

# Cystic fibrosis: transition from paediatric to adult care

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## Summary

There is a current caseload of 350 children with cystic fibrosis at the Royal Brompton Hospital, and adult caseload of more than six hundred. Approximately 100 young people aged between 13 and 18 will transfer to adult care during the next five years. The transfer process between services was identified to be in need of review. The initial objectives were to review current practice for young people ready to transfer from paediatric to adult care, and to assess the needs of the professional, patient and caregivers at this time. In June 2000, a new system was introduced to the families, which offered them joint transition consultations with paediatric and adult cystic fibrosis care teams. A hospital-wide standard for transition was approved. In June 2002 an audit of the transition clinic system indicated an improvement in the process of transfer from paediatric to adult care. However, further service development is required to cater for the challenges and individual needs of adolescents.

**T**HE AUTHOR has been in post as a cystic fibrosis homecare nurse for children at the Royal Brompton Hospital for five years. During the first year in post it was identified that there was no formal, standard transition service for young people transferring from paediatric to adult cystic fibrosis care.

The current caseload of children and young people with cystic fibrosis at the centre is approximately 350, with an adult caseload of more than 600. There are 100 young people aged between 13 and 18 years who will be able to transfer to the adult service during the next five years. The increasing young adult population has prompted the interest in transition planning and review of service development for this group.

It is generally accepted that the process of transition should be gradual, with team planning and co-ordination, but there has been little research examining what services are being provided at

present and what makes transition successful from the professional's and the family's perspectives. The current life expectancy of a person with cystic fibrosis is 30 years, although it is estimated that babies born in the 1990s with cystic fibrosis will survive to an average of 40 years (Elborn 1991); this prognosis has increased greatly over the past decade with advancing research and treatments, and the development of specialised paediatric cystic fibrosis centres.

Betz (1998) states that advances in medical treatments and technologies have led to improved long-term outcomes for children diagnosed with chronic conditions, thus there is a need for new services to meet the needs of this increasing adult population. Transfer from the paediatric to the adult cystic fibrosis unit can be a difficult and stressful time for the patient and his or her family and carers. It is an area which, according to Sawyer *et al* (1997), is not developing as fast as the clinical requirements demand. To conform to clinical governance, services in place should be improved and developed, and in this climate, nurses will become increasingly accountable for the quality of patient care.

For patients graduating from paediatric care there should be a clear indication that there is a positive, purposeful future ahead, and this can be made clear to them by planning for their progression to adult services (Conway 1998, Pownceby 1996). Centres have developed multidisciplinary expertise in the management of cystic fibrosis disease, and the organised delivery of care can now meet the needs of the ever-increasing adult population of patients with cystic fibrosis (Elborn *et al* 1991). According to Harvey (1998) clinical governance 'includes strategies which allow good practice to be shared and encourages input from patients' thus, in an area such as transition where the patient is the centre of the process, current practice can be reflected on and developed.

## Objectives

When reviewing the centre's approach to transferring care, the objectives were to:

- Review current practice for young people with

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## Key words

- Cystic fibrosis
- Nursing: care
- Paediatric nursing
- Respiratory systems and disorders

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cystic fibrosis who are ready to transfer from paediatric to adult care.

- Establish the needs of the professional, the patient and the caregivers at this time.
- Plan to introduce a new system whereby needs are further met.
- Formalise the new approach with a hospital-wide standard.
- Audit the new service at the end of two years.
- Review service following completion of the audit.

### The transition service

A literature review examining the subject area was carried out. It was discovered that there is little research pertaining to the area of transition between services for young people with cystic fibrosis. Much of the research written is in relation to other chronic illnesses, including spina bifida and diabetes. The American Society for Adolescent Medicine has defined good transition as 'the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented healthcare systems' (Viner and Keane 1998).

Over the subsequent year, by talking with the young adult population at the Royal Brompton Hospital, it was identified that they all had similar concerns about moving up to a new service. These included getting to know and trust a new team, the inclusion of parents in the young adult's care, and the format of hospital admissions. The paediatric and adult multidisciplinary teams at the hospital were questioned to identify the difficulties from a professional viewpoint. It became apparent that the main concerns were with establishing a formalised transition programme, incorporating both of the multidisciplinary teams, that would be effective from the families' and the caregivers' viewpoints. There are exceptions to moving to adult care, such as when a patient is in the terminal stages of illness, at which point it is unanimously agreed that transfer is inappropriate. Many young people with cystic fibrosis have seen peers die as a result of their disease, and it can be difficult to move into the unfamiliar territory of an adult service.

Discussions regarding the transfer to adult care start with families when the young person with cystic fibrosis is between the ages of 14 and 16, with a final agreement to move before the patient's 18th birthday. The topic of transition should be introduced to the family at least a year before transfer is expected, allowing them time to explore their feelings and resolve any concerns that they may have. It is commonly recognised that adolescence is a difficult time, with many changes including completing education, commencing employment and entering relationships. The impact of living with a chronic illness rests heavily on top of everything else.

Following discussions between the adult and paediatric cystic fibrosis teams, it was decided that one way to move the transition service forward would be to introduce joint outpatient consultations between the two teams. At present the cystic fibrosis clinics are held in the same department with some sessions held by the paediatric and adult consultants overlapping.

An agreement was made by paediatric and adult cystic fibrosis teams that in June 2000 a new system would be introduced whereby patients are offered a formal handover appointment in the paediatric outpatient department, with the paediatric and adult teams present. Patients are able to meet formally with the medical staff, and then informally with the adult cystic fibrosis nurse consultant, dietician and physiotherapist. The essence of the joint consultation is to introduce patients to the new team in an environment with which they are already familiar. The patient is guided through the process by one of the paediatric cystic fibrosis nurses, who also gives the family the opportunity to visit the inpatient ward and day case unit, and meet again the adult cystic fibrosis team.

During 2001, two cystic fibrosis nurses, one from each team, jointly wrote a standard for transition, in discussion with the department of practice development at the Royal Brompton & Harefield NHS Trust. This document was sent to both multidisciplinary teams for consultation before being agreed by the trust. It covers all areas of the transition process, and considers hospital and community perspectives. The aim of the standard is to ensure that the transition from paediatric to adult care is a planned, collaborative process involving the young person, family and professional caregivers, and considering all patients' physical, psychological, social and cultural needs.

### Audit of the service

Since the joint transition appointments were introduced in June 2000, all patients have been given the opportunity to transfer to the adult service through the joint appointment system. It is planned that these clinics will continue to be held regularly and at present patients are offered an appointment within three to six months following the final decision to move to adult care.

The standard for transition was audited in June 2002 from the professional and patient/caregiver perspectives, and future changes to service provision are being agreed and made. Overall the audit of the new transition clinic system showed that there has been an improvement in the process of transfer from paediatric to adult care, but that the move is still very stressful for families and the verbal preparation given does help prepare for the future. The audit of ten patients provided a snapshot of the feelings and experiences of the young adults

and their families, providing an insight into how the service may be affecting other patients. The audit reinforced the initial findings from previous discussions: that the information given to all families verbally and in a written information pack at the time of transfer was not clearly remembered; and that meeting a new team was difficult for families, especially for some parents who felt loss of control when finding themselves left out of their child's care.

## Discussion

Following the audit, it has become apparent that the service available for young adults with cystic fibrosis at the Royal Brompton & Harefield NHS Trust needs further development. Following consultation with both teams it has been agreed that the service provision for this group of patients is to be further improved and now separate transfer clinics are being held. It is hoped that in time a better-established transition service will be introduced, with adolescent clinics running alongside the children's clinics, catering for the challenges and individual needs that the adolescent population have.

Viner and Keane (1998) highlight five key elements of an effective transition programme that can be easily implemented. These are:

- A policy on timing of transfer.
- A preparation and education programme.
- A co-ordinated transfer process.
- Administrative support.
- Primary care involvement.

So, as healthcare professionals, what can we do to help this age group at a time of need? Developing age-appropriate services, with committed staff, in the hospital and community, is only the beginning. Specialised adolescent cystic fibrosis centres do not exist although some hospitals have designated adolescent units.

The Cystic Fibrosis Trust (2001) recognises that adolescence and young adulthood is a difficult time for those dealing with the psychological and practical burden of cystic fibrosis, and that the role of the cystic fibrosis nurse specialist at this time includes:

- Promoting self-care and responsibility in the young adult and offering advice and support to parents.
- Liaising with schools and colleges to support continuing education.
- Working in liaison with colleagues to ensure that adolescents receive appropriate knowledge regarding issues such as fertility, pregnancy, contraception, safe sex, cross-infection, further education/employment and smoking/substance abuse.
- Using specialist expertise and knowledge to advise on the appropriate time for transition and transfer to adult care for each patient.


Problems at transition may be avoided by effective planning, in preference to a haphazard and idiosyncratic handover, which often happens when patients are transferred to adult services when

unwell, or at a milestone such as leaving school, or at a crisis time such as pregnancy (Viner and Keane 1998). Paediatric professionals are often criticised for their inability to 'let go' of their patients (Conway 1998); this lifelong relationship is hard for both family and professionals to move away from. Trust often takes years to build up and the dependent relationship with professionals may be nurtured in a paediatric setting (Conway 1998). During the period of transition it should be remembered that young people and their families should not be expected to abandon the security of their familiar paediatric health care completely (Rosen 1993). Court (1991) supports this, agreeing that paediatric teams avoid dealing with the specific needs of young adults, that is, by not enabling appropriate transfer to adult services, and instead extending their care through adolescence to young adulthood.

## Conclusion

The *Clinical Guidelines for Cystic Fibrosis Care* (CF Trust, BPA, BTS 1996) advise that a comprehensive cystic fibrosis service (level 1 or 2) should ensure 'smooth transition of patients from paediatric to adult care'. Without any set guidelines until recently, it has been difficult to assess the effectiveness of transition programmes, and the need for further research and interest has been identified. Blum (1993) cited that programme models in practice for transitional care in practice required evaluation. The recently published *National Consensus Standards for the Nursing Management of Cystic Fibrosis* (CF Trust 2001) have stated the national expectations for the transfer of care from paediatric to adult services, and from this it is hoped that a national audit will ensue.

In conclusion, there seems to be little written proof yet that transition is working well in many areas, but perhaps through this unique insight that is not so. It is commonly recognised that transition during adolescence is a time of difficulty for the patient, the parent/carer and the professional. To improve transition either clinical services need to be better linked, or new services need to be developed looking specifically at the right time for transfer, and incorporating good communication and effective liaison. Areas that have developed new services running well should share their research, protocols and ideas, and standards of care should be agreed between all the members of the multidisciplinary team and developed to achieve the requirements of clinical governance.

The implementation of joint transition appointments with both teams working together should start to provide a more streamlined service. The two teams are, after all, dealing with the same disease and are divided merely by the age of the patient. The service is again under review and should be subject to further improvement and development over the next year .

## REFERENCES

- Betz C (1998) Adolescent transitions: a nursing concern. *Paediatric Nursing*. 24, 1, 23-28.
- Blum W *et al* (1993) Transition from child-centred to adult health-care systems for adolescents with chronic conditions. *Journal of Adolescent Health*. 14, 7, 570-576.
- Conway S (1998) Transition from paediatric to adult-orientated care for adolescents with cystic fibrosis. *Disability and Rehabilitation*. 20, 6-7, 209-216.
- Court J (1991) Outpatient-based transition services for youth. *Pediatrician*. 18, 2, 150-156.
- Cystic Fibrosis Trust (2001) *National Consensus Standards for the Nursing Management of Cystic Fibrosis*. London, Cystic Fibrosis Trust.
- Cystic Fibrosis Trust, British Paediatric Association, British Thoracic Society (1996) *Clinical Guidelines for Cystic Fibrosis Care*. London, Royal College of Physicians.
- Elborn J *et al* (1991) *Cystic fibrosis: current survival and population estimates to the year 2000*. *Thorax*. 46, 12, 881-885.
- Harvey G (1998) Improving patient care: getting to grips with clinical governance. *RCN Magazine*. London. Autumn, 8-9.
- Pownceby J (1996) *The Coming of Age Project* (Summary Report). Bromley, Cystic Fibrosis Trust.
- Rosen D (1993) Transition to adult health care for adolescents and young adults with cancer. *Cancer*. Suppl May, 71, 10, 3411-3414.
- Sawyer S *et al* (1997) Chronic illness in adolescents: transfer or transition to adult services? *Journal of Paediatrics and Child Health*. 33, 2, 88-90.
- Viner R, Keane M (1998) *Youth Matters: Evidence Based Best Practice for the Care of Young People in Hospital*. London, Action for Sick Children.

## Useful addresses

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[www.rbh.nthames.nhs.uk/childrencf](http://www.rbh.nthames.nhs.uk/childrencf) (for clinical guidelines for the care of children with cystic fibrosis). Revised and published September 2003.