The Peter Pan problem: transfer of chronically sick boys to adult care

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With improved treatments, increasing numbers of boys with chronic illnesses are living into adulthood. The transition between paediatric management and adult services needs to be handled carefully. Christopher Woodhouse discusses some of the issues.

Until the second half of the 20th century, most boys with one of the major illnesses of childhood, whether congenital or acquired, would have died before reaching adulthood. Those that survived may have had such severe disability that ‘normal’ adult life would have been unlikely.

Good medical treatments for type 1 diabetes, asthma, tuberculosis, gram-negative infections, chronic renal disease and many others, have all come into general use within the last 75 years. Similarly, developments in surgery, anaesthetics and nursing have allowed the reconstruction of major congenital anomalies. However, much of this requires sophisticated and expensive care. In less developed countries, congenital anomalies and chronic illness account for nearly 50% of infant deaths, and the rate is inversely correlated with the per capita gross domestic product.1

Unfortunately, very few chronic conditions are cured in the full sense of the word. They are not usually amenable to a treatment that gets rid of the condition and leaves the boy normal, with no requirement for continuing supervision or later treatment. So, the new problem that has arisen is how to help such boys get through the difficulties of adolescence and become established in normal adult life.

EXTENT OF THE PROBLEM
The prevalence of chronic illness in children in the UK is 17–19%. In the USA,
Boys could be married with children while still attending a paediatric hospital

There are many barriers, practical and emotional, to establishing adult care for chronically ill children. It requires money, training, a political willingness and a cohort of doctors with the necessary skills. One of the most difficult to overcome is the emotional attachment of boys and their parents to the holistic care offered in the child-centred paediatric environment. They become progressively more anxious as they realise that Peter Pan is fiction.

THE REQUIREMENTS OF TRANSITION

Viner has identified three elements to ensure safe transition:6

- There needs to be a cultural shift in staff attitudes and training. In particular, medical practice must adapt to the needs of the adolescent and not vice versa.
- Systems must change to ensure that all paediatric chronic illness and disability services have effective transition programmes in place.
- Young patients must become effective partners in their own transition.

Although most healthcare systems have defined ages for the end of childhood, children actually mature at different rates. The GP is in the best position to see how a boy is growing up and how the family is responding to the changes. When asked a question by the parents, it is useful to address the answer to the boy; his self-respect will be boosted and a conversation may follow that will help in assessing his involvement with his own management. The Gillick case established that children can make decisions about their care well before the standard age of consent.

It is also essential to maintain contact with the young outside the traditional face-to-face consultation. This means using social media and messaging systems, while at the same time ensuring that confidentiality is not compromised. Research with adolescents born with exstrophy, but doubtless applicable to other groups, has found that there is a dominant wish to be regarded as ‘normal’ by peers. Attachment to a school disability nurse, for example, immediately marks them as different and limits the activities in which they are allowed to participate. Direct messaging, rather than visits and maintaining confidentiality, are essential in maintaining ‘normality’.

In hospital practice, transition arrangements are becoming more common and should now be regarded as a standard for proper care. Most subspecialties in paediatrics are researching pathways that are appropriate to their own patients, and adolescent medicine is recognised in some hospitals. The American Academy of Pediatrics (AAP) recommends that transition should begin between 18 and 21 years old.6 This seems to be much too late: boys could potentially be married with children of their own while still attending a paediatric clinic or hospital!

The model that is emerging in urology, as in many other specialties, begins at 11 or 12 years old, when an assessment of the child’s long-term needs is made by the paediatric team. At about 13 or 14 years of age, the child starts to attend a clinic with both the paediatric urologist and members of the team who will be taking over. This allows mutual introductions and the beginning of a medical record for adult care. It has been shown that continuity of care is a key factor in successful transition.7 At least four to five visits are required for the adolescent to build the same level of trust with the new doctor that was experienced with the paediatrician.8

There then follows a transfer phase in which the consultations and decisions are made predominantly by the adolescent/adult clinicians, but the paediatricians remain involved. During this time, it is most important to introduce the sexual
and fertility aspects of the medical condition, especially where it affects the pelvic organs. Full fertility is likely to be established before the move to long-term adolescent care is finalised.

At an agreed point, the final transfer is made to adolescent/adult care. However, although the urologist will be the central point of contact and should arrange appropriate follow-up (at least annually), a team of other specialists and nurses who understand the specific conditions is needed to look after the non-urological aspects that invariably come with the primary condition.

Other specialties have established similar protocols. Some hospitals have departments for adolescents in many areas, including cardiology, rheumatology, oncology, psychology, nephrology, orthopaedics and endocrinology, to name but a few.

CARE BEYOND ADOLESCENCE
An area of some debate is whether transition into adolescent care is an end in itself, or whether lifelong follow-up is desirable. Common observation shows that adolescence is a complex period in life, both for the boy and his parents. It is not surprising that there are special needs for those with a serious chronic illness or congenital anomaly.

The chronic conditions of childhood can be divided into two groups:
• those that have a clear parallel in adulthood, such as asthma and diabetes
• those without an equivalent or where the effects of the condition in childhood radically change its progress in adulthood, such as exstrophy.

Those in the first group can, at some convenient time, transfer from adolescent medicine to full adult care.

Those in the second group, in the view of this author, require specialist care for life. In urology (and several other areas), there is no adult equivalent – there is no adult exstrophy, prune belly syndrome or disorders of sex development. Even the similarities that neural tube defects and posterior urethral valves have with acquired adult conditions are deceptive. This creates a new subspecialty yet to have an agreed name.

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REFERENCES

KEY POINTS
• Boys with chronic illnesses and congenital anomalies are now surviving into adulthood
• There is reluctance by paediatricians, the patients and their parents to make arrangements for adult life
• Medical practice must adapt to the requirements of the patients to make these arrangements
• Structured programmes of transition are emerging in most paediatric subspecialties
• Care through adolescence is not an end in itself and lifelong management is necessary