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'Everybody's business': transition and the role of adult physicians

Helena Gleeson, Sara McCartney and Victoria Lidstone

ABSTRACT – The outcome of transition from paediatric to adult care is often judged by what happens after transfer. Young people at the point of transfer are reported to have low levels of knowledge and independence. These observations could be interpreted in one of two ways: either that the transition process before transfer is inadequate or that the transition process needs to continue into young adulthood and therefore adult care. The second interpretation is further supported by brain development continuing into the third decade. There is also growing evidence for the effectiveness of young adult clinics in the process of transition. To optimise transition, adult physicians need not only to work with paediatricians to achieve continuity during transfer, but also to look critically at their service as to how it can be changed to meet the needs of young people. In addition, they need to develop knowledge, skills and attitudes to communicate effectively and address a young person's developmental and health needs.

KEY WORDS: transition, adolescents, young adults, age appropriate care

Introduction

Transition has been described as 'a multi-faceted, active process that attends to the medical, psychosocial and educational/vocational needs of adolescents as they move from child-centred to adult-orientated care'.[1] There is evidence that optimal transition is not being achieved for a significant proportion of young people. The recent report from the Children and Young People's Health Outcome Forum (CYPHOF) states that transition services in the UK need to adopt 'an approach combining both a pull (from adult care) as well as a push (from paediatrics)'.[2] Adult physicians need to know how to 'pull' effectively to provide a service that meets the needs of young people transferring into their care (Fig 1).

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Transition does not end at transfer

Transition is a process and, although most literature focuses on the process up to transfer to adult services, it is after transfer that outcomes of transition are judged. Studies have shown that young people drift away from adult care and suffer deteriorating health. We suggest that it is time to focus on the transition process continuing beyond transfer, into young adulthood. This approach is further supported by evidence from neuroscience that the brain continues to develop into the third decade, with implications on thought processing and risk taking.[3] The extension of transition into young adulthood allows additional time for young people to become autonomous in their healthcare and achieve their full adult potential, the latter potentially delayed or disrupted by growing up with a chronic condition. Adult physicians need not only to aim for continuity of care with paediatric colleagues, but also to adapt their skills and services to meet the young person's changing needs.

Working with paediatricians

A recent survey of paediatric and adult gastroenterologists found differing perceptions of whether young people were prepared at the time of transfer; the main areas of concern were lack of knowledge and self advocacy.[4] By developing close working relationships, the responsibility is shared for how young people are prepared for transfer. Transition policies should be drawn up with a shared goal of continuity across a number of domains (Table 1).[5]

Interventions to support transition

Structured transition programme

A UK-based multicentre study in rheumatology found that a structured transition programme with individualised transition planning was associated with improved quality of life.[7] Such programmes should be multidimensional (Box 1),[6] including condition-specific and generic health education and skills training which have been found to be associated with improved clinical outcomes in the majority of transition studies.[7] Starting the programme during early adolescence (aged 11) was associated with the greatest gains in knowledge.[6]

Introducing the adult team

Transition clinics jointly run by paediatric and adult teams were associated with positive outcomes in only three out of eight studies.[7] Although meeting the adult team prior to transfer is undoubtedly seen as a positive, careful organisation is required to

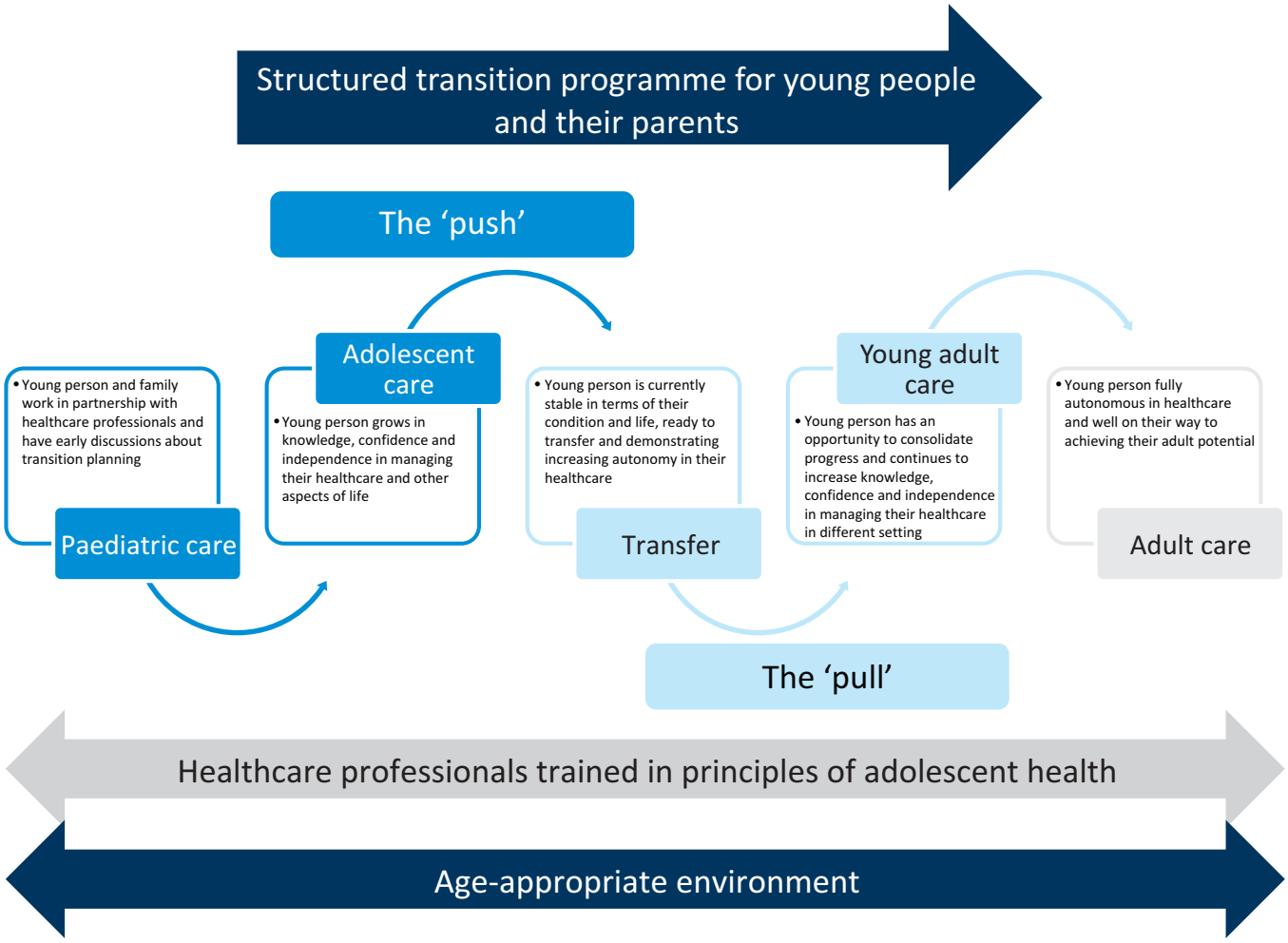

Fig 1. Transition process from paediatric to adult care: the 'push' and 'pull'.

ensure that young people are not overwhelmed by multiple people in the consultation and left unsure as to who has management responsibility.[5] Joint clinics could either be age-banded, enabling young people to be seen over a period of time in a young person-friendly environment with their peers, or for the purpose of handover with one (or several) appointments providing an opportunity for the paediatric team to introduce the young person to the adult team. Where an age-banded or handover clinic is not possible, transfer could be organised to their local adult clinic, with 'back-up' appointments at the paediatric clinic that continue to run until the young person feels settled and at ease with the new environment. Arranging visits to the adult service before transfer might also be welcomed by the young person, and many services offer 'look around' adult inpatient facilities if a young person is likely to make use of these in the near future.

Transition coordinators

A role spanning paediatric and adult services could fulfil a valuable integrating function. In two out of three studies, the presence of a transition coordinator was associated with positive benefit.[6] The role could be fulfilled by an administrator who could assist young people in navigating the healthcare system, a healthcare professional who could provide holistic care, or a professional with skills in working with young people.

Identifying young people ready for transfer

Identifying the readiness of a young person for transfer is challenging and an area of current research. Confidence and skills to manage independent hospital visits, greater perceived independence during consultations, a more positive attitude toward transition and who reported more discussions related to future transfer were found to be associated with young people being ready to transfer.[8] Ideally, transfer should not occur during a flare up of the condition or medication change, or if there is upheaval in the young person's life in general. Transfer summaries should be written and agreed with the young person and should provide information about them, their condition, past and present investigations, management and treatment. Information regarding ways of making contact with the adult service should also be provided.

Table 1. Domains of continuity in the process of transition.[5]

Continuity	Description
Relational (staffing)	A therapeutic relationship with a named health professional
Longitudinal (staffing)	Care from as few professionals as possible, consistent with needs
Management	Continuity of condition management through a common purpose and plan
Cultural	Seamless progression from a child to adult service culture across service interfaces
Flexible	Adjustment to the needs of an individual over time
Developmental	Care that grows with the changing demands of the client group and works to facilitate that change
Informational and/or cross boundary	Excellent information transfer following the service user, including effective communication between professionals and services

Box 1. Multidimensional areas included in structured transition programme (adapted with permission, from McDonagh *et al.* 2007).[6]

- Disease-specific information
- Autonomy in healthcare, including lone consulting
- Roles of healthcare professionals and differences between paediatric and adult care
- Plans for transfer
- Body image, growth and puberty
- Peer support, bullying and disclosure
- Independent living
- Education and vocation
- Generic health issues, including diet, dental health, exercise, drugs and alcohol, sexual health, in addition to driving and trips away from home
- Information-seeking strategies and internet safety

Adapting adult services

Ask young people what they want

One easy way to decide how adult services should be adapted is to ask young people. Participation by young people can be encouraged in many ways to the benefit of services and young people alike. The RCPCH have produced a document called 'Not just a phase' detailing the ways that participation can be used effectively.[9] Involving young people is one of the criterion in the Department of Health (DoH) 'You're Welcome Quality Criteria', which sets out ways that services can be adapted to become young person friendly (Table 2).[10,11] This document has been used in some regions in the UK to support commissioning negotiations for young people's services.

Young adult clinics

In a recent systematic review on transition, three out of four studies showed that running a clinic specifically for young adults in the adult setting was beneficial.[7] Renal transplantation services have recently published their experience of setting up a young adult clinic: benefits included improved adherence and engagement with healthcare, resulting in reduced transplant failure rates.[12] Young adult clinics provide an opportunity for contact with peers and to settle into the new environment. Consideration should be given to: improving accessibility by running clinics in the afternoon to early evening, allowing young people to be seen out of school and/or college hours and miss less time from work; providing longer appointments to allow time for lone consulting and psychosocial screening; and reviewing the standard adult 'did not attend' policy is key so that young people are not discharged for non-attendance without exploring the reasons why.

Table 2. You're Welcome Quality Criteria for young person-friendly health services.[10]

Criteria	Description
Access	Outlines how to ensure that services are accessible to young people
Publicity	Highlights the importance of effective publicity in raising awareness of the services available and explaining the extent of confidentiality. Effective publicity enhances access
Confidentiality and consent	Addresses confidentiality, consent and safeguarding, and how these are implemented by staff and understood by service users. This theme supports, and is supported by, local safeguarding arrangements
Environment	Addresses service provision, environment and atmosphere, with the aim of ensuring that they are young-people friendly (at the same time as being welcoming to all service users, regardless of age). The 'environment' is taken to include the atmosphere created by physical arrangements as well as staff attitude and actions. The environment can contribute to ensuring confidentiality for service users
Staff training, skills, attitudes and values	Addresses the training, skills, attitudes and values that staff need to deliver young people-friendly services and to ensure that the needs of young people are met
Joined-up working	Addresses some of the ways to ensure effective joined-up delivery
Involvement in monitoring and evaluation of patient experience	Addresses the importance of young people's involvement in service development, monitoring and evaluation
Health issues for young people	Outlines the health needs of young people as they go through the transition into adulthood. Includes universal issues affecting all young people and issues affecting those with specific long-term health needs

Young people as inpatients

The first experience of adult services for a young person might be during an inpatient admission. Hospital admissions for chronic conditions (eg diabetes, epilepsy or asthma) have increased in 10–19-year olds by 26% over the past 7 years.[13] Young people on adolescent wards (compared with adult wards) were more likely to report excellent overall care, feeling secure, having confidentiality maintained, feeling treated with respect, confidence in staff, appropriate information transmission and appropriate involvement in own care.[14] However, dedicated adolescent inpatient facilities currently do not exist in most centres. Therefore, the focus needs to be on providing age-appropriate care through staff training, flexible visiting so that family or friends can provide support, nursing young people with those of similar age and providing dedicated social areas for young people. For young people who are likely to require inpatient admissions, arranging visits to adult services to meet staff and providing information about day-to-day and expected acute care, as well as wants and needs, should be part of transition planning. This is particularly important for young people with conditions that are not frequently seen on adult wards and those with learning difficulties and/or complex disability.

The first consultation and beyond

Young people and parents have identified that the quality of their relationship with a healthcare professional is important (reference 15). Surveys of UK adult physicians demonstrate that lack of training is a significant barrier to providing age appropriate care.[4,16] Work is underway through the Royal College of Physicians (RCP) to improve training of future adult physicians in the care of adolescents and young adults. Useful approaches are detailed below and training resources are available, including the Adolescent Health elearning Programme, which is free to all NHS employees (www.rcpch.ac.uk/AHP).

Continuity and confidentiality

Key to the relationship with the adult physician is continuity. Young people have reported that it takes at least four to five visits before they trust a particular doctor.[17] If continuity is actively promoted, 77% of young people with diabetes were less likely to be hospitalised following transfer to adult care.[18]

Young people have a right to confidentiality. Concerns about confidentiality can deter young people from consulting their doctors: this is particularly true for older adolescents and young women.[19] Adult physicians should take the time to explain about confidentiality and it's limits at the first consultation and not assume that it is fully understood. The DoH You're Welcome Quality Criteria recommends displaying information about confidentiality in clinics for young people.[10]

Parents and lone consulting

For parents of children who have been unwell, particularly for those who have had a serious long-term health condition, the shift from care-giving to providing advice and support when needed is difficult.[20] The consultation is an opportunity for parents to satisfy their information needs and provide ongoing support for their child. Navigating this can be challenging for adult physicians. It is important to balance the information needs of parents and acknowledge their role,[21] while ensuring that the young person recognises that the process revolves around them.

Actively encouraging lone consulting with the young person for part, or all, of the clinic appointment, is helpful in increasing the confidence of the young person in their own healthcare and facilitating changes in the parental role.[22] Lone consulting has been associated with improved quality of life, readiness for transition and more successful transfer.[15] However, surveys have shown that less than half of all adult physicians see young people on their own.[23]

Table 3. HEEADDSS: a psychosocial interview (adapted with permission).[27]

H: home	Where do you live and who lives there with you? How do you get along with each member? Who could you go to if you needed help with a problem?
E: education and employment	What do you like about school and/or work? What are you good and not good at? How do you get along with teachers and other students and/or work colleagues? Inquire about bullying. What are your future plans?
E: exercise and eating, including body image	Are you happy with your weight? If you were going to lose weight, how would you do it?
A: activities and peers	What sort of things do you do in your spare time? Are most of your friends from school and/or work? Do you have one best friend, a few friends or lots of friends?
D: drugs, including smoking and alcohol	Many young people at your age are starting to experiment with cigarettes or alcohol. Have you or your friends tried these or other drugs? How do you pay for them? Do any members of your family smoke or drink?
D: depression, including suicide	What sort of things do you do if you are feeling sad, angry or hurt? Some people who feel really down often feel like hurting themselves or even killing themselves. Have you ever felt this way? Have you ever tried to hurt yourself?
S: sexuality and sexual health	Some young people are getting involved in sexual relationships. Have you had a sexual experience with a boy or girl or both? Inquire about contraception and avoidance of sexually transmitted infections
S: sleep	Inquire about sleep. Adolescents who are depressed and anxious have difficulty falling asleep

Self-management of chronic conditions

Moving to a new service provides an opportunity for a new start and a new relationship between adult physician and young person. At the beginning of this relationship, the adult physician should remain open and 'assume nothing'. A young person's knowledge about their condition can be low,[4] so exploring this is important. Finding out what the young person finds most difficult about having their condition and how it affects their life is a good starting point. Poorly developed abstract thinking can affect a young person's ability to plan for the future, which might affect motivation and ability to self-manage, including adherence with medication. Therefore, focus should be placed on short-term benefits.

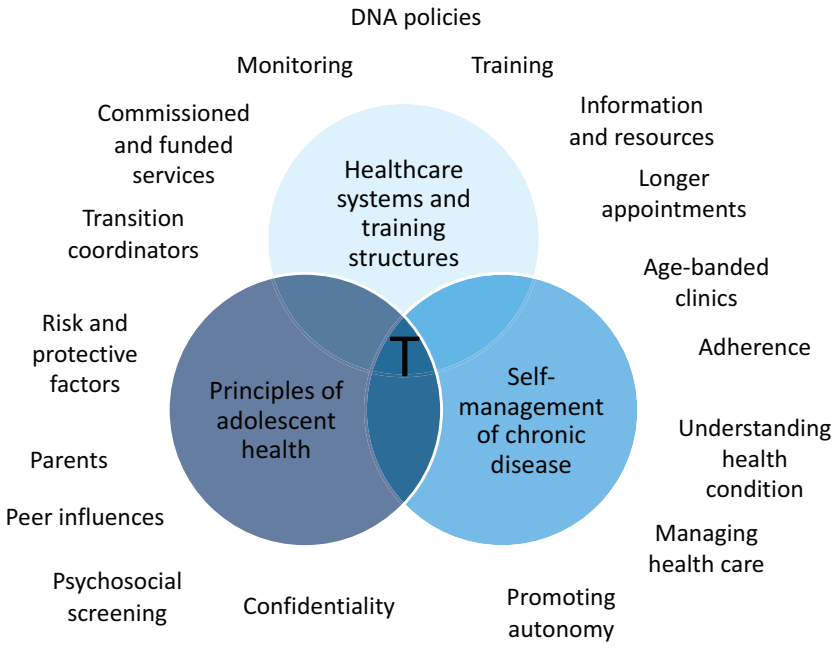

Fig 2. Summary of essential elements for age-appropriate care transition.[30] T = transition.

Psychosocial screening and health promotion

Psychological and social development are an important consideration in this age group. Young people with chronic conditions are at risk of not fulfilling their potential as adults.[24,25] It is during adolescence that 'risky' health behaviours develop that can continue into adult life; such behaviours are reported to be more common in young people with chronic conditions compared with their healthy peers.[26]

Using a psychosocial screen enables the adult physician to adapt their consultation to address both developmental aspects and health behaviours, and provides an opportunity to develop a rapport with the young person. The 'HEEADDSS psychosocial interview for adolescents' is the most widely used interview scheme and covers home, education and employment, eating and exercise, activities, drugs, depression and suicide, sex and sleep (Table 3).[27] Confidentiality needs to be raised at the outset and parents and other adults should not be present. Using HEEADDSS screening has been shown to be helpful in identifying concerns in up to one-third of patients.[28]

Adult physicians might feel that they do not have all the answers for this age group. Depending on the issue identified providing information and signposting young people to local services or relevant websites (such as www.teenagehealthfreak.org and www.youthhealthtalk.org) may be sufficient.

Monitoring outcomes

Ongoing monitoring and evaluation are key to ensure that young people are engaged with healthcare and to guide development of transition and adult services (Table 4).[15]

Table 4. Proposed standards and outcomes for monitoring and evaluation of transitional care.[15]

Proposed standard	Outcome
Quality standards	Measure services against the You're Welcome Quality Criteria for young person-friendly health services and standards set out in DoH transition documents including: opportunities to be seen alone, transition planning, psychosocial screening and transfer summaries
Effectiveness and safety	
Attendance outcome	Attended first two appointments in adult service
	Engaged with adult services 1, 2, 3 years after transfer
Clinical outcomes	Markers of condition and/or disease control and/or complications
	Unplanned hospital admissions
Non-clinical outcomes	Living independently
	Education and/or vocation
Patient reported outcomes	Assessment of disease and/or condition knowledge
	Assessment of self management and advocacy
	Assessment of quality of life
Experience	Young people and their carers' satisfaction with transitional care

Support from RCP, specialist societies, associations and healthcare trusts

The RCP has formed a steering group across specialities to focus on the needs of this age group and of adult physicians in caring for them, with a focus on training, clinical governance, standards, aspects of service delivery, and public and patient involvement. Specialist societies and associations can also have a key role in identifying needs within their specialty and their patient population (Box 6). For example, Together for Short Lives, a national charity involved in care of children and young people with palliative care needs, has published and rolled out 'The Transition Care Pathway'.[29] Trusts, in association with commissioners, need to agree on which interventions can be delivered across specialties to optimise transition. Adding transition and age-appropriate care to the new outcome framework, as recommended by the CYPHOF, would protect and facilitate development in this area.[2]

Summary

The adult physician is in an ideal position to improve transition for young people with chronic conditions. Transition does not stop at transfer but continues into young adulthood and through the early years of attending the adult service. It should be considered complete only at the point that the young person has achieved their adult potential for independence in healthcare and self-management. To optimise transition and age-appropriate care (Fig 2), adult physicians need not only to work with paediatricians to achieve continuity during transfer, but also to look critically at their service as to how it can be changed to meet the needs of young people. They also need to develop knowledge, skills and attitudes to communicate effectively and address a young person's developmental and health needs.

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Royal College of Physicians

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Supporting international training links

The Royal College of Physicians (RCP) works with partner institutions abroad to support training for international medical graduates (IMGs) by facilitating placements, General Medical Council (GMC) registration, and a Tier 5 visa.

Candidates must meet selection criteria appropriate for GMC registration and immigration requirements and are interviewed by a joint panel of UK and partner institution consultants in country. The RCP currently has sponsored IMGs awaiting placements in medical specialties, including CMT-level GIM rotations, and ST3+ in the following:

interventional cardiology > rheumatology > renal medicine > diabetes and endocrinology > medical oncology > nuclear medicine > intensive care gastroenterology.

If your hospital or trust would like to submit a clinical training fellowship towards the MTI scheme for placement, or if you would like more information on the MTI, please visit:
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