Think transition

Developing the essential link between paediatric and adult care

EXECUTIVE SUMMARY

RCPE

Royal College of Physicians of Edinburgh

The Royal College of Physicians of Edinburgh Transition Steering Group

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Think transition: developing the essential link between paediatric and adult care

SUMMARY

- Many more children with chronic illness are now surviving into adulthood and need to be optimally equipped and supported to enable them to live fulfilling lives. Young people who need continuing healthcare into adulthood have generally been transferred from paediatric services at a time of great change in their lives, both physical and emotional. This guidance includes recommendations and key messages based on the limited evidence available and current practice to support clinical teams caring for young people and their families through transition. It should be read in conjunction with the *Report of the Age Appropriate Care Working Group*, produced by the [Scottish] National Steering Group for Specialist Children's Services (available online at http://www.specialchildrensservices.scot.nhs.uk).

- As well as addressing the generic issues raised by optimising transition care, the guidance considers four exemplar conditions which, between them, highlight some of the diverse issues that need to be addressed in providing the best care for young people with chronic illness. Young people have influenced the guidance by sharing their perspectives and reminding us of the importance of an individualised approach to transition.

- The key recommendations and messages are reproduced below in summary form. Readers interested in the evidence and detailed discussion should refer to the full document published at http://www.rcpe.ac.uk/clinical-standards/documents/transition.pdf

GENERIC ISSUES

This section summarises the generic issues that are widely applicable to young people moving from paediatric to adult care. They include:

- Core principles for transition;
- Education and independence;
- Ethical issues;
- Inequalities in health;
- Remote and rural issues;
- Fertility and sexual health.

CORE PRINCIPLES FOR TRANSITION

Each hospital should have a transition policy setting down the principles of transition from paediatric to adult healthcare. A transition programme should allow flexibility in relation to the specialty, hospital or team.

Transition is not synonymous with transfer – it must begin early and be planned carefully. Ages at final transfer will vary, but it normally should take place in the late teens.

The transition process should address specific health problems and how they affect the young person's social, psychological, educational and employment needs and opportunities.

The transition process should extend beyond the day of discharge/transfer from paediatric services, with the ongoing care received in the adult sector being of equivalent quality and intensity.

Young people must be involved in developing their transition programme to enhance their sense of control and independence.

Recommendations

- Young people should be given the opportunity to be seen without their parents.

- Transition services must address the needs of parents/carers, whose role in their child's life is evolving at this time.

- Transition services must be multidisciplinary and multi-agency. Optimal care requires that a sound co-operative working relationship is developed between adult and paediatric services, particularly where the young person has complex needs with multiple specialty involvement.

- The co-ordination of transitional care is critical, requiring an identified co-ordinator who supports the young person until he or she is settled within the adult system. This could be an adolescent nurse specialist, transition co-ordinator, community nurse, youth worker, etc.

- Young people should be encouraged to take part in transition/support programmes and/or put in contact with other appropriate youth support groups.

- The involvement of adult physicians prior to transfer supports attendance and adherence to treatment.

- Transition services must undergo continued evaluation. No one model fits all.

EDUCATION AND INDEPENDENCE

The education needs of everyone involved in the process are critical to the development of successful transition programmes. Education is required for young people, their parents and carers and all health professionals with a role in transition.

TRANSITION EDUCATION FOR YOUNG PEOPLE
Preparation for self-management of the young person's condition throughout childhood
Dedicated time for education sessions
Positive promotion of transition as a step towards adulthood
Experience of attending paediatric clinics alone as a rehearsal for adult services
Awareness of their legal rights as children and as adults (including consent and confidentiality)
Knowledge about their disease, its management and their responsibility for their own health
Preparation for transition with accurate information about adult services, including in-patient services
Understanding of how to use an independent advocate if they choose to do so
Awareness of local and internet-based peer group support
Awareness of general healthcare and how to access general medical services
Coping and self-advocacy skills
Self-care skills if relevant (e.g. for a young person with learning difficulties)
Other related life issues (e.g. educational or housing issues, benefits, employment options, etc.)

TRANSITION EDUCATION FOR PARENTS/CARERS
The rationale for self-management from early in the disease process
Awareness of the legal rights of their child and their responsibilities as parents
Preparation for transition with accurate information about adult services
Preparation for their changed status in relation to their child's autonomy
Preparation for changes in health service provision for adults with chronic disease
Understanding of the natural history of their child's disease and the possible risks for deterioration
Preparation for letting go and accepting their child's healthcare decisions

EDUCATION FOR HEALTH PROFESSIONALS (INCLUDING THOSE IN PRIMARY CARE)
Recognition of the importance of transition and an understanding of its complexity
Knowledge of the legal rights and status of children, young people and their parents
Knowledge of the national and local health services accessible to young people
Understanding of the challenges and common behavioural responses of young people under stress
Awareness of the demands of education and society on young people
Understanding the theories of resilience and self-efficacy as they apply to coping with chronic disease
Educational theory that identifies learning styles and maturational readiness for self-directed learning

EDUCATION FOR PROFESSIONALS INVOLVED IN TRANSITIONAL CHRONIC ILLNESS
Understanding the concept of transition in relation to the specific role of the chronic disease team
Knowledge of the team structure and dynamics of both their own team and partner specialist teams
Understanding the importance of team education on facilitating transition, including joint training for paediatric and adult teams
Knowledge of locality-specific differences in the provision of transition
Understanding the importance of patient-centred programmes for young people with a specific chronic disease
Awareness of the strengths and vulnerabilities in individual young people and their families
Awareness and understanding of the roles of transition co-ordinator and "key worker"
Understanding the practical limitations on treatment needs at key stages, e.g. leaving home or shared accommodation

ETHICAL ISSUES IN TRANSITION

During childhood, healthcare decisions are made by proxies, usually parents, who should act in the child's "best interests". The gradual process of maturing from childhood to adulthood, where healthcare decisions are generally made by the individual concerned, forms the most significant ethical challenge in the discussion of the ethics of transition care. The key principles of biomedical ethics, outlined below, create a framework to guide the principles that should underpin all forms of transition.

Beneficence and nonmaleficence

These are the duties to do good and avoid harm. Empirical evidence for transition is sparse, and further research and/or audit is required to determine the benefits and potential harm that could result from different models of transition or, perhaps more likely, lack of transition support.

Justice

The principles of resource allocation and prioritisation in cash-limited healthcare systems raise significant issues for patient-specific transition services and the approach to triage.

Respect for autonomy

This is manifest is two major ways:

- Autonomy over the decisions about when and how to enter transition and achieve transfer;
- Confidentiality – the necessity of ensuring great sensitivity and judgement in respecting the wishes of young people. The ethical dilemmas that this may give rise to within families must be appreciated by the healthcare team involved in transition.

INEQUALITIES IN HEALTH

The impact of deprivation and/or social exclusion on the health of young people can be profound, with significant effects on the health outcomes and well-being of the individuals concerned. In general, insufficient research has been carried out regarding the management of chronic illness among these potentially vulnerable patients groups. The evidence that exists and best practice point to the following recommendations:

Key messages

- Staff should be trained to identify at an early stage those who may be at higher risk, so that there can be adequate preparation for transfer.
- A transition co-ordinator should manage the transition of potentially vulnerable young people to adult services and continue for a period after transfer. Young people should be involved in the choice of this person. The Care Co-ordination "key worker" model provides a useful framework for training and implementation. This role is not limited to health.
- Young people and their families should be actively involved in the transition process and provided with information in an appropriate format.
- Cultural mediators may help address important cultural and social factors, particularly in relation to young people from ethnic minority or gypsy/traveller communities. This role would complement that of the transition co-ordinator.
- Communication between services is critical – novel methods for facilitating up-to-date record keeping and information sharing should be used more widely, such as hand-held records. This may be particularly important for looked-after or accommodated young people, or those from gypsy/traveller communities.
- The relationship between GPs and young people and their families should be fostered during the transition process.
- Young people with neuro-disability and their families require specialist support. Adult services need to be developed where they do not exist or where an adequate service is lacking. Improved access to adult allied health professional services is also required.
- These developments will require commitment from health boards to advancing transition care for more vulnerable groups.

REMOTE AND RURAL ISSUES

The management of young people with chronic illness living outwith urban centres has not been adequately investigated. Further research is needed into how to optimise multi-disciplinary input, consolidate patient education and structure the transfer to adult services for this group.

This guidance has been developed following consultation with healthcare professionals and young people from remote/rural areas on current systems in place, and identifies potential areas of improvement. Recommendations from the Scottish Government and the Remote and Rural Steering Group have also been taken into account.

Key points

- The model of paediatric care will depend on the place of residence, structure of local services and support arrangements. Examples include any of the following, alone or in combination:
  - specialty clinic in a distant tertiary centre;
  - specialty clinic in a distant district general hospital run by a local paediatrician or visiting consultant;
  - clinic in a rural general hospital or community hospital run by visiting consultants from a district general hospital or tertiary centre;
  - predominantly GP-managed care with support from a distant district general hospital or tertiary centre.
- The responsible paediatrician, local and specialist multidisciplinary team members and the GP should discuss how best to provide care for each person of secondary school age requiring transition.
- Training needs of local staff should be identified early.
- Where numbers requiring transition in a locality are low, it may be helpful to develop the role of the local community children's nurse by offering transition nurse specialist training.
- A key worker should be appointed to manage transition – this could be the GP or a local allied health professional, nurse or youth worker.
- The model of service to which the young person will eventually transfer should be identified.
- Age-banded multidisciplinary clinics should be introduced, with at least one joint adult/paediatric clinic prior to transfer. If there are inadequate patient numbers or resources to facilitate these transition clinics, extra effort should be made to "bridge the gap" via GP or local hospital services with extra support from remote specialist services. Telemedicine may facilitate more collaborative clinics.
- Young people should be provided with written or multimedia information about their adult services.

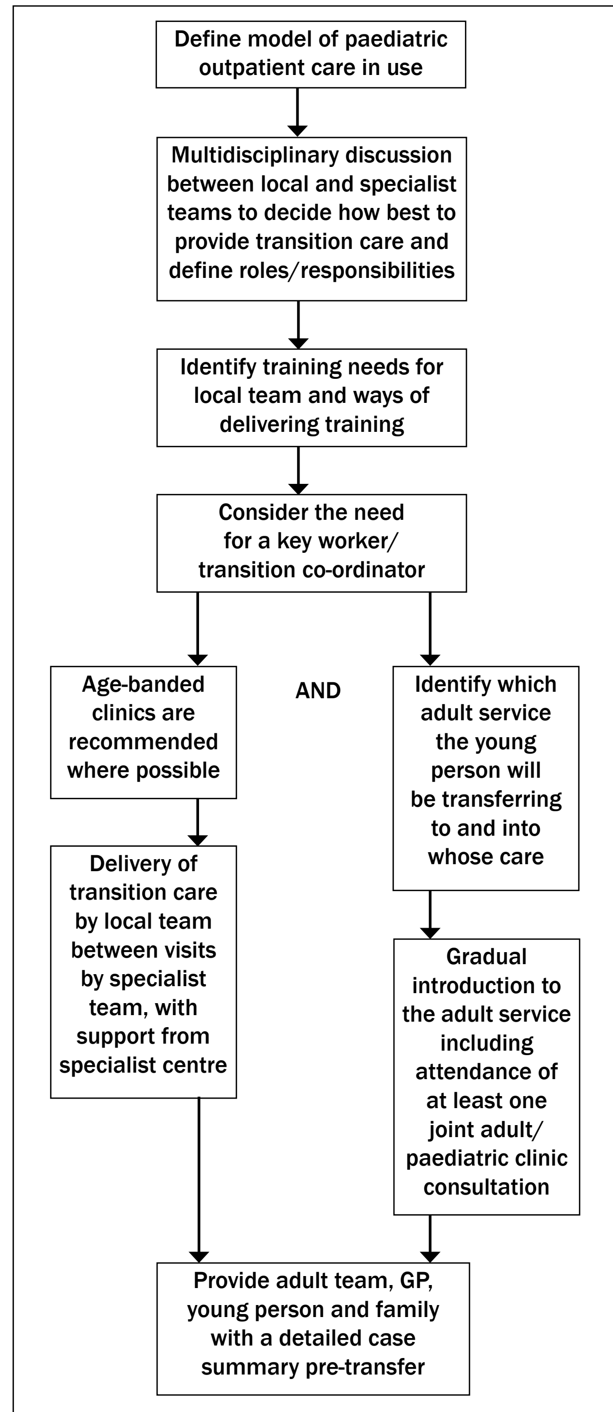

FIGURE 1 Transition pathway for young people with chronic illness living in remote/rural areas (Sophie Khadr)

- Young people, their families, the GP and the adult healthcare providers should be given detailed case summaries on paper or in electronic form.
- The chosen transition pathway should be formally assessed for effectiveness and acceptability.

The flowchart above summarises a proposed pathway for young people in remote and rural areas requiring support through transition.

FERTILITY AND SEXUAL HEALTH

With increasing life expectancy and improved disease control in many chronic illnesses, discussions concerning fertility and sexual health cannot be ignored. Healthcare professionals caring for young people need to be aware of a wide range of issues related to fertility, including:

- Genetic counselling – the timing of discussions and whom to include is important.
- Impact of fertility status on health – the risks of a pregnancy both to the mother and unborn child.
- When best to explain about fertility issues to young people and their families – young people with life-limiting conditions or those where the disease or treatment reduces fertility may need earlier counselling.
- The ability to have children – earlier choices made by parents may require explanation and justification.
- Contraceptive advice – the timing may be critical; young people and their parents may have very different views.
- Likely pregnancy complications.
- Personal/societal pressures around having children.
- Ability to care for children.

The relative importance of each of these will vary within and between patient groups.

DISEASE-SPECIFIC ISSUES

These sections collate the key messages and recommendations for four disease-specific groups (cystic fibrosis, renal failure, type 1 diabetes mellitus and survivors of childhood cancer). These exemplar conditions were selected because of the likely differences in approach, the numbers of young people affected or the relative scarcity of current services. The full report includes an assessment of the available research, recommendations based on evidence where it exists, and current practice.

CYSTIC FIBROSIS

Increasing life expectancy and complexity of care in cystic fibrosis require the development of robust protocols for transition from paediatric to adult centres. Evidence and experience support the following:

RECOMMENDATIONS FOR THE TRANSITION OF CYSTIC FIBROSIS PATIENTS
Patients should begin to be informed about transition early, around 12–13 years, but it may be useful to introduce the concept of transition to parents when their child is very young.
Patients and families need a clear plan and timetable for transition, together with detailed information about the adult centre. Written information is important.
Close liaison between adult and paediatric teams is needed for an efficient transition, with advance handover of comprehensive clinical records.
In the UK, actual transition is usually begun at the age of 15 and completed by the age of 16.
Joint clinics, where the patient is seen by paediatric and adult teams together, are especially valued by patients and families.
Parents find transition very stressful and need time to develop trust in the adult team and adjust to the adult model of care.
Transition coincides with other major life changes, and patients commonly rebel against their cystic fibrosis treatment just as they are asked to take responsibility.
Gradual empowerment of patients to take control of their treatment is appropriate. It is welcomed by most but worries some and often unsettles parents.
With careful advance planning and good communication between all parties, the great majority of patients are able to make the transition to adult centre care without difficulty. Indeed, many see it as a positive "rite of passage".

CHRONIC RENAL DISEASE

Transition is a difficult time for young people with renal failure; it is well recognised that this is a time of increased transplant loss. Adherence to medication, diet and other interventions are often problematic during adolescence, and transition to an unfamiliar environment may aggravate the situation.

RECOMMENDATIONS FOR THE TRANSITION OF RENAL PATIENTS
Start early, ideally around 12 years of age, and present transition as a natural progression in care.
Assess the health beliefs of the young person regularly to adapt interventions to changes in cognitive capacity.
Transition should be a multi-agency, multidisciplinary process, ideally with a key worker identified.
Include regular assessment of the young person's areas of needs and particular difficulties, as well as strengths, to allow individualised planning.
Include a written transition plan in the case notes to document input required/provided.
Provide continuous education about the illness and the treatment, including written information, from an early age to promote understanding of the condition by parent and patient.
Involve primary care early in the course of the patient's illness. Many patients attend the paediatric nephrology unit or local paediatric unit rather than their GP's surgery.
Provide a written summary for the adult unit (and patient) about past medical history, including procedures and operations.
Plan for educational/vocational/careers provision.
Ask the young people what would help them.
Ensure the availability of mental health professionals, probably psychologists in most cases, as required.
Provide information packs/handouts about adult services.
Arrange visits to the adult facilities to allow familiarisation.
Include joint clinics with adult services to allow the young person to get to know the new staff.
Review patients regularly during adolescence, particularly transplant patients, to pick up the consequences of non-adherence early.
Where possible, transfer patients to adult services at the same time as others their age or arrange a "buddy system", where young people meet patients who have transferred previously.
Develop a formal process to say "goodbye" to the known service and staff.
Develop young adult clinics within adult services for the first few years after transition.

TYPE 1 DIABETES MELLITUS

The most common age of type 1 diabetes mellitus (T1DM) diagnosis is during childhood, with significant numbers of patients transferring to adult care during their late teens. As these young people move through transition the concerns are that their glycaemic control appears to deteriorate and that they have specific health needs relating to the physical and socio-cultural changes of adolescence.

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE RECOMMENDATIONS FOR THE TRANSITION OF T1DM PATIENTS
Young people with T1DM should be encouraged to attend clinics on a regular basis (three or four times per year) because regular attendance is associated with good glycaemic control.
Young people with T1DM should be allowed sufficient time to familiarise themselves with the practicalities of the transition from paediatric to adult services because this has been shown to improve clinic attendance.
Specific local protocols should be agreed for transferring young people with T1DM from paediatric to adult services.
The age of transfer to the adult service should depend on the individual's physical development and emotional maturity, as well as local circumstances.
Transition from the paediatric service should occur at a time of relative stability in the individual's health and should be co-ordinated with other life transitions.
Paediatric diabetes care teams should organise age-banded clinics for young people and young adults jointly with their adult specialty colleagues.
Young people with T1DM who are preparing for transition to adult services should be informed that some aspects of diabetes care will change at transition. The main changes relate to targets for short-term glycaemic control and screening for complications.

The following aspects should be considered when establishing a transition service:

- The children's team needs to communicate and be comfortable working closely with the adult team, in both routine and emergency situations.
- Both must share a philosophy, as well as an understanding, of the social positioning in their culture of adolescence.
- The transition clinic should be served by both teams.
- Agreement should be reached about venue, age range, the involvement of parents and peers, clinical standards and care strategies.
- The service should have easy access to psychological support.

Education programmes should include advice and direction on the management of diabetes and various lifestyle issues, including alcohol, smoking cessation, avoidance of recreational drugs, pre-pregnancy planning and contraception, extreme sports and work.

Recommendations

The limited evidence from the UK suggests that transition clinics should:

- Start at around 18 years of age (following on from age-banded clinics in the paediatric service);
- Encourage the participation of adult health professionals in the older age-banded (e.g. 16–18 years) clinics in the paediatric service;
- Facilitate the participation of families and peers;
- Encourage an intensive approach to insulin therapy, accompanied by formalised and frequent screening for micro- and macrovascular complications;
- Develop effective communication between paediatric and adult services about patients;
- Design an audit system to test the effectiveness of the transition service.

LONG-TERM SURVIVORS OF CANCER

The number of long-term survivors of childhood cancer continues to rise. Increasing awareness of the late complications of cancer therapy requires vigilant, long-term follow-up with early intervention, treatment and appropriate counselling. There is no evidence available to define the optimum follow-up for long-term survivors, and there is wide variation in when survivors are currently discharged.

At present, this group of patients is generally followed up by paediatric oncologists in a paediatric environment long into adulthood. This is neither appropriate for young people nor practical for the paediatric oncologists co-ordinating their care. There are few adult services or facilities available and new services are required to ensure safe transition into age-appropriate, long-term follow-up.

Recommendations

Key messages from a review of transition services for this new and growing group of patients include:

- Multidisciplinary long-term follow-up of childhood cancer survivors is essential to ensure that patients are followed up efficiently in age-appropriate environments.

- As patients approach adulthood (16–18 years), clinical risk stratification of their follow-up needs will enable adolescents to benefit from a transition process that takes them into an appropriate pathway. This could include:

  Level 1 – low risk; for follow-up in general practice, supported by a “late effects” specialist nurse.

  Level 2 – some risk of future complications; followed up in adult specialist clinics, supported by a late effects specialist nurse.

  Level 3 – significant risk of late effects, albeit that some may not manifest until well into adulthood. It is likely that many patients will have therapy-related complications and require transfer to adult services with an understanding of the late effects of childhood cancer treatment.

- A late effects nurse specialist can play a key role in supporting and co-ordinating care as young people progress through the transition period.

- Effective transition from specialist paediatric oncology care to appropriate adult supervision will be important. Active engagement of young people in their long-term follow-up/supervision may support the development of strategies to improve their future health.

WHERE NEXT?

This guidance identifies evidence-based practice (where it exists) and comments on good practice within current services. It also identifies significant gaps in our understanding of, or ability to support, young people with chronic illness through this critical stage in their lives. The next steps must include:

Next steps
Developing clear transition policies within local health plans.
Creating descriptions of local adolescent services for young people, their families and healthcare professionals. It should be clear to patients and their families who is responsible for their care.
Targeting research efforts into different models of care, with particular emphasis on addressing the inequalities challenge and delivery of support to young people living in remote and rural areas.
Addressing the long-term follow-up needs of childhood cancer survivors.
Promoting good practice for early adoption by other teams, particularly where there is limited reliable research evidence.
Seeking appropriate outcome measures to assess the impact of changing models of care.
Securing attention (and resources) for vulnerable groups and patients with complex disabilities. Local policies should identify and quantify these needs.
Adding an awareness of the special needs of young people to all health-related education curricula and training programmes.
Developing specialist training for the emerging roles in adolescent medicine.