear that home nurses were worried about helping CF patients, because they were not up-to-date with CF and CF care. A specialist course was organized to increase knowledge and competence in the primary setting.

**Method:** Home care nurses were contacted through advertisement in a Belgium nursing-magazine and letters to different home care organizations. A 4-hour course was developed, using a power-point presentation, photographs, practice material and 2 dummies to practice on. The following topics were included:

1. CF multi-centre care: detailed medical and psychosocial information
2. Infection and cross-infection: importance of hygiene issues
3. Hospital protocol for home IV treatment. This protocol includes patient/parent training in hospital, use of material, regulations and reimbursement
4. Totally implanted venous system (TIVS): indication, advantages and disadvantages, TIVS use for home IV therapy
5. Peripheral catheter placing and use
6. Patient Controlled Analgesia (PCA) pump for continuous IV therapy: use during home IV treatment

**Results:** 96 nurses applied for the course; 82 attended. Satisfaction with the course was not assessed but many nurses expressed their enthusiasm. Some nurses mentioned the need for more information and training specifically about TIVS. Nurses were invited to join a list of trained home care nurses that could be contacted by the CF centre. 33 nurses and 6 home care organizations registered.

**Conclusion:** Educating home care nurses is an important task for CF specialist nurses; the presented course enhanced the relationship between primary and secondary care and likely added to the quality of home IV care for CF patients.

**444 Intravenous therapy: a cost saving initiative**

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**Background:** Medication issued to a patient cannot be returned and issued to anyone else (Royal Pharmaceutical Society – RPhS) A disclaimer was requested to RPhS in view of wastage of expensive intravenous (IV) medication by Manchester Adult Cystic Fibrosis Centre (MACFC) but was refused. We needed to devise a method to reduce wastage, when we prescribe 260 2/52 courses of IV antibiotics on an annual basis.

**Methods:** Two stock lists were produced, one for patients to complete and one for pharmacy. Patients listed how much disposable equipment and IV medication they had stored at home, noting expiry dates. Using the information from the patient's stock list, only the quantities required for a 2/52 course of IV's was then transferred to the pharmacy stock list and supplied. If patients were admitted part way through a course of IV's they were asked to bring their remaining drugs, which the aseptic unit would re-use for that patient. We calculated the cost savings through this new policy.

**Results:** In 2005, 30 lists were completed by patients prior to attending clinic to commence a course of IV's. Cost savings on equipment and drugs stored at home ranged from £16 to £5068. 3 patients had stored £1100, £2100, and £5068 worth of IV's and equipment at home. Cost savings on 30 lists were £870 for equipment, £32,397 on IV's, totaling £33,267.

**Conclusion:** Completing a stock list makes patients very aware of the amount of equipment and drugs they are storing at home as well as expiry dates. A stock list initiative is a minimal cost to the MACFC but gives great savings to our budget. We now encourage all patients who have home intravenous treatment to complete a stock list prior to commencing treatment.