Think transition

Developing the essential link between paediatric and adult care

RCPE

Royal College of Physicians of Edinburgh

The Royal College of Physicians of Edinburgh Transition Steering Group

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“Sometimes I feel like there’s no point in me going on my own... They’ll phone to check I told my mum... It’s my health, I should remember”

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http://www.rcpe.ac.uk/clinical-standards/documents/transition.pdf

From the President of the RCPE

This guidance was designed to raise awareness of the important issues facing young people as they move from paediatric to adult care, and to provide all concerned with practical support to improve their experiences. The College believes it will be of wide interest to clinicians of all disciplines and in all healthcare settings and, of course, to young people and their families. I commend it to you.

This project reflects the practical yet innovative and energetic approach to life of the late Dr Gordon Piller, a past trustee and enthusiastic supporter of the Royal College of Physicians of Edinburgh. Gordon was a well-respected research scientist who devoted his working life to the care of children, latterly as Chief Executive of Great Ormond Street Hospital. The transition topic was very much his initiative, and we are grateful to him and the Children's Research Fund for the grant that has supported the work.

I would like to thank all those who have contributed to the project. I know that the chairman and members of the steering group will welcome comments and updates for our "living" web-based version of this guidance, at http://www.rcpe.ac.uk/clinical-standards/documents/transition.pdf.

Neil Douglas
President, Royal College of Physicians of Edinburgh

The purpose and use of the guidance document

"A painful passage o'er a restless flood"
– William Cowper (1731–1800)

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 require continuing healthcare into adulthood have generally been transferred from paediatric services at a time of great change in their lives, both physical and emotional. Growing up presents challenges for all young people in today's society and can be difficult and turbulent. Experimentation is normal, but its consequences in terms of, for example, sexual health, poor concordance with treatment and disaffection with the healthcare system can be particularly problematic for those with serious chronic diseases.

The process of maturing from childhood to adulthood is complex for young people, their carers and health providers. Young people move from a model where healthcare decisions are made by parents and others acting in their "best interests" to systems where they are expected and encouraged to do more for themselves. There are issues about how best to recognise developing autonomy, the appropriate development of services and facilities and the best use of limited resources. If paediatric and adult services provided truly age- and developmentally appropriate adolescent care, transition care would happen naturally. The ultimate goal is to embed transition care as part of adolescent health provision.

Training in and understanding of the ongoing health needs of young people are essential for health professionals and should be informed by the views of young people themselves. The recent Royal College of Paediatrics and Child Health UK national adolescent health e-learning training initiative, which is available to all health professionals (paediatric and adult, doctors and nurses) at http://www.e-lfh.org.uk, includes modules on chronic illness and transition and will be especially valuable. NHS Education Scotland is also exploring the development of adolescent care training packages. These organisations have been specifically represented on this steering group, as have NHS Quality Improvement Scotland, with a view to the eventual development of standards for adolescent healthcare provision for young people.

Particularly vulnerable groups should be identified and their needs co-ordinated and addressed. Until now, transition has been primarily paediatrically driven, and it is therefore especially pleasing that this report has been developed under the auspices of the Royal College of Physicians of Edinburgh. Adult physicians have key roles in the development of adolescent services and transition care. Engaging adult care providers remains a significant challenge in many areas.

Adult services may require development or establishment where none existed previously. Communication between service providers needs to be improved, not least in terms of the care of young people in those parts of Scotland remote from the major conurbations and specialist centres.

As the National Service Framework published by the Department of Health in 2006 states transition should be "a purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents with chronic physical and medical conditions as they move from child-centred to adult-oriented healthcare systems".

The National Steering Group for Specialist Children's Services emphasises, in its *Report of the Age Appropriate Care Working Group* (available at http://www.specialchildrensservices.scot.nhs.uk), that "the transition of patients from children's to adult services is a key element of successful care which needs to be well planned and structured" and that "service provision needs to be responsive to the emerging autonomy and independence of adolescent patients and to encourage them to take responsibility for their own healthcare". It has noted that the recommendations in the present report, which are complementary to its own, should be adopted and progressed.

There is, therefore, a requirement to ensure that the transition to adult services of young people with long-term conditions is recognised in its own right by health professionals, service providers and young people themselves as a vital element of the patient journey. Successful transfer from paediatric to adult services should be the culmination of a period of planned transition. This active process needs to be co-ordinated and reviewed with continuing input from the young person concerned. It should be age- and developmentally appropriate and although, in many circumstances, it will take place by 18 years of age, it is important to avoid set age limits. Transfer of care must not occur when the issues generated by a change of service will further complicate the challenges for the young people concerned and their families.

As well as addressing the generic issues raised by transition care we have chosen to look at 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 illnesses. There are other areas and conditions that we have been unable to address specifically in the present guidance, which is not intended to be comprehensive. The document hopefully highlights issues that are transferable and adaptable.

I am pleased to say that young people themselves have played a key role in developing this guidance, and I am most grateful to them and the many others listed as members of the steering and sub-groups for their contributions.

Many of these recommendations are based on experience rather than evidence, and further research in this area is required. At present there are no outcome data to support one form of transition over another. Small patient numbers and heterogeneity among patient groups make these difficult but not impossible to acquire. Further information from focus groups and through patient, parent and staff questionnaires should be encouraged. Adult and paediatric units need to work together to develop transition services for young people.

The importance of developing services, facilities and units specifically designed for young people is also highlighted in the *Report of the Age Appropriate Care Working Group*, which should be read in conjunction with this document. Both publications highlight the need for the development of appropriate training and facilities and recognise the importance of multi-agency input in relation to, for example, education and employment issues. Together with those of the Age Appropriate Care Working Group, the recommendations in this guidance will, if implemented, ensure that services are designed, developed and provided which will greatly improve the care provided to young people with chronic health problems in Scotland.

Professor Chris Kelnar
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Why it's important – as reported by the Young People's Health Advisory Group

For too long the transition of young people from paediatric to adult services has not been as good as it could be and, as a result, many young people have had experiences that are less than helpful during this important phase in their lives.

By the time young people transfer to adult services they are maturing and becoming independent. Not only are they going through transition in terms of their healthcare but other aspects of their lives are changing too. This period of intense change must be recognised by adult services. So often young people feel overwhelmed and left behind because they are not aware of their rights and responsibilities in an adult world.

Children and young people with chronic illnesses and disabilities who have been using paediatric health services throughout their lives may have become used to taking a back seat when going to the hospital or attending other healthcare appointments. It is important to empower young people to make their own decisions, particularly as they assume more responsibility for their own healthcare. The change from paediatric to adult services should be a smooth one so that patients feel informed and in control of their health.

There are many types of young patients: some may have the same illness but not the same age or personality, which is why transition must be carefully structured and, as the National Steering Group for Specialist Children's Services' *Report of the Age Appropriate Care Working Group* states, "needs to be responsive to the emerging autonomy and independence of adolescent patients and to encourage them to take responsibility for their own healthcare".

Good communication is vital, and the manner in which doctors and other healthcare staff communicate with young patients is important to the relationship they build. If health professionals can establish a good relationship with patients it will make this aspect of the young person's life a lot easier to cope with. Effective education and training are key to achieving this.

This guidance provides health professionals with some much-needed recommendations, which, if taken on board, should ensure that young people experience a positive and supported transition from paediatric to adult services, just as they deserve.

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- Young people interviewed about their remote/rural chronic illness care

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SECTION 1
Guidance on generic issues

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

"I used to hope my parents would make all the decisions... I have to start making my own"

1. Core principles

SUMMARY

- There is often confusion around the definition of transition from a health perspective, and the practicalities of what transition demands of clinicians. In healthcare terms, transition is "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented healthcare systems",[1] as distinct from the simple act of transfer.
- This section focuses on the basic principles of what should be involved in preparing and supporting young people in their transition from a paediatric healthcare environment and their establishment within the adult health sector.
- Paediatric and adult medical teams play key roles in meeting the challenges of transition.

INTRODUCTION

Within the UK there have been calls from the Government for "services for adolescents [to be] given greater focus and priority. The transfer of young people, particularly those with special health needs, from child to adult services requires specific attention."[2] The importance of transitional care has since been highlighted in the National Service Framework for Children[3] and the intercollegiate report *Bridging the gaps: health care for adolescents*.[4] With the requirement for paediatric and adult health services to take the needs of this group into consideration when planning and developing services, safe and effective transition is now "a key quality issue for the National Health Service".[5]

It is inevitable that young people (aged 12–19 years) with a chronic medical condition or physical disability will have to transfer from paediatric to adult services,[6] since advances in medicine mean that children with such conditions are now surviving well into adolescence and adulthood. To improve health outcomes and allow young people to take their place in society to the best of their ability, a period of transition, or preparation, is required.

BACKGROUND

Young people who require ongoing healthcare in the adult sector are largely transferred from paediatric services during one of the most vulnerable periods of their lives. There is strong and growing evidence of the fundamental inter-relationship between physical, mental and social health, and there is also evidence that patterns of health behaviour established during adolescence are maintained throughout adult life[7] (e.g. smoking, substance abuse, eating disorders, levels of physical activity, obesity and sexual risk taking). As a result, improving the healthcare of young people has become a national priority,[8] and features in the *National framework for service change in the NHS in Scotland* report of 2005.[9]

The Scottish Government initiative "Patient focus/public involvement"[10] clearly sets out how we should be striving for a patient-focused NHS. The definition of patient focus is an NHS that listens and talks to its patients and carers, demonstrates an understanding of the needs of those using the service, and is able to respond flexibly. The United Nations Convention on the Rights of the Child (UNCRC), Article 12,[11] and the NHS Reform (Scotland) Act (2004) also place a responsibility on the inclusion of children and young people who, given the opportunity, are keen and able to participate meaningfully in decision making, whether it be about their healthcare or about service evaluation or design.

DISCUSSION

It could be argued that if we had true age- and developmentally appropriate adolescent health services, incorporating all facets of adolescent health, transition would flow naturally. As this is not yet the case, it is important to understand concurrent adolescent developmental issues in conjunction with chronic health issues, as young people's reactions to, understanding of and involvement in their healthcare will change over time.

One positive change clinicians can make during transition is to provide opportunities for young people to see them independently of their parents. This has been shown to be a predictor of successful transfer to adult care[12] and is associated with improvements in health-related quality of life.[13] It is also a key method of demonstrating transition,[14] is valued by young people themselves[15] and is considered both feasible and best practice in the majority of hospitals in the UK.[16] These opportunities need to be introduced sensitively, however, because children's adolescence can

provoke many emotions in their parents, such as loss or fear, sparking a crisis in the parents' own emotional well-being. It is, therefore, essential that the needs of the parent(s)/carer(s) are taken into account during the transition phase. Their continued presence and participation in their child's healthcare is important, but care must equally be taken to ensure that they are prepared for the necessary changes that will evolve. It is important that parents/carers understand the philosophy of transition, are aware of consent issues and of their child's rights to confidentiality, and so are prepared to work with healthcare professionals in achieving the best for their child.

YOUNG PEOPLE'S VIEWS

"My parents are afraid of the change."
– Kirsty, 17

"My dad was too intense and involved… I don't speak to him about it at all now."
– Andrew, 17

"[I'd like to] see the doctor on my own, so it's actually me listening instead of my mum. I need to get used to listening and finding out things."
– Mark, 16

As stated earlier, health problems can impact on many areas of adolescent life, and accurate, age-appropriate information is essential. For this reason, many commentators advocate a multi-professional approach to intervention.[17,18] This may involve collaboration between doctors, school health service professionals, young offenders' teams, social workers, youth workers and specialist treatment centres. Liaison between health and education services is also valuable for adolescent sexual health and relationship issues. Multi-professional collaboration may help to ensure that adolescent health services are provided seamlessly and that adolescents do not suffer harm during the transition between children's and adult services.

YOUNG PEOPLE'S VIEWS

"[Education around lifestyle issues] should have been done earlier. People start to drink really early. You should teach about it in first or second year when you're still naïve and listen… I was handed leaflets, but the information isn't realistic, so you just chance it."
– Andrew, 17

Emerging evidence supports the generally accepted notions that the process of transition should begin as early as possible, generally by secondary school age, and in the later stages involve opportunities to meet and interact with adult clinicians.[19] However, there is no "right" time or age for the subsequent transfer to take place. Chronological age should not be the only criterion for deciding when to transfer a patient; the transfer must also take place at a developmentally appropriate time.[1] There is often a dilemma between the practicalities of transferring according to age versus maturity, and a range of ages are mentioned in this document. This is not meant to confuse but is a reflection of the different disease-specific and psychosocial needs of young people. The process is often multifaceted, for example where there are several different specialties involved or a young person has learning disabilities or other complex needs. Importantly, when deciding on transfer timing, account should be taken of the many other transitions and significant events taking place in the young person's life at the time, such as exams, relationships and peer pressures, and transitions from school to work, parental home to independent living, and so on.

Transition is a longer process than is generally appreciated and, in many situations, it may not be appropriate for transfer to be made until the late teens or, in exceptional circumstances, beyond this age. To achieve cohesion in such cases may require someone to co-ordinate the different processes involved.[20–22] Young people should be consulted and their wishes taken into account when choosing their transition co-ordinator. However, at present there are limitations to the availability of people with appropriate training/skills for this role, which is an issue that must be addressed.

Peer support is immensely important to young people and plays a vital role in adolescent development,[23] often taking precedence over family support. For young people with chronic illnesses, it can seem that they are alone in the world with their particular problem. Young people respond well to group situations where they can be empowered and supported in exploring their health problems in the context of their daily lives and the pressures of growing up in today's world.[24] Hospital youth workers, though thin on the ground, are an excellent resource to access if help is needed in developing peer support groups.[25] Failing that, local council youth workers can be very supportive in any healthcare setting and can continue their involvement with young people into their twenties, i.e. after transfer to adult services.

YOUNG PEOPLE'S VIEWS

"But if you can go and… somewhere in the hospital… socialise with people your own age it also helps."
– Richard, 17

As in all areas of the health service, evaluation must be carried out in order to provide evidence of benefit, identify areas where improvements can be made and allow adaptation to changes in the pattern of service provision. Until recently there has been a lack of robust evidence for the beneficial effects of transition, but this is changing. Recent research has shown significant improvements to health resulting from a planned transition.[13] Centres participating in this research also report a general improvement in adolescent and transitional care issues.[26]

As the transition process spans paediatric and adult services, a transition policy that sets out what is expected and involved in the process is essential. One of the components of any policy advocated should be access to an interested and capable adult clinical service, which has close links with the paediatric service. The adult service should have an understanding of the developmental needs of young adults and participate actively in transition.[27] Individual specialist disciplines should provide specifically for the needs of young people and, where numbers justify, consider developing a separate young people's service.[28]

Achieving continuity into adult services is a significant challenge for the NHS in Scotland. Adult physicians will play a key role in meeting these challenges. Their involvement during the transition process and prior to transfer has been shown, among other things, to improve young people's attendance at appointments through to improved disease control.[29,30] The dearth of high-quality education in adolescent health has been a barrier to involvement for some, but this situation is rapidly changing (see Education and independence, pages 14–18), and it is hoped that more physicians will see the benefits that accrue to their practice through a better understanding of adolescent development and age-appropriate treatment of young people.

GUIDANCE

- A transition programme is an essential part of quality care for young people with chronic illnesses, and 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 to adult services. Transition is an active process and not a single event like transfer. Transition must begin early, be planned and regularly reviewed with the young person, and be both age- and developmentally appropriate. Age at final transfer will vary, but transfer should normally take place in the late teens.

- The transition process should address not only specific health problems, illness education and self-management, but also the way these health problems affect the young person's wider health, 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, regardless of social circumstances, origin or place of residence.

- Young people must be involved in developing their transition programme to enhance their sense of control and independence in their healthcare. A useful forum for this development is within "age-banded" or "dedicated" adolescent clinics if there are sufficient patients to warrant them. Separate clinic or not, young people should be given the opportunity to be seen without their parents.

- Transition services must address the needs of the parent(s)/carer(s), whose role in their son's/daughter's life and healthcare is evolving at this time. Both paediatric and adult clinicians may need to make some changes in their approach to young people to facilitate this.

- Transition services must be multidisciplinary and multi-agency, involving the specialty team(s) at the paediatric, district or rural general hospital, the adult providers and general practice, education, social services and voluntary agencies. There is no one model that fits all situations and so it is particularly important that a sound co-operative working relationship is developed between adult and paediatric services irrespective of the setting.

- Co-ordination of transitional care is critical, particularly for those with multiple specialty involvement, learning disabilities or other complex needs. In these cases, a co-ordinator should be identified to oversee each young person's transition. To ensure seamless transition, this person should either link with a counterpart within the adult service or remain involved until the young person is settled within the adult system. Healthcare centres should actively consider the need for an Adolescent Nurse Specialist/Transition Co-ordinator and, where these professionals are in post, their skills should be fully used in the transition process.

- Young people should be encouraged to take part in transition/support programmes. Where these do not exist, efforts should be made to develop such programmes or put young people in contact with appropriate youth workers and youth support groups.

- Positive involvement of adult physicians along with paediatricians, prior to transfer, has a positive outcome on attendance at appointments and disease control, and should occur routinely.

- Transition services must undergo continued evaluation. This will be the responsibility of each individual specialty.

WHAT'S NEXT?

A cultural change in the attitude and behaviour towards young people within the NHS is needed, one that acknowledges and adheres to relevant legislation (e.g. the Age of Legal Capacity (Scotland) Act 1991), recognises adolescence as a unique developmental stage and so understands adolescent behaviours in this context and actively and sensitively promotes young people's involvement in their own healthcare.

The development of a transition policy is required in all healthcare settings where young people are treated. This, together with related procedures, integrated care pathways or transition programmes will help clinicians in all fields incorporate transition into common practice, and enable more robust audit or research into both the process and its effects on young people's long-term health outcomes.

Regular review of developments within this field in the UK, Europe and the wider world will help inform practice and may avoid duplication of effort. For example, the piloting of an integrated care pathway and transition policy specific to Great Ormond Street Hospital (GOSH) is currently under way. This may, in the near future and with GOSH's consent, be deemed suitable for adaptation in other hospital settings.

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2. Education and independence

SUMMARY

- Growing up presents challenges to every adolescent; those with chronic disease are not exempt from these trials. It is logical to focus on the needs of the young person with chronic illness for education about transition, but the process of change also affects parents and health professionals.
- Preparation for transition should be a part of chronic disease management in childhood. Progressive sharing of knowledge and skills in disease management among the child, the parents and the healthcare team helps promote optimal outcomes at each stage of the process.
- Allocation of time for education about transition may seem a luxury in the hard-pressed clinic setting, but lack of preparation, fear of the unknown and the tendency for resistance to change can lead to wasted therapeutic efforts, the loss of confidence in self-management skills and the risk of loss of concordance with care.
- A basic education about the health needs of adolescents forms an essential part of the training of any health professional involved in their care. Education about transition for chronic disease care can be readily incorporated into specialist disease-specific education.

INTRODUCTION

The purpose of this section is to explain the need for education and training for all those involved in the care of young people with chronic diseases. In harmony with the concepts of partnerships in healthcare, self-management, the expert patient and the expert parent, several disparate groups must be targeted, chiefly the young person, parents and carers and health professionals. Guidance for each of these groups is outlined. Although this project has considered specific diseases, it is appropriate to generalise this education and training in managing chronic disease to any condition affecting a young person during adolescence.

Young people are expected to move from paediatric to adult services within a specified period, usually identified by chronological age. The age limits, decisions about when to impose these limits and question of how much flexibility can apply generally rest with several different authorities. These include the consultant(s) in charge of clinical care, the nurse managers in charge of inpatient and outpatient facilities, the healthcare managers in charge of facilities and the Department of Health in charge of health policies in the UK. If the concept of patient-focused care is to apply to young people with chronic diseases then a degree of flexibility around the age of transfer to each component of adult services is necessary. Any regulation on these issues must be clearly stated and agreed by all those involved, to avoid young people or their families being given confusing or conflicting information and expectations.

Health rights have been increasingly promoted over recent years. The emphasis on patient and public participation through such organisations as NHS Quality Improvement Scotland attempts to ensure the active involvement of users in the planning and provision of healthcare.[1] The legal status of children and young people changes over the adolescent years, and so their own and their parents' legal authority in relation to healthcare decisions also changes. The General Medical Council has recently issued guidance on the medical care of children and young people.[2]

It is important to differentiate between transition and transfer in the context of chronic disease. Transfer from paediatric to adult services is a sequence of actions that requires careful preparation and follow-on plans but can be identified and contained within a predictable timeframe. In terms of healthcare delivery and management, education for transfer can follow the "patient pathway" model with best practice guidelines leading to an audit of performance against standards, including quality standards.[3,4]

Transition, on the other hand, includes transfer but is a more complex process of progressive change from parent-focused clinical management, involving the child as compliant with decisions about care, to a patient-focused approach that depends on patient concordance with disease management. To achieve successful transition the child must learn about his or her medical condition, understand the rationale for treatment and acquire self-efficacy skills. Self-efficacy refers to young people's personal judgements of their own abilities to engage in behaviours that lead to specific desired outcomes.[5] In the context of transition this involves them accepting themselves as people with chronic diseases and with the power to look after themselves, and

to know how to the access necessary support for disease management. Many of the essential skills for transition are the skills that children need to cope with growing up. Young people learn these skills in relation to personal health as part of their general education, and the same progressive approach from the time of diagnosis facilitates the process for any chronic disease.[6] The specific needs of young people who have been in the care of local authorities should be considered throughout their transition plans, and options for the choice of key workers discussed with them accordingly.

BACKGROUND

Transition is a period of change and the need to manage change is well recognised in the health services. Keeping the focus on health service provision throughout the transition helps to ensure that the specific issues relating to service providers and users can be identified. This project focuses on the needs of the young person with chronic disease whose specific needs during transition are significant.[7–9] The healthcare needs of all adolescents are the subject of many specialist texts and adolescent health itself is a medical sub-specialty.[10] Education resources on adolescent health for health professionals are widely available.[11–15] In relation to coping with chronic disease, the physical, mental and intellectual changes that occur in adolescent years are relevant to transition.[16]

Change management can be facilitated by training: to recognise the need for change, set targets, identify key steps to be taken to achieve agreed targets, agree responsibilities for reaching each step and its consequence, recognise the stress involved in making the changes and plan coping strategies, and celebrate when the change results in a satisfactory outcome – independence and autonomy.[17,18] The challenge of navigating transition involves a linked multidisciplinary team approach. It may help to identify a key worker who has the training, skills and experience to support the young person and his or her family through the stages of transition.[19]

Being familiar with the composition of the relevant specialist teams, the new clinic and inpatient facilities and the priorities of the transition process, the key worker can accompany the young person to early appointments to the adult unit, help with independent medical consultation and advocate for the young person if that is what he or she wishes. Young people may choose a member of the paediatric team, an independent advocate or voluntary befriender to offer continuity and support their autonomy. Others might wish to establish a pre-transition link with a named member of the adult team.

For conditions such as diabetes, the adult services will involve both secondary and predominantly primary care in a different relationship from the paediatric equivalent.[20–22] In this situation, all these teams should be involved in transition planning and the key worker or other transition co-ordinator must work across all three sectors.[23] When the young person is moving away from home during the transition period, it may be more appropriate to establish a key worker link from the new adult service and to consider the potential for peer support in an educational setting.[24] This situation has much in common with that of the remote and rural service transition, and a similar approach can usefully be adopted.

Adolescents are biologically programmed for change. Their physical, emotional and social development is reaching the stage when independent adult life is beckoning, and coping with a life that includes a chronic disease is just one aspect of this experience for the individual.[25,26] Parents and carers are, if not prepared for the transition to adulthood, at least expecting this stage in their child's development and may be anticipating their child's increasing independence in a positive or negative light. How parents or carers view handing over to their child the management responsibilities for the chronic disease care also differs for individuals.[27,28]

The healthcare professional is not necessarily prepared for this phase of a patient's life and may need education and training how to best approach this aspect of disease management. The paediatric specialist team members often have a very close long-term relationship with the children and families in their care. Transfer to adult services involves ending this relationship and entrusting their best efforts to another team. Such changes can be unexpectedly stressful and preparing to cope is an important element of continuing professional education.[29,30]

A formative approach to preparing for the transition to adult care is not always easy and seldom quick. Recent acknowledgement of the adverse effects of poor preparation for transition in relation to non-attendance at specialist clinics, non-compliance with essential medications and poor outcomes has been reported from different specialist services including diabetes and renal disease.[31,32] Common themes that improve the success of transition to adult care include the flexibility to initiate and complete transition at the appropriate developmental stage for the young person. Assessing this readiness may rely on the skills of a transition co-ordinator from the paediatric team who should be trained to assess the level of maturity of young people and their consequent potential to accept more responsibility for their own care.[33] The co-ordinator can help colleagues in both paediatric and adult services to adapt their approach to the young person, and to understand the issues influencing their ability to accept the demands of their treatment and disease monitoring. Concurrently, parents are trying to adapt to their changing role from accepting and implementing treatment plans to supporting their children as their children take control of their conditions.

Since the identification of the issues involved in the transition to adult care over a decade ago,[34] there have been several reports emphasising the importance of transition care and acknowledging the need for improved services targeted to the care of the young people in transition.[4,35,36] The education of staff for this service development is recommended,[30,37] but there is limited evidence for the

content or delivery of such educational materials. The British Paediatric Rheumatology Group has recommended a transition training approach that has content relevant to all chronic disease transition.[38]

The US initiative Assisting Children through Transition and the UK charity Contact a Family produce training materials for families on surviving transition and on working in partnership with professionals. The joint Royal College of Paediatrics and Child Health and Contact a Family project "Parents and Paediatricians Together" identified ways in which parents can be empowered to become expert in their child's healthcare needs and treatments.[39]

An equivalent training package for young people in transition and their parents could offer an opportunity to help them acquire the coping skills they will need as they enter the adult healthcare services.[40,41] Young people relate most strongly to their peer group, and an evidence base is emerging for the usefulness of face-to-face peer support as another way of promoting health and self-advocacy and facilitating illness education.[24] Internet-based support and self-management programmes and other technologically mediated methods are also being explored as a means of delivering training in a youth-friendly way.[16]

Child health services, including specialist paediatric services, are available to every child, and both parents and professionals have a responsibility to ensure that every child benefits from them and is protected from harm.[4,42] Chronic diseases such as the exemplar conditions considered in this report involve sub-specialist teams that offer a relatively closed group of professionals aiming to offer holistic care to the affected children and their families. In the wider societal context, children's services are widely regarded to be best provided through integrated services involving education, child and family social services and voluntary agencies serving children. Children with chronic diseases may have had relatively little contact with primary care due to their frequent attendance at hospital and the demands of their complex treatment.[24]

In adult services the disease determines health service provision and the support services are aimed at disease-specific needs. Whether it is the individual or the parents who seek help, it will not be provided on the basis of age and legal status. The specialist team may include disease-related social work services, but the team dynamics are likely to differ from the paediatric equivalent. Primary care is expected to meet generic health needs on a patient-led basis.[43] Inpatient care is very different in an adult ward from the familiar children's hospital setting. Even an older adolescent who is unaware of the extent of the differences can find admission to a general adult unit frightening. The healthcare team can help prepare for the future with education that builds confidence to cope with new experiences.[44,45]

GUIDANCE

Transition education for young people

- Include preparation for the self-management of the condition throughout childhood.

- Allocate dedicated time for education sessions.

- Encourage young people to see transition as a step towards adulthood and not as a rejection by their trusted paediatric team.

- Independent visits to a young person's familiar clinic allow rehearsal for the adult clinic experience.[46]

- Ensure young people's awareness of their legal rights as a child and as an adult, and awareness of issues around consent and confidentiality.

- Provide appropriate knowledge about the young person's disease, its management and their responsibility for their own health. Features of this may include:
  - Updates on their disease and its effect on them as an individual.
  - Rationale for treatment.
  - Consequences of non-adherence.
  - Possible side effects of treatment.
  - Effects of their condition on everyday living.
  - Recognising problems and taking appropriate action.
  - Effect of drugs, alcohol, etc.
  - Disease course, +/- future concerns (health professional's versus young person's).
  - Fertility issues, including pubertal development/delay ("am I normal?").

- Prepare for transition with accurate information about adult services, including team structure and any important differences in practice. Allow adequate time to identify concerns and to address them, as well as rehearsal for adult clinic attendance – routines, personnel, administration, etc. If the young person is likely to require hospital admission to a local unit this too should be included in transition planning.

- How to use an independent advocate if the young person chooses to do so.

- How to access any recommended personal or internet peer support groups.

- Ensure awareness of general healthcare and how to access general medical services. Health promotion may be delivered on an individual basis, or as part of a workshop or activity programme with other young people through education services or youth work.

- Provide access to learning for coping and self-advocacy skills.[47,48]

- Provide access to improving self-care skills if relevant (e.g. for a young person with learning difficulties).

- Provide opportunities for the young person to discuss other concerns with skilled staff, e.g. educational or housing issues, or to ask advice regarding benefits, employment options, etc.

Education of parents/carers

- Include the rationale for self-management from early in the disease process.

- Ensure parents are aware of the legal rights of their child, their responsibilities as parents and the changes that apply with age and their child's legal capacity.

- Prepare for transition with accurate information about adult services, adequate time to identify concerns and to address them and rehearsal for adult clinic attendance – routines, personnel, administration, etc.

- Encourage parents to accept and understand their changed status in relation to their child's autonomy and how their role changes with transition.

- Prepare for changes in health service provision in general for adults with chronic diseases.

- Update parents on the natural history of their child's disease and acknowledge the possible risks of deterioration.

- Prepare parents for letting go and accepting their child's healthcare decisions.

Education for health professionals

Although the emphasis here has been on the need for all members of multidisciplinary chronic disease teams to learn about transition, awareness of the importance of this process is relevant to all professionals who have contact with young people with chronic diseases.[49] The acute general wards in district hospitals admit many young people who have had experience of paediatric care, including inpatient care on a children's ward. The differences in care delivery in an adult environment can be disorientating for such young people, and the recognition of their need for explanation and reassurance is important to reinforce their confidence in self-efficacy. Young people will attend their general practitioner with new expectations of involvement in healthcare. The potential for the primary care team to take a more active role in the transition to adulthood for the young person fits well with the emphasis on long-term condition care in the community and empowering patients to become expert in their own healthcare.[40,43]

1. *Generic education for all healthcare providers*

- Recognition of the need for transition and the complexity of the process.

- Knowledge of:
  - The physical and mental health needs of every adolescent, including health promotion and general health maintenance.
  - The legal rights and status of children and young people and of parents/guardians.
  - National and local health services accessible to young people.
  - The challenges and common behavioural responses of young people under stress.
  - The demands of education and society on young people.
  - An understanding of theories of resilience and self-efficacy as they apply to coping with chronic disease.
  - The educational theory that identifies learning styles and maturational readiness for self-directed learning.

2. *Education for professionals involved in transitional chronic illness care*[16, 37]

- Consider the concept of transition in relation to the specific role of the chronic disease team.

- Recognise the team structure and dynamics of both the professional's own and partner specialist teams.

- Allocate dedicated time for team education on facilitating transition. Consider joint training for both teams involved.

- Prepare specific and generic materials explaining the transition process in the locality, recognising individual differences based on the young person's access to the services.

- Identify issues relevant to the adolescent with a specific chronic disease.

- Acknowledge strengths and potential vulnerabilities in individual adolescents and their families, including readiness for learning new skills and responsibilities.

- Identify transition co-ordinators to ensure all necessary tasks for transition are completed as well as a "key worker" to support the young person and family through the process.

- Consider practical limitations on treatment needs resulting from age-related events – e.g. leaving home, sharing accommodation, having limited cooking skills or money for food.

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Useful websites

- Adolescent Health Project: http://www.rcpch.ac.uk/ahp
- European training in effective adolescent care and health (EuTEACH) programme: http://www.euteach.com

3. Ethical issues in transition

SUMMARY

- **Arguably the most widely used system for analysis and discussion of issues in modern medical ethics is that based on the "four principles of biomedical ethics" as developed by Tom Beauchamp and James Childress. The four principles are: respect for autonomy, beneficence, non-maleficence and justice (see body of chapter for definitions). These principles have been used for analysis of the ethical issues involved in transition from paediatric to adult care.**

- **Where the evidence base for effective methods of transition is underdeveloped, this gives rise to difficulty in the application of the principles of beneficence, non-maleficence and justice to the issue. In situations where there is an absence of clear evidence as to what is beneficial (with its corresponding duty of beneficence), what is harmful (with its corresponding duty of non-maleficence) and what represents the best use of scarce resources (with the corresponding duty of justice), the most pressing ethical consideration is the need to establish robust service evaluation, audit and research into transition methods. Where evidence for benefit (or harm) exists, the principles of beneficence and non-maleficence as articulated below would apply in considering the ethics of transition care.**

- **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. Alongside the development of autonomous decision-making capacity is the delicate issue of confidentiality.**

INTRODUCTION

The four principles of biomedical ethics – respect for autonomy, beneficence, non-maleficence and justice – are among the most widely taught methods for analysing ethical situations in healthcare practice. Beauchamp and Childress (who are most closely associated with the development of these principles) claim that they have a prima facie status.[1] This has not received universal support but has considerable endorsement by others, including those writing in a UK context.[2] Whether or not they are accepted as prima facie principles, they can be seen as a useful set of tools for unpicking and analysing the ethical dimensions of a healthcare dilemma.

In this chapter, we use the four principles of biomedical ethics, as listed above, to articulate the ethical dimensions of the transition from paediatric to adult care. We begin with consideration of the closely related principles of beneficence and non-maleficence before a brief consideration of justice. The principle usually listed first – respect for autonomy – is dealt with last because it is the single principle of the four that is potentially the most vexatious in transitional care.

We should add that an analysis using the four principles would not be the only way to proceed. There are a multitude of ethical schools of thought. A deontologist would seek to articulate the duties involved in transition care, while a utilitarian would ask what methods maximised the outcomes that were desirable in the particular situation at hand.[3] Neither of these systems gives the full picture of what is required in transition care. Kenneth Boyd has articulated elsewhere the possibility of approaching questions in medical ethics from the points of view of "principles, persons and perspectives".[4] "Principles" is the approach taken here. But why?

Focusing on the element of "persons" appeals most strongly to a school of ethical thought often called virtue ethics. While this ethical approach dates back at least as far as Aristotle (circa fourth century BC), it has seen something of a renaissance recently with modern advocates such as Rosalind Hursthouse[5] and Philippa Foot.[6] This approach suggests that the most ethical course of action would be answered by considering: "What would a virtuous person characteristically do in a specified situation?" Clearly there must be an articulated set of virtues. In the context of medical practice this may be considered to be a demonstration of the ideals of professionalism – good communication, empathy, compassion, competence

(including an awareness of the particularities of the developmental phase of adolescence) and so forth. A "persons" approach in this instance seemed to us to beg the question at hand. Conscientious clinical professionals already know well the elements of "virtuous" medical practice; the question at hand is what is special about the situation of transitional care.

A "perspectives" approach is a complex analysis and recognises that a moral problem is not something "out there" or given, like a natural object but rather an interpretation of events seen from a perspective shaped by history and tradition. While not strictly a case-based approach, there is a strong element of such casuistry in this type of analysis. Since much of the rest of this guidance draws upon particular clinical conditions and the problems of transition that go along with them, it was felt that the "perspectives" approach would be less helpful than an articulation of general ethical principles that apply in an overarching manner to the issue of transition care. So it is to a "principles" analysis that we now turn.

Briefly the four principles of biomedical ethics can be defined as follows:

(1) Beneficence. Broadly speaking, this is the duty to do good. In the context of healthcare, it is most frequently articulated as a duty of care. It can also encompass the duty to provide what, according to the best evidence available and according to the physician's best clinical judgment, is most likely to produce the best outcome for the patient (however this may be defined).

(2) Non-maleficence. This is the duty to avoid causing any preventable harm. The statement of this duty as applied to medical care dates from the time of Hippocrates. The World Medical Association's Declaration of Helsinki states: "In current medical practice and in medical research, most prophylactic, diagnostic and therapeutic procedures involve risks and burdens."[7] In other words, few healthcare activities are entirely free from the risk of causing some degree of harm. The principle of non-maleficence requires that doctors seek to minimise such harm.

(3) Justice (and, more specifically, distributive justice). This describes the principle that applies when there are competing legitimate claims for a healthcare resource that is limited in supply and thus cannot fully meet all relevant healthcare needs. The principle of justice seeks to establish which of such claims ought to have priority when not all such claims can be met.

(4) Respect for autonomy. This is literally the respect for "self-rule" (from the Greek derivation *auto* = self + *nomos* = law or rule). In the context of healthcare, respect for autonomy recognises that people with sufficient decision-making capacity (and this includes almost all adults as well as many children) should, after being given sufficient information to form an adequate understanding about the decisions at hand, be permitted to make their own decisions about their healthcare. While this leads to recognition of the fact that any adult with capacity can refuse any medical treatment, it does not lead to what may be seen as a corollary that they may demand any medical treatment. This will be expanded upon further in the context of transition.

GUIDANCE

What follows is a consideration of each principle with specific reference to the issue of transition from paediatric to adult care, in an attempt to illustrate the ethical dimensions of this aspect of clinical practice. After the discussion of each of the principles, there is more detailed consideration of how they apply to one very important ethical component of medical practice in the transition from childhood to adulthood: the issue of the confidentiality of personal medical information.

Beneficence and non-maleficence: the duty to do good and avoid harm

From an a priori perspective, it seems indubitable that a smooth transition from the care of a paediatric team to an adult care setting will benefit patients from the perspective of a sense of their own confidence in the care being provided and a sense that their ongoing treatment is a matter of concern for those providing their healthcare.

Yet what empirical evidence exists to back up what, from an a priori point of view, seems obvious? In another chapter of this guidance (see Chronic renal disease, pages 49–56), evidence has been cited that satisfaction with healthcare provision is associated with adherence to treatment.[8] The exact components of transition that will lead to satisfaction with healthcare provision have yet to be fully examined, however, and more research is needed in this regard.

It also seems clear, again from an a priori perspective, that there are risks in any transition from one setting of care to another. Important elements of treatment may be forgotten, or patients may simply feel abandoned with a subsequent loss of motivation to adhere to what may be a difficult treatment regimen. Again, empirical evidence of impact on health outcomes is sparse, but some evidence exists that, in the early years following transition, outcomes among some patients with chronic illnesses are worse. For example, an increased rate of failure of kidney transplants in the year following transition has been cited.[9] The fine details of the benefits of effective transition and the potential harms associated with transition are beyond the scope of this chapter and are more appropriately addressed in other parts of the guidance. From an ethical viewpoint, where there is evidence of benefit there is a resultant duty of care to provide that benefit where possible. Where there is evidence of harm there is an ethical duty to avoid such harm, wherever possible.

A further duty arises where the evidence base is sparse, and that is a duty to undertake research (which may come under the classification "audit" – a dubious distinction[10] – but which still seeks to address the question of gathering evidence as to the benefits and harms associated with transition).

Quoting the Declaration of Helsinki again, "even the best proven prophylactic, diagnostic, and therapeutic methods must continuously be challenged through research for their effectiveness, efficiency, accessibility and quality." And surely if "even the best proven methods" need to be held under the spotlight of ongoing research, how much more is there an ethical requirement to build a better evidence base for methods yet to be proven? Whether labelled "audit" or "research", implementation of a strategy of transition from paediatric to adult care needs effective evaluation.

Justice

For the purposes of this chapter, we ignore the question of competing claims for resources between different services. This would be to consider whether the need for greater attention to paediatric–adult transition has a greater claim on currently available resources than other healthcare issues. In the context of this chapter, we will work from the assumption that such a claim has been considered and that the extra resources needed for transition have been found to be justified.

This leaves the question of justice within the paediatric–adult transition services. It is probably a reasonable assumption that, however transition is delivered, there will be a greater need for the transition services than the system is able to supply. In such a case, some kind of prioritisation, not dissimilar to a triage procedure, is likely to be necessary.

Respect for autonomy

The question of respect for autonomy manifests itself in two major ways in the ethics of transition from paediatric to adult care. The first is the question of whether, and to what extent, patients and patients' families are able to choose the age at and method by which they make the transition. There are practical corollary questions that emerge from this:

- Is there scope for an overlap period with the timing of transition ultimately decided by the informed patient (within reasonable limits)? For example, asthmatic children may opt to move to adult respiratory service at any time between the ages of 14 and 18. depending on their own choice.

- To what extent is it possible to make individual exceptions to general policy? Consider the case, for example, of an 18-year-old patient with severe cystic fibrosis who is not expected, based on his or her individual condition, to live much beyond 20 at most: could he or she opt to remain with the same care team?

- It is recognised that competent adult patients can refuse any medical treatment, but the converse is not true: they may not demand any treatment. It is not necessarily appropriate, in the context of the ethical principle of respect for autonomy, to allow the wishes of an "ageing" paediatric patient to remain in a paediatric setting or of a patient younger than the usual age of transition to have treatment in an adult care setting. There may be overriding issues of justice, in other words, concerning the use of a scarce resource that could be diverted to an "age-appropriate" patient. Beneficence and non-maleficence may also come into play. Physicians in adult specialties may not have the required competencies to provide optimal care to paediatric patients and vice versa.

The above comments focus narrowly on the respect for the autonomy of children and families within the provision of transition services. However, what of the burgeoning autonomy of the maturing child from dependency on the family itself? One of the characteristics of the transition from childhood to adulthood is the emerging capacity to make important decisions about one's own life and future independent of (though desirably with) parental guidance. This applies across all areas of life: finance, choice of career, romantic relationships and with respect to making choices about healthcare. Methods for assessing the capacity for decision-making are beyond the scope of this discussion.

However, we propose to illustrate how this emerging capacity for independent decision-making requires sensitive handling in an important practical aspect of ethical medical practice: confidentiality.

Capacity and confidentiality

We propose to begin this discussion with consideration of two cases. Consider the hypothetical examples of two 19-year-old women with moderately severe asthma. Let us call them Katie and Jane (to avoid depersonalising language like "Patient A" and "Patient B"). Katie was first admitted with a serious asthma attack at the age of nine. She has required specialist supervision for her treatment ever since. Jane, on the other hand, is a newly diagnosed asthmatic and has recently been referred for specialist treatment. So we have two patients, both aged 19. What are the differences between them and how does this illuminate the ethical dimension of confidentiality in the transition phase?

First of all, let us consider Jane, the newly diagnosed 19-year-old asthmatic. Unless there are other factors (e.g. disabilities or other illnesses) that have necessitated continued dependence on her parents or other guardians, she is going to be treated as an adult with a full capacity to make decisions about her medical care and about the confidentiality of her medical details. On admission to hospital, she will determine whether or not her parents are contacted and, if so, will have the final say on what medical details are given to them. It may well be that she would contact a sibling or a close friend and only later inform her parents. The main point is that respect for her autonomy gives her freedom of choice over whether to consent to (or to refuse) treatment and who will be given details of her medical condition. By and large, she will be the one expected to pass on what information she chooses about her condition to parents, siblings, friends or whomever she wishes to inform. There may be exceptions to this: for example, if she were unconscious on a ventilator in intensive care, then normal practice would be for medical staff to provide some information about her condition to the next of kin. However,

such exceptional situations are not particularly illuminative with regard to transition.

Consider now the more complex situation of Katie. When first admitted at the age of nine, it is most likely that her parents would have had the primary decision-making role with respect to consent for care. While she may have been assessed as having a sufficient degree of maturity to give consent for treatment, it is most likely that her parents would have been making the decisions and, as her guardians, should have made such decisions in her "best interests". As Katie grows older, however, the situation becomes more complicated. From a legal point of view, the Age of Legal Capacity (Scotland) Act of 1991 allows that "a person under the age of 16 years shall have legal capacity to consent on his [sic] own behalf to any surgical, medical or dental procedure or treatment where, in the opinion of a qualified medical practitioner …he [sic] is capable of understanding the nature and possible consequences of the procedures or treatment".[11]

The situation is much more complex where a young person wants to refuse treatment. While some Scottish-based experts (Mason and Laurie) believe that a person under the age of majority may not refuse recommended treatment that has been sanctioned by legal guardians, this argument appears to have been based on cases in England.[12] Others have argued that Scottish law may differ and that young persons judged mature enough to give consent have an equivalent right to refuse such treatment.[13] However, this view was based on one case that may not be a relevant precedent in that, because of the nature of the case, mental health legislation was subsequently used to apply compulsory treatment. Elliston has written more extensively on the subject. She also disagrees with Mason and Laurie and expresses her own viewpoint that true respect for autonomy requires equal respect for a refusal as for acceptance of treatment.[14] However, although her conclusion asserts legal support for this view, she couches this with the observation: "Against this, as we shall see, the English courts have been able to avoid this result, even in the face of similar statutory provisions, so it may be possible that Scottish courts would also try to do so."[14] Thus it remains unclear at present whether the courts would allow a life-threatening refusal of treatment on the part of a minor in Scotland. We stress at this point that this chapter has not been written by lawyers and thus cannot constitute legal advice. Appropriate medico-legal advice should always be sought should a relevant situation actually arise!

The issues with respect to consent have their parallels in the domain of medical confidentiality. For the most part, nine-year-old Katie's treatment will be a family affair and parents will be fully informed at every step of the way. By the time Katie is 19, she is fully entitled to the usual confidentiality extended to the medical treatment of adults. She may still choose to involve her parents in her medical treatment, but this is essentially her choice and allowing this to happen is a matter of respecting her autonomy.

However, Katie is also free, in the same way as Jane, to have her medical details kept confidential, even from her parents. We have chosen a fairly broad age comparison (nine versus 19) so as to begin with the "extremes". Most nine-year-olds will have decisions made for them by parents and most 19-year-olds are fully autonomous. Similarly, the medical details of the nine-year-old will routinely be discussed with parents, while the opposite is the case with the 19-year-old.

Any transitional arrangement will need to maintain a great deal of sensitivity about the movement from the state of dependence on parents acting in the child's best interests to the burgeoning autonomy of the growing and maturing young person. If we were to consider the situation of Katie being admitted with asthma at the age of 15, the consent and confidentiality questions would be more complex. If deemed mature (according to the above criteria) and requesting that parents not be told certain details, it is likely that this should be respected, unless strong reasons can be given to the contrary. The ethical dilemmas as well as the emotional tensions and sensitivities that this may give rise to within families must be appreciated by the healthcare team involved in transition. While there is no specific evidence to support this, it seems intuitively likely that paediatric teams would tend to err on the side of involving family, while adult care teams would tend to err on the side of focusing on the patients themselves and allowing patients to involve family as they choose. The transition process will need to consider how best to bridge these differences.

Confidentiality is not the only issue that emerges with the development of sufficient maturity for decision-making capacity. However, we believe it to be not only a major issue but one that illustrates well the sensitivity with which the transition process needs to be handled.

WHAT'S NEXT?

- While not everyone may agree with all the points in the ethical analysis presented above, all conscientious health professionals and health services managers involved in transition care will wish to engage seriously with the relevant ethical issues and use their awareness of such issues to orient planning and delivery of such care.

- It is not always evident what the most appropriate "next steps" in achieving such engagement with the ethical issues are for an individual, and it would be inappropriate to be too prescriptive in this matter. However, two broad points, generally applicable to everyone, can be made with regard to the next steps:

  – All of those involved in the transition from paediatric to adult care, from both a clinical and managerial point of view, should seek to achieve a "reflective awareness" of the ethical issues involved in this transition in a manner best suited to their individual circumstances;
  – Sufficient opportunities to achieve such a "reflective awareness" should be available in the contexts of undergraduate training, postgraduate training and in continuing professional development.

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4. Inequalities in health

SUMMARY

- It is important that young people with chronic illness from potentially vulnerable groups are supported adequately during the transition phase. Staff training is required to enable the early identification of those who may be more at risk during this time so that there can be adequate preparation for transfer.
- It is recommended that a transition co-ordinator be nominated to manage the transition of these young people to adult services, including continuity of care for a period after transfer. The Care Co-ordination Network key worker model provides a useful framework for training and implementation.
- It is imperative that young people and their families are fully involved in each stage of the transition process, and in all decisions made about their care. Cultural and social factors require attention, in addition to the provision of language services where needed. Cultural mediators may be of assistance in addressing some of these issues, particularly in relation to young people from ethnic minority or gypsy/traveller communities. Young people with complex neuro- and/or learning disability and their families need specialist support.
- Communication between services must be optimised during the transition phase to enable better continuity of care. Novel methods for facilitating up-to-date record keeping and information sharing, such as gypsy/traveller hand-held records, should be used more widely.
- Health boards must commit to advancing the development of transition care for more vulnerable groups and to developing adult services where they do not exist or an adequate service is lacking, particularly for young people with neuro-disability. Improved access to adult allied health professional (AHP) services is also required.

INTRODUCTION

Differences in health outcomes that exist between individuals and groups in a given population are not, in themselves, inequalities. However, when factors such as socio-economic status, gender or ethnicity give rise to predictable differences in health outcomes in subgroups of the population, these become inequalities in health.

Chronic illness during adolescence can itself be the cause of inequality, whereby health or developmental outcomes are worse in those affected than among the general population. For example, Stam et al. found that young adults with a history of chronic illness as children attained fewer developmental milestones by early adulthood than their contemporaries, or reached these at an older age.[1] Mental health difficulties are estimated to be twice as prevalent in those with chronic illness as in healthy young people under 16 (20% versus 10%).[2,3] There is also increasing evidence that young people with chronic illness engage in risky behaviours to at least similar if not higher rates than healthy contemporaries, in spite of the potential for greater harm (e.g. detrimental effects of smoking on diabetes/cystic fibrosis outcomes).[2] Despite having more frequent contact with healthcare services than others their age, adolescents with chronic illness receive suboptimal general and preventative care, for example with respect to smoking prevention/cessation and reproductive health matters.[2]

Other causes of health inequality compound the challenges already faced by young people with chronic illness. The impact of deprivation and/or social exclusion on the health of young people can be profound, with significant effects on health outcomes and general wellbeing.[4] The Scottish Government is keen to combat this issue through improving access to care.[5] The white paper *Partnership for Care* committed the NHS in Scotland to ensuring that "whatever the individual circumstances of people's lives… they have access to the right health services for their needs".[6] Particular emphasis has been placed on patient focus and public involvement (PFPI) and improving joint working between social work and health. The NHS Reform (Scotland) Act 2004 has placed a duty on NHS boards to promote public involvement and equal opportunities.[7]

Adolescence can be a turbulent time for many young people. Transfer to adult health services may be an exacerbating factor during this period, so it is important that all young people with chronic illness receive adequate support during a transition phase. Some of the issues

specific to certain vulnerable groups and ways of surmounting these are discussed in this chapter on inequalities in health.

DISCUSSION

Little research has been carried out that specifically explores inequalities in healthcare experiences and outcomes among young people with chronic illness. Undoubtedly, more information gathering is required. Even basic statistical data about the prevalence of chronic illness are lacking in some cases, for example among refugee and asylum seeker populations in the UK.[8]

We know that socio-economic disadvantage is a risk factor for inequalities in health. Children and young people from low-income families are much more likely to experience social exclusion, lifestyles that put health at risk and poorer access to health services.[9] Smaller rises in income, unemployment, poorer quality of housing or homelessness, and a lack of access to private means of transport are all associated with worse health outcomes.[10] In general, those who have the most difficulty accessing healthcare services tend to be the families that need them the most.[11] It has been recommended that resources for young children should be targeted to need.[12] It seems logical that the same should apply to young people with chronic illness living in relatively deprived circumstances.

Further general health trends have emerged from equality and diversity work carried out by NHS Scotland as part of the Fair for All initiative, exploring the relationships between health and age, gender, disability, sexual orientation, race/ethnicity and religion/belief. For example, more teenage girls than boys take up smoking,[13] which could have a gender-specific effect on chronic illness outcomes among young people. Mental health problems and tobacco, drugs or alcohol use are more common among lesbian, gay, bisexual or transgender (LGBT) people than in the general population,[14] which again may impact negatively on those with chronic illness. In addition, LGBT individuals frequently experience stigma in the NHS, potentially influencing their engagement with healthcare services and the quality of their chronic illness care.[14]

This chapter does not aim to provide a complete review of all circumstances where inequalities in chronic illness care may exist. Instead, we will focus on several groups where there has been some study into ways of providing comprehensive and joined-up healthcare: ethnic minorities, including gypsy/travellers; looked-after or accommodated young people; and those with significant neuro- and/or learning disability.

ETHNIC MINORITY GROUPS

NHS Scotland has made it a requirement for health services to be culturally competent.[5,15] Culture affects how and when individuals access services, and these patterns are further influenced by socio-economic and environmental factors and the experience of discrimination.[16] Failure to consider cultural aspects can result in poor continuity of care, failures of communication and understanding, and substandard healthcare.[17,18] Lack of adherence to medication or advice may be interpreted as "cultural" when it is in fact down to ineffective communication.[18]

The most detailed studies of young people with chronic illness from ethnic minority communities have been carried out in relation to disability. This research points to a high level of unmet need among disabled black and ethnic minority youth. Recurring themes include a lack of awareness of services, poor provision of information and cultural insensitivity within services.[19] Such issues may impede successful transition to adult services. Those living in rural areas of Scotland from ethnic minority communities find it particularly difficult to access appropriate information and healthcare provided in a culturally sensitive manner.[20]

Among younger children, a survey of just under 600 ethnic minority parents caring for a disabled child revealed that these families were more disadvantaged than white families in similar situations.[21] They wanted more information about their child's disability and about services. Limited availability of translated materials and interpreting support could make access difficult. Families with a key worker were more likely to say they had a positive relationship with health services.

Cultural mediator/advocacy services have been suggested to empower service users and their families to be able to communicate more effectively with healthcare professionals.[20] Cultural mediation (or brokering, as it is known in North America) is "the act of bridging, linking or mediating between groups or persons of differing cultural backgrounds for the purpose of reducing conflict or producing change".[22] Beyond offering interpreting services, cultural mediators can improve the common knowledge of healthcare professionals and patients, be involved in developing educational materials for both groups and improve patients' access to services and satisfaction.[23] Mediators may be from a variety of backgrounds (e.g. translator, outreach worker, community member, social worker, nurse) but should receive appropriate training.[23]

The use of cultural mediators should not be the sole means of providing culturally competent services.[16] Training is required to improve the knowledge, attitudes and awareness of all healthcare staff. This can be done in a variety of ways. For example, the National Resource Centre for Ethnic Minority Health (NRCEMH) has produced a resource pack for healthcare professionals with details of the process that asylum seekers go through in the UK.[24] The pack includes information about the cultures/religions of the most common refugee/asylum seeker groups in Scotland, in addition to contact information for useful services, including government and voluntary agencies. Preliminary evaluation suggests that healthcare professionals have found the resource pack informative and easy to use.[25]

GYPSY/TRAVELLER COMMUNITIES

In a recent English epidemiological survey, adult gypsies/travellers, who are considered members of an ethnic minority group, reported significantly poorer health than comparable groups of non-urban residents, residents from socially deprived inner-city areas or representatives from other ethnic minorities.[26] These results echoed the findings of previous studies.[27] Traditional models of health service provision in the UK are designed to suit the requirements of the settled majority population.[27] Mismatches between health service systems and the nomadic lifestyle of gypsies/travellers are numerous: examples include difficulties keeping appointments, lack of a postal address, transport problems and the time taken to issue appointments.[20,27,28]

There is a tendency among gypsies/travellers to seek to access health services only when the direct need arises.[27] General practitioners (GPs) have been known to be reluctant to register gypsy/traveller families at their practices.[20,27,28] Cultural differences and conflicting attitudes result in poor continuity of care and record keeping for gypsy/traveller family members. Clearly, this is likely to have a significant impact on chronic illness care and the transition to adult services among young people from these communities.

In late 2005, gypsy/traveller-held records were introduced across Scotland with the aim of improving continuity of care.[29] Despite distribution to NHS boards, health professionals and primary-care settings, uptake has been poor. Reasons for this include concerns from GPs around confidentiality issues and a perceived potential for misuse of the records.[30] A series of training sessions held in 2007 sought to address these issues and increase usage of the records. If these objectives can be achieved, the gypsy/traveller-held records may help improve the continuity of care for young people in transition. Other initiatives (e.g. dedicated gypsy/traveller health visitors[27] or key workers[28]) could similarly be adapted for use within the transition care framework.

LOOKED-AFTER OR ACCOMMODATED YOUNG PEOPLE

Looked-after or accommodated young people (LAAYP) have many of the same physical and mental health risks and problems as their peers, but to a greater degree.[31] Levels of substance misuse are higher,[31] and self-harm is more prevalent.[32] Males are especially vulnerable, and recent reports have identified the growing mental health needs of LAAYP from black and ethnic minority communities. Those preparing to leave care and move into (semi-) independent living in their teens are at particularly high risk.[31] Practically, emotionally and educationally, many young people are poorly equipped to cope with life after having been in the care of social services.[31]

The *Forgotten Children* report[33] concluded that the primary cause of poor health among this group is the history of unmet need prior to being accommodated. This is compounded by the failure of conventional health systems to adapt to the needs of a mobile population and the lack of communication between agencies. As a result, many LAAYP do not receive the health assessments and treatments they require.[31] Multiple moves may involve changing health board areas, resulting in appointments being missed, delayed, changed or cancelled. The recording of young people's needs may not be kept up to date. It is important to note that young people accommodated within an extended family environment may be no less disadvantaged in this respect.

Many LAAYP find it hard to trust and engage with regular health services.[32] Professionals' awareness of their particular circumstances may be low and there is the additional stigma and fear associated with visits to clinics.[31] Children with disabilities may be further disadvantaged if their condition is either misunderstood or overlooked when they become looked after away from home.[32]

These issues can only be addressed by having a co-ordinated approach to intervention.[33] Flexible services provided on an outreach basis are more likely to be successful. Joint working between social services and health professionals can help give carers the skills and confidence to provide appropriate care and help for vulnerable young people.[32,34] Specialist nurses have been appointed in many areas to oversee the health of LAAYP. Their remit incorporates identification of health needs, facilitation of contact with health professionals and health promotion.[32,34] There are already areas of overlap with transition care that could be developed. The role of these specialist nurses could be expanded further to include aspects such as co-ordination of transfer to adult services.

DISABILITY

Evidence suggests that for most adolescents with significant neuro- and/or learning disability, the process of transition to adult services is problematic.[35] These young people have a wide range of social, educational and financial needs, in addition to, often, multiple health problems that may need the involvement of several specialists.[36] There is a higher incidence of mental health difficulties and challenging behaviour among those with learning disabilities. Yet many experience a reduction in hospital care, therapies and social services input after transfer.[35,37–39] Other ongoing needs after transfer, such as education, are also poorly met.[35]

CASE STUDY 1 (Speak 4 Yourself Scotland)

A has a degenerative condition and profound and multiple disabilities. Transition is a worry for her parents. At the moment, they have open access to the children's ward at the hospital, but that is changing and now there will have to be a referral from the GP. Considering the complexity of and progressive deterioration in A's condition, they find it hard to see how this will work. They had not realised that some of the equipment A uses would have to go back to children's services and that they would have to apply to adult services.

Many young people and their families are provided with insufficient information regarding options that are available during and after transfer to adult services.[35,40] They may not be properly involved in decision-making.[35,39] Those without speech are particularly vulnerable to being excluded from the transition process.[35,39] Yet research has shown that transition planners pay inadequate attention to the things that are most important to young people with disabilities[19,35,39] and have low expectations of what they might be capable of achieving.[35] As a result, it may fall to parents to advocate for their children.

CASE STUDY 2 (Speak 4 Yourself Scotland)

D has a severe physical disability. At school, he saw a physiotherapist once a week and had a weekly swimming session, in addition to other multidisciplinary input. In spite of this, he still required several orthopaedic operations. Since he left school he has not been offered any physiotherapy or swimming. He is concerned about what might happen to his legs now.

Proper preparation[19,35,40] and active case management[35] during the transition phase and around the time of transfer have been recommended repeatedly. Evidence suggests that a specialist, multidisciplinary approach improves transition for young people with neuro-disability at no greater overall cost.[35] Yet, frequently, there are insufficient numbers of specialist staff to work with young people and their families during this period.

If there is no adult service for young people to transfer to, they and their families may be left feeling vulnerable and let down.[41] The absence of a responsible team in adult services impedes the transition process and results in some young people being retained within the paediatric service beyond their late teens.[41] Various models have been suggested to address this problem for those with complex neuro-disability:[36,37] identification of a rehabilitation consultant to lead an adult service (perhaps with initial or continuing input from community paediatric colleagues), specific training to enable greater involvement by interested GPs or a lead role for the community learning disability service. The latter would only apply to those with intellectual impairment.

GUIDANCE

Although this guidance is primarily aimed at healthcare professionals working with individuals, inequalities are a population health phenomenon and they require population health interventions. In addition to the recommendations that follow, the Scottish Government and health boards must address the determinants of inequalities.

1. **Identification of needs:** It is important that the needs of young people with chronic illness from vulnerable groups are identified early to ensure adequate transition care and subsequent preparation for transfer. Staff training and support are required in order to facilitate this. There should be regular specialty team discussions around which young people are considered to be most at risk, including those who are simply from chaotic families and have a history of poor attendance or suboptimal disease control. Clinicians should seek to ensure that all their patients experience a successful transition phase, regardless of their background or circumstances. Awareness of other transitions or events taking place is required. For example, in the case of LAAYP, transfer to adult services should be delayed if any change of residential placement is foreseen.

2. **Transition co-ordinator/key worker:** It is recommended that a transition co-ordinator or key worker be nominated to manage the transition of young people from at-risk groups to adult services. The Care Co-ordination Network's key worker model provides a useful framework for training and implementation.[42] Adequate training of those who are keen and able to assume this role is essential. It is important that there is a good relationship between the transition co-ordinator, the young people and their families. This may be crucial in promoting engagement with the transition process. It is suggested that young people are involved in choosing their transition co-ordinator or key worker, with support from the specialty team. Depending on the young person's illness/condition and personal circumstances, their transition co-ordinator may be a:

   - GP
   - Community paediatrician
   - Hospital nurse specialist (e.g. cystic fibrosis)
   - Looked-after children's nurse
   - Community transition nurse
   - Social worker
   - Physiotherapist
   - Cultural mediator/advocate
   - Occupational therapist
   - Youth worker
   - Youth justice worker
   - Worker from charitable/support agency
   - Learning disability team worker

   The transition co-ordinator's remit should transcend health to include maintaining an overview of other aspects of the young person's care. For example, where appropriate, they should seek to identify who will be assuming responsibility for the young person's employment, financial, day care and long-term accommodation needs after transfer. Some families do not know what help they need or what assistance is available. The co-ordinator should refer the young person on to other supportive services as required, especially in the voluntary sector.

3. **Information provision:** The transition co-ordinator should ensure that young people and their families are provided with plenty of information during the transition phase so that they know what to expect.

Information must be available in the appropriate language and translating or alternative communication services should be optimised. It is imperative that young people and their families are fully involved in each stage of the transition process, and in all decisions made about their care. It cannot be assumed that health or other professionals can make decisions on young people's behalf, without adequate consultation.

4. **Cultural mediation:** Beyond the provision of language services for those from ethnic minorities, social and cultural factors are also important and require attention. This also applies to young people from gypsy/traveller communities. Cultural mediators may be of assistance in addressing some of these issues, which may otherwise hinder effective healthcare. This advocacy role is distinct from that of the transition co-ordinator, although there may be some overlap.

5. **Inter-agency communication:** It is important that communication between services is optimised during the transition phase to enable better continuity of care. The responsibilities of professionals involved in each young person's care should be clearly outlined, as should the responsibilities of the young people and their families. Methods for facilitating up-to-date record keeping and information sharing should be employed, for example mobile case records for young people from gypsy/traveller communities. Where non-attendance is an issue, it may not be enough to send out another appointment to a young person and his or her family. Some young people may need to be more actively re-engaged and, if so, there should be discussion around who does this and how.

6. **New/improved services:** Adult services need to be developed where they do not exist or where an adequate service is lacking, particularly for young people with complex neuro-disability. There should be discussions about whether a life-long service is appropriate for some conditions. Options need to be actively explored and progressed. Local arrangements may determine the model(s) of care chosen. For those with neuro-disability, the lead healthcare professional post-transfer could be a neurologist, a consultant in rehabilitation medicine, an interested GP who has received appropriate training or, in the case of those with intellectual impairment, a consultant from the community learning disability service. To enhance the family's relationship with their primary care team, community nursing practitioners could participate in transition clinics with community paediatricians. Improved access to allied adult therapeutic services (e.g. physiotherapy) must be facilitated, with expansion of those services as required. Links with and support from charitable agencies should also be explored.

7. **GP involvement:** Regardless of whether or not GPs are nominated as transition co-ordinators, their relationship with the young people and their families should be fostered during the transition process (and, indeed, from much earlier on), particularly in the case of young people with significant neuro- and/or learning disabilities.

8. **Follow-up:** Continuity of care will be important after the patient has transferred to adult services. The transition co-ordinator must be able to commit to a period of continued involvement after transfer. The duration of continued input should be informed by the young person's needs.

WHAT'S NEXT?

- Health boards must commit to advancing the development of transition care for more vulnerable groups. For example, the Care Co-ordination Network's key worker model is evidence-based, but standards have not been adhered to due to under-resourcing.

- It is also the responsibility of health boards, in conjunction with clinicians, to delineate which services should assume responsibility for young people graduating from paediatric healthcare settings. The Age Appropriate Care Working Group is expected to recommend that a scoping exercise is carried out to determine to what extent adult services do not meet the needs of young people with complex needs or specific long-term conditions.[42]

- Simple but constructive solutions like improving the uptake of patient-held records, providing families with more information and drawing on the skills of cultural mediators may result in rapid improvements in patient and family satisfaction. Maximising the range of healthcare professionals and support workers who can elect to be trained to assume a transition co-ordinator role will increase the overall number available while making the most of limited resources.

- Interventions and outcomes will need to be considered in terms of efficacy and young people's satisfaction.

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5. Remote and rural issues

SUMMARY

- Recent government reports have highlighted the importance of remote/rural healthcare issues. Managed clinical networks have been advocated as a means of delivering safe, effective and sustainable services locally with support from specialist centres.
- Transition care for young people with chronic illness living outwith urban centres has not been adequately investigated. Further research is needed into how to optimise multidisciplinary input, consolidate patient education and structure the transfer to adult services for this group.
- The generic principles of transition can be applied to young people living in remote/rural areas. Aspects that will enhance communication between services and empower local healthcare teams are particularly important.
- If small numbers or limited resources preclude transition clinics being held as regularly as would happen in a larger centre, efforts should be made to "bridge the gap". To optimise the involvement of local healthcare team members (including primary care colleagues), educational needs in relation to both transition care and the chronic illness concerned should be addressed. Roles, responsibilities and support systems should be mutually agreed in advance.
- Ways of facilitating a gradual introduction to the adult service should be explored, including, ideally, at least one joint clinic consultation held between paediatric and adult teams prior to transfer.
- The pathway adopted for use should be formally assessed for effectiveness and acceptability.

INTRODUCTION

The challenges faced by children and families living in remote and rural areas of Scotland in accessing healthcare have been well documented.[1,2] Service users and their families expect high-quality healthcare wherever they live and would prefer it to be provided as locally as possible. For young people with conditions such as diabetes, cystic fibrosis and chronic renal insufficiency, travel to distant secondary or tertiary centres for chronic illness care causes significant disruption to family life.[1,2] Substantial costs are incurred in terms of living and travel expenses, parental work missed and time out of school or college.

YOUNG PEOPLE'S VIEWS

"Mum has had to take a lot of time off work for health appointments, even a visit to Raigmore needs a day off, to Glasgow or Edinburgh two days are needed."
– Speak 4 Yourself Scotland member, Highlands

Remote/rural healthcare professionals need to be generalists capable of managing a wide range of clinical conditions, often in the context of geographical, workforce and resource constraints.[2] Increasing specialisation and small numbers have led to greater centralisation of many paediatric speciality services,[1,2] threatening aspects of local healthcare provision. Recent government reports have highlighted this issue, calling for delivery of safe, effective and sustainable services as close to home as possible.[2–4] Managed clinical networks (MCNs) have been advocated as a means of providing care locally and maintaining local skills with support from specialist centres.[2–4]

The Remote and Rural Steering Group for NHS Scotland has recommended that all remote/rural areas have explicit support arrangements in place with a specialist children's hospital by 2008.[4] Emerging models will vary depending on local needs and resources, but prerequisites include a collaborative, team-based approach with the provision of outreach support, negotiation of protocols/care pathways and a commitment to education and training.[4] Ready and reliable access to telemedicine and teleconferencing facilities and exploration of e-health options are essential to these developments.[2,4]

It is important that young people living in remote and rural areas are no less supported during transition and subsequent transfer to adult services than those living in larger urban centres. For example, due to geographical limitations, age-

banded and/or joint adult/paediatric clinics may be impeded or fewer in number. On the other hand, there may be more flexibility in a smaller centre, facilitating the delivery of individualised transition care. Health boards and healthcare providers (local and specialist, adult and paediatric alike) must build on the advantages of remote/rural healthcare systems and find practical solutions to the more challenging aspects of transition care.

DISCUSSION

To date, no studies have evaluated transition from paediatric to adult healthcare services in remote/rural areas in terms of process or outcome. Further research is needed into how to optimise multidisciplinary input, consolidate patient education and structure the "handover" to adult services in the remote/rural context. In the absence of this work, it is necessary to extrapolate from the results of broader studies looking at general chronic illness care in remote or rural areas. Few studies have been carried out involving children or young people, and of these only a minority have been randomised controlled trials (RCTs). The bulk of available evidence pertains to telemedicine. However, despite an increase in the uptake of telemedicine, much of this literature refers to pilot projects and short-term outcomes.[5]

It is important to take into account local examples of good practice and potential areas of improvement in remote/rural chronic illness and transition care. In researching this chapter, clinicians from across Scotland were asked to contribute their views and a focus group discussion was held with a group of community children's nurses working in remote/rural areas. In addition, several young people living in a remote/rural area were interviewed about their experiences of chronic illness and transition care.

Benefits of outreach clinics and shared care

The report *Delivering for remote and rural healthcare* stipulates that, where possible, most care should be provided locally rather than in distant district general hospitals (DGH) or tertiary centres.[4] Among sub-specialties in paediatrics, this has been achieved most successfully in diabetes care, with a number of outreach clinics held in Scottish rural general hospital (RGH) or community hospital (CH) settings. This has positive implications for the development of local multidisciplinary transition care pathways and simplifies transfer to local adult services, where diabetes clinics are well established. However, the provision of age-banded and/or joint adult/paediatric clinics is more limited than in a larger centre.

YOUNG PEOPLE'S VIEWS

"I had an appointment at the teenage clinic [in Oban] with my doctor and the doctor from the adult service, but I missed it so I won't meet the adult doctor before my first appointment [post-transfer]. But I've met the [adult] diabetes nurse." – Young person, Oban

Outreach clinics and shared care for conditions such as cystic fibrosis (CF) have been more difficult to achieve in RGHs due to smaller numbers of service users and lack of associated services (e.g. limited laboratory support). However, it is important to appreciate the effect that centralisation of services has on the perception of local healthcare, particularly among young people becoming more independent in their views. One interviewee explained that he travelled to a DGH for appointments and scheduled admissions "because they can't do anything up here because there's no CF doctor to do stuff".

Input from local healthcare teams has the potential to consolidate transition care closer to home. In the aforementioned example, local adult respiratory expertise exists, but it is not yet being used by specialist teams. Remote/rural healthcare professionals should be empowered to play an effective role in multidisciplinary care and patient education. This requires both willingness from specialist centres to involve peripheral teams and readiness of local team members to participate in the delivery of care with support. Good communication is essential, including efficient sharing of information, clear definition of roles and ready access to guidelines and protocols.

Use of telemedicine in outreach and shared outpatient care

While it cannot and should not replace face-to-face outreach clinics, telemedicine has the potential to increase the flexibility and quality of locally provided outpatient care. Local practitioners should be involved to ensure that they are fully included in ongoing care. Two small studies, both with methodological weaknesses, examined the impact of specialist telemedicine consultations on asthma care among children living in remote/rural locations.[6,7] With subjects acting as their own controls, both studies reported improvements in asthma symptoms at the end of a defined time period. One study reported fewer acute attendances due to asthma exacerbations;[7] the other reported improved quality of life. However, the overall impact of the intervention on primary care clinicians' ability to manage asthma more effectively on their own was unclear.[7] Hence the sustainability and relevance of specialist telemedicine consultations to remote/rural care, and whether they lead to the development and maintenance of local skills, remain uncertain.

In Queensland, Australia, telemedicine was integrated into an existing outreach programme for children with diabetes living in remote/rural areas.[8] Travel was reduced for specialist staff while maintaining (and sometimes increasing) the contact service users had with the specialist team. Telemedical services were established at three levels: routine specialist clinics, ad hoc consultations for collaborative management during acute presentations and the delivery of education to staff and patients. Which of these three components had the greatest impact, however, was unclear. The feasibility of a telemedicine-enabled diabetic retinopathy screening service for children and young people has also been investigated in Queensland, with

positive results.[9] Australian clinicians have previously estimated that only two-thirds of young diabetics in Queensland had their eyes screened in accordance with international guidelines.[9]

Few paediatric studies have examined the cost-effectiveness of telemedicine as an intervention. A study by Smith et al. looked at the costs incurred by families travelling to specialist clinics from a remote/rural area and the time spent travelling.[10] Both were reduced for those who had a consultation via videoconference in their regional area, compared with those who attended the specialist children's hospital. More formal cost-benefit analyses are required.

Multidisciplinary team working in outreach/shared outpatient care

The role that nurses and allied health professionals (AHPs) play in chronic illness care continues to grow.[1,4] Specialist multidisciplinary staff may be fewer in number in remote/ rural areas, but local teams have a wide range of skills, and with educational opportunities, development of protocols and provision of advice can be supported to deliver safe and effective care.[4] Flexibility is important as the complement of staff will vary from place to place. Where community children's nurses are attached to an RGH or CH, their remit may include support of young people with diabetes, CF, neuro-disability or other chronic conditions, with input from respective specialist teams. In other situations, the health visitor or a specialist nurse from the adult service may play a prominent part. In all cases, the GP is an important link.

There are advantages to being looked after by a small team in a more close-knit environment:

YOUNG PEOPLE'S VIEWS

"[The Community Children's Nurse] has more time for you… there aren't as many people to share her with."
– Young person, Oban

It is helpful if a member of the local team can assume a key worker role. This enables better co-ordination of care between local/specialist and adult/paediatric centres and provides a steady point of contact for young people and their families. Local multidisciplinary team members may be uniquely placed to provide better continuity of care between paediatric and adult services. In Lochgilphead, for example, paediatric and adult physiotherapists are part of the same team, and the same dietician and speech and language therapist cover both adult and paediatric services.

There are some circumstances where greater local expertise and modest expansion of the local healthcare team is needed despite the ability of remote/rural teams to assume multi-faceted roles. Psychological services for children and young people with chronic illness are sparsely provided throughout Scotland in general, but especially so in remote/rural areas. Internet-based resources (e.g. handsonscotland.co.uk) may be useful, but must combined with greater resourcing of specialist teams to enable provision of adequate outreach support.

HEALTH PROFESSIONALS' VIEWS

"We arranged psychology input for a child from Islay at Yorkhill Hospital. The journey was so stressful that the family stopped going after a couple of appointments: it was counterproductive."
– Community Children's Nurse, Mid Argyll

Outreach education for young people and remote/rural healthcare teams

As mentioned previously, the education of both staff and families is central to chronic illness care in remote/rural areas, and this applies equally to transition. It is important that medical, nursing and AHP skills in remote/rural areas are recognised, with the opportunity for further training and career development.[4] It has been suggested that ongoing education of staff could be achieved through outreach teaching from specialist units, rotation to paediatric centres and e-learning.[5] Telemedicine offers the potential to deliver education to more than one site at the same time.[1,4] It is important that support is delivered in a way that empowers local services to remain involved in the care of specialty patients, and builds on existing skills.[1] Structured programmes are required that do not take for granted that education will happen on an ad hoc basis. Training opportunities must be made available, and the time commitment involved in training and travel should be recognised in contracts and job plans.

An Australian example of a system for delivering education to staff and patients has already been described.[8] In a different study in Germany, at-risk diabetic patients (whose glycated haemoglobin [HbA1c] levels were considered either too high or too low) were offered an intensive education programme delivered in person by a mobile education team from a specialist centre.[11] Improved metabolic control, diabetes knowledge and quality of life were reported. The education team also developed and provided training curricula and a diabetes manual, and offered annual collective continuing education for medical and nursing staff at local hospitals.

'Home care' interventions

In addition to its use in hospital settings, telemedicine has been explored as a way of providing care at home[12,13] and could be a means of supplementing care for young people living in remote/rural areas. So far, however, results have been largely inconclusive. In paediatrics, clinicians have experimented with using telemedicine to improve glycaemic control in children and young people with diabetes. Liesenfeld et al. analysed patient data that had been stored on glucosemeters and transferred via modem to a remote diabetes centre.[14] Each patient was then telephoned to discuss the information that had been received and to make any necessary adjustments to the insulin regime. Improvements in HbA1c concentration were reported

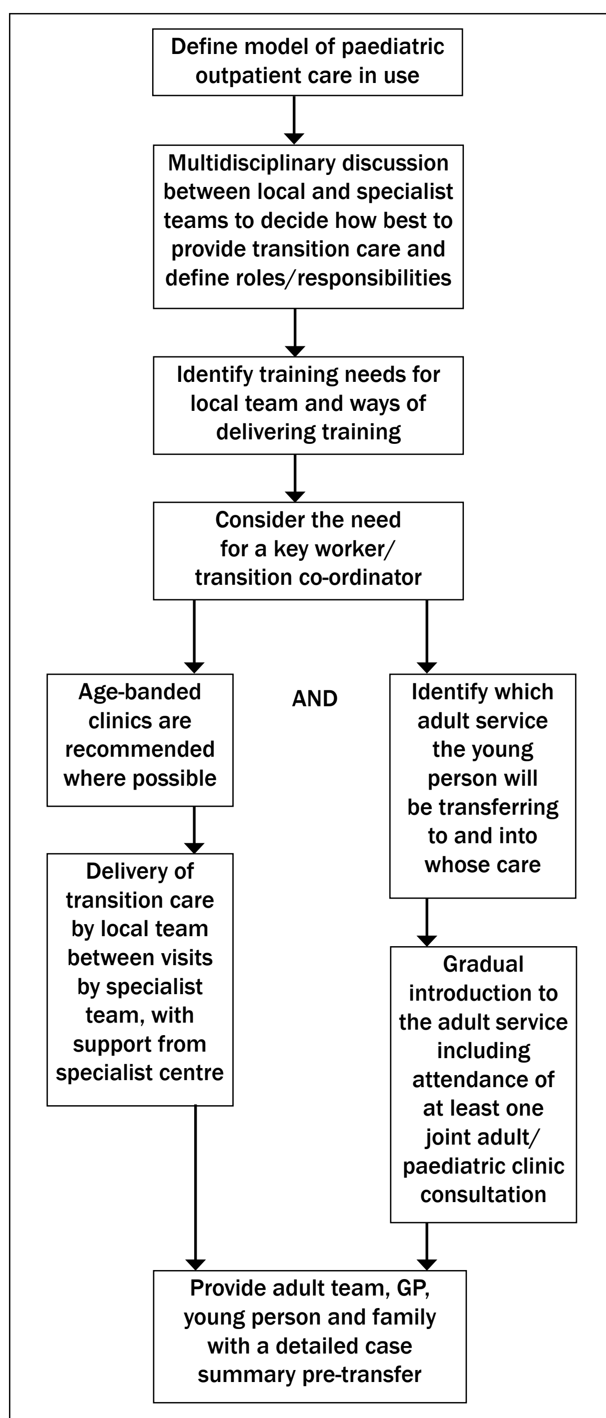

FIGURE 1 Transition pathway for young people with chronic illness living in remote/rural areas (Sophie Khadr)

relative to measurements prior to entering the study. In contrast, an RCT of 106 diabetic patients reported no significant impact on glycaemic control among those whose blood sugars were home monitored compared with controls.[12] No improvement was seen in terms of HbA1c concentration, emergency room visits, psychological status or family functioning.

A Scottish RCT examined the impact of Sweet Talk, an automated text messaging support service, on diabetes care.[15] Young people were randomised to conventional insulin therapy, conventional therapy plus Sweet Talk or intensive (basal bolus or pump) therapy plus Sweet Talk. Glycaemic control was better in the group receiving intensive therapy than in other groups, but this may have been due to more effective insulin delivery and better patient education (e.g. carbohydrate counting) rather than the use of the Sweet Talk service. Self-efficacy scores and the perception of support from the diabetes team were better for the group randomised to conventional therapy plus Sweet Talk than those on conventional therapy alone. However, there was no impact on the diabetes knowledge score or the perception of support from family or friends. In all these developments based on healthcare technologies, it needs to be remembered that their sustainability and long-term benefit require local "champions" and identified healthcare professionals committed to the relevant specialty service.

GUIDANCE

The generic principles of transition can be applied to young people with chronic illness living in remote/rural areas. Some adaptation may be required, depending on the condition in question and on how healthcare is provided locally. The pathway adapted for use needs to be sustainable while at the same time striving to achieve a high standard of care.[4]

The purpose of the guidance in this chapter is not to outline the general transition process (for this see Core principles, page 10) but to concentrate on issues of particular importance to remote/rural areas. Key aspects include attention to education and training and the optimisation of team working and communication between services. The main points are summarised in Figure 1.

1. **Define the model of paediatric outpatient care in use.** This will depend on the place of residence, structure of local services and support arrangements for the chronic condition in question. Examples of care may include, alone or in combination:

    - A specialty clinic held in a distant tertiary paediatric centre;
    - A specialty clinic held in a distant DGH by the local paediatrician/specialist or the local paediatrician and visiting specialist;
    - A general/specialty clinic held in a local RGH/CH (no dedicated paediatrician) by a visiting paediatrician from a DGH/tertiary centre;
    - Predominantly GP-managed care, with support from a DGH or tertiary paediatric centre.

2. For each young person of secondary school age requiring transitional healthcare, **a discussion should be held between the responsible paediatrician, local and specialist multidisciplinary team members and the GP** about how best to provide that care, where possible in their locality. Roles/responsibilities should be agreed in advance. The agreed plan may need to be reviewed/adjusted during the transition period.

3. **Training needs for staff should be identified early** in the process, particularly if the local healthcare team and/or GP will have a lot of responsibility during the transition process. Various means of delivering training are available (e.g. local/remote study days, teleconferenced sessions, e-learning, sharing of protocols).

4. Where the numbers of young people in transition in a remote/rural area are small, **discuss formally incorporating transition nurse specialist training/ responsibilities into the role of the local community children's nurse**, or similar. Adequate support will be required from specialty teams. It is not realistic to assume that all aspects of transition care can be delivered by the same person across several specialties. Certain elements may to be prioritised for delivery by the specialty team.

5. **The appointment of a key worker to manage transition** for young people with more complex social, geographical or medical circumstances within a defined specialty or indeed locality may be appropriate. This could be the GP, a local AHP, nurse or youth worker involved in the young person's care or a nurse from the receiving adult service.

6. **Identify which service the young person will eventually transfer to**, and into whose care:

   - Predominantly GP-managed care, with support from hospital specialists as required;
   - Predominantly RGH care (specialist service or general supported by remote specialist service), e.g. diabetes, chronic renal failure;
   - Specialist service at a remote hospital, e.g. CF.

7. **Age-banded multidisciplinary clinics are recommended** for young people with chronic illness, with attendance of at least one joint adult/paediatric clinic prior to transfer. If there are inadequate patient numbers or resources to facilitate local adolescent clinics being held as regularly as would happen in a tertiary centre, efforts should be made to "bridge the gap". Examples of how to do this might include:

   - Greater involvement of the GP and/or local multidisciplinary healthcare team between transition clinics, with clear guidelines/protocols and adequate support from the remote specialist service. There should be clarification of whom to contact for specialist advice and their contact details.
   - The use of telemedicine to facilitate more frequent collaborative clinics between local healthcare teams and remote specialist paediatric colleagues than are achievable in person. This is likely to be more acceptable to clinicians and families if a good working relationship already exists between both sites.

8. As stated above, **it is recommended that at least one joint adult/paediatric clinic is attended prior to transfer**, to enable a face-to-face introduction to members of the adult team (clinician and/or specialist nurse):

   - This may be held in either the paediatric or the adult setting. Telemedicine may be used to facilitate further joint clinics if is logistically difficult for both teams to attend in person.
   - Attendance by GPs should be encouraged if they are significantly involved in the young person's care.

9. **Young people should be provided with written or other multimedia information** about the adult service that they will be transferring to. Where applicable, an informal visit to the site of adult service provision should be facilitated.

10. **Young people and their families should be provided with detailed case summaries** of their care in either paper or electronic form prior to transfer, with copies to GPs and adult healthcare providers. The GP should be kept up to date throughout the transition and subsequent transfer process and included in all correspondence.

11. **The transition pathway adapted for use should be formally assessed** for its effectiveness and acceptability.

WHAT'S NEXT?

- A number of MCNs have been formalised within paediatrics across Scotland to date. Many specialist paediatric and adolescent transition services are likely to be commissioned at a national or regional level.[16] In conjunction with this process, practical strategies for delivering education and training, supporting and developing clinical practice in remote/rural locations and implementing and evaluating transition protocols need to be reinforced. Some remote/rural expansion will be necessary in key areas and, if sensibly designed as part of managed networks, should enable effective shared care.

- The Scottish Paediatric Telemedicine Project (SPTP, supported by the Scottish Centre for Telehealth) already has a role in some MCNs in an educational and/or clinical capacity, but this could be expanded. It is not yet clear how best to use telemedicine in the remote/rural transition context and which applications are most likely to be sustainable and have the best outcome. It may be most effective to use telemedicine to build and sustain networks of professionals serving the needs of patients rather than focusing most of the attention on medical consultations using this technology.

- Clinicians and planners should be mindful of some of the recommendations from the initial evaluation of the SPTP,[17] such as ensuring user training and the provision of technical support. Simplification and standardisation of network infrastructure and support were also suggested prior to a wide-scale implementation of internet protocol-based video-conferencing.

- Formal evaluation of strategies implemented to improve remote/rural transition care is required.

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6. Fertility and sexual health

SUMMARY

- With increasing life expectancy and improved disease control in many chronic illnesses, discussions concerning fertility and sexual health cannot be ignored. The need for young people to know about and understand issues surrounding their sexual health may not be appreciated by their parents or the clinical team. Knowledge of these issues will allow young people to make informed choices regarding contraception and the timing of parenthood, to understand the impact of sexual activity and pregnancy on their own health and increase their awareness of the likelihood of reduced fertility or infertility and potential ways of overcoming this.
- Some disorders are hereditary, and early genetic counselling may be appropriate. In others, the health of patients during pregnancy or their ability to care for their children may be the predominant issue. Some disease entities may follow a fairly consistent and predictable pattern with regard to such issues, whereas others will follow varying paths, depending on the primary disease or its treatment.

INTRODUCTION

During pubertal progression, children develop an awareness of sexuality and fertility, which may be associated with additional concerns and anxieties for adolescents with significant health problems. They may worry that they are not "normal" as a result of their illness or that it will affect their ability to have and care for children or affect the health of their offspring. Advances have been made in the treatment of some illnesses so that fertility is now an important issue where it had not been previously.[1,2] It is important for physicians caring for such young people to be aware of these concerns, to discuss them and counsel children appropriately.[3–5]

BACKGROUND

Genetic counselling is extremely important for all heritable conditions, but the specific risks and concerns may vary depending on the mode of inheritance. Detailed genetic testing involving other family members may be required, and the wishes of the young person may differ from their siblings, parents or carers. In addition, it is important to acknowledge the attitude of the young person's partner, for whom testing may also be recommended and who may therefore need, as well as want, to be included in such discussions. The patients themselves, however, may not want their partner to know such detail about their illness, and this poses ethical issues as to whether such information should be disclosed.[6]

The effects of fertility on the patient's own health may be significant. With certain illnesses or previous treatments, pregnancy may give rise to specific concerns, necessitating special care for both the mother and her unborn child.[2,5,7] Contraceptive advice is important for all and will need to take the individual's medical and social needs into account. Early contraceptive advice is particularly important where pregnancy needs to be planned and carefully managed from the start.[3,8,9] Where fertility is reduced, there may be a lack of understanding of the need for contraception and, where it is reduced or absent, a lack of understanding of the need for barrier contraception as a protection against sexually transmitted diseases.[4,10]

Early discussions about fertility are more relevant in some conditions than others. If there is a risk that the disease will significantly shorten life, lead to premature ovarian failure or otherwise reduce fertility, earlier discussion is often beneficial so that there is time to talk through issues and address questions without time constraint.[10,11] Clinicians should, however, be sensitive to the child's desire to discuss these issues. It may not be helpful to try to introduce too much too early. It is worth remembering that the health professional's idea of what is most important may be different from the young person. For example, among boys with cystic fibrosis (CF), there may be confusion around the difference between infertility and impotence.[10] Simple clarification of this distinction may be what is most helpful at an early stage. In some illnesses, puberty may be delayed and/or dependency on the parents prolonged, and in these situations early discussion may not be so pressing.

Where children or young people are treated with drugs that may reduce or abolish their fertility, sperm and egg donation may need to be discussed. However, options for the preservation of fertility in adolescents are limited to sperm cryopreservation in postpubertal boys; all other options are currently experimental.[12] Future assisted reproduction would not usually be discussed with a child. Instead, these discussions will take place with the parents and decisions made on their child's behalf will later need to

be explained and even justified to them as adolescents. Information on the teratogenicity of past or current drugs should be discussed as particular precautions may be necessary with regard to avoidance of pregnancy or abstinence from sexual intercourse. This may be applicable to both young men and women. If such drugs are to be used, confirmation that a young female patient is not pregnant is essential. Investigations involving irradiation or X-rays should also take this point into account.

Young people with significant health problems may feel under personal or peer pressure to have children. There may be anxieties about finding a partner who will accept someone with ongoing health or fertility problems and a feeling that time is running out. They may equally feel under pressure not to have children. There may be issues surrounding the ability to care for their children through their own ill health, a significantly shortened or uncertain life span or the possibility that the child will have similar health problems to their own. The role of the specialty team is to provide young people with information in response to their priorities and needs, to enable them to make informed choices.

A number of disease categories where the disease itself or the treatment may compromise fertility are considered in the following section. The examples include CF, survivors of childhood cancer, type 1 diabetes mellitus (DM) and chronic renal disease.

GUIDANCE

Aspects of fertility considered in this chapter include genetic counselling and the timing of discussions with patients and/or parents. Potential issues to be discussed are shown in Table 1. The relative importance of such issues will depend on whether they are viewed from the health professional's or the young person's perspective, on the illness concerned and also, in the case of renal disease and cancer, on the specific diagnosis and treatment within that illness category. Patients are cared for within a multidisciplinary team (MDT) whose composition at any stage in a patient's journey may vary and reflect the needs of the patient at the time. The core MDT members that will remain fairly constant throughout this journey include the clinician, specialist nurse, dietician, play specialist/youth worker, social worker and psychologist. Allied health professionals (e.g. physiotherapists), members of the hospital outreach teaching service and a community paediatrician may also be involved. A clinical andrologist or fertility expert, gynaecologist or obstetrician may join this MDT at the relevant time.

Cystic fibrosis

Genetic counselling

Cystic fibrosis is a recessively inherited disease, with one in 25 people carrying the defective gene that causes the condition. It is important to know, therefore, if a partner is a carrier as this will confer a 50% risk to the offspring. Issues such as antenatal testing may need to be raised. Family issues are important as testing of other family members such as sisters or brothers may be indicated.

TABLE 1 Aspects of fertility to be considered

Aspects
Genetic counselling
Own health
Early explanation
Ability to have children
Contraceptive advice
Difficulty with pregnancy
Personal/societal pressures around having children
Ability to care for children

Bringing up fertility issues

Discussions with young people with CF about fertility should take place early. Women with CF might have slightly reduced fertility due to changes in cervical mucus, but female infertility may also be secondary to low body weight. Nevertheless, most women with CF are fertile and should receive the same contraceptive advice as other women. Most men with CF are infertile due to congenital bilateral absence of the vas deferens, yet in a Scottish survey of adults with the disease, only 43% reported having had any discussion about fertility issues with health professionals.[13] The need for discussion is of particular significance as treatment for male infertility in CF is now widely available. Surveys have also shown that men with CF are more likely to learn of the likelihood of infertility later than desired.[10] More than half of Scottish males with CF interviewed thought that fertility discussions should take place before the age of 16 years.[13]

During adolescence, as many as one in three men with CF report having assumed that they did not need to use condoms because they were likely to be infertile.[10] In the same way as for any adolescent, it is important to explain the increased risk of sexually transmitted disease through unprotected sexual intercourse. It is important that health professionals address this aspect as data from Sawyer et al. show that, although infertility is discussed with 100% of young people with CF, the use of condoms is discussed with only 38% of the young men.[14] There is clearly a need for training and education in this area for health professionals. Many women with CF also believe that their fertility is reduced and may as a result be less likely to use contraception,[10] which is inappropriate. There may be poor knowledge of the potentially deleterious effects of pregnancy on their health, again underlining the importance of early discussion.[14a] If a young female is well enough to become pregnant, there is a higher incidence of vaginal candidiasis during pregnancy due to the continued antibiotic therapy.

Looking to the future

Although the life expectancy of those with CF is continuing to increase, the average life expectancy is between 30 and 40 years of age. Young people may feel under pressure to find a partner and start a family. Surveys have demonstrated that the majority of men and women with CF would like to have children.[10,13] Individuals may have concerns regarding their ability to care for their children as their own health deteriorates.

Cancer

Genetic counselling

Genetic counselling can occasionally be important: for a very small number of cancers (about 5%) there is a genetic inheritance/predisposition and thus a cancer risk to the offspring.[15,16] The issue of testing unaffected siblings may arise, and the wishes of various family members may differ. There is no evidence to support an increased risk of cancer developing in the offspring of survivors of childhood cancer following natural conception.[17] The risks to offspring born by assisted reproductive techniques are not known.

Bringing up fertility issues

Infertility is an important and well-recognised complication of childhood cancer therapy for males and females treated at all ages. The extent of the damage is dependent upon sex, age and the nature and dosage of the drugs received.[18] The dose and site of radiotherapy treatment may also have an impact on future fertility. In males, testicular damage is often associated with reduced or absent sperm production and with the relative preservation of secondary sexual characteristics and potency. However, hormone replacement may need to be considered. Radiotherapy may also impair erectile function. The majority of female survivors of childhood cancer will have regular menstrual cycles; however, for a minority, loss of ovarian function may occur, resulting in premature ovarian failure and impaired fecundity. Premature menopause will also be associated with the loss of ovarian sex hormone production, and consequently these women are at increased risk of osteoporosis. This may be managed by the use of hormone replacement therapy, either in the form of standard hormone replacement or the oral contraceptive pill.

At the time of the cancer diagnosis it is important to counsel the patient (where possible) and the family about the potential risk to future reproductive function. Attempts to preserve fertility are limited by the stage of pubertal development.[19,20] Semen cryopreservation can be offered to all sexually mature males, but there are no clinical options available currently for pre- or peripubertal boys. In vitro fertilisation or intracytoplasmic sperm injection techniques may be useful when the quality of stored sperm is poor. For girls, if radiation is required, a limitation of dose to the ovary can be attempted, but it is technically difficult in children. Embryo cryopreservation is only available to adult females with a partner. For pre-pubertal girls and the majority of young women, options remain experimental.[19] The issue of gamete preservation will need to be addressed early, often soon after presentation; therefore these discussions may be with the parents rather than the patient. Decisions taken by parents on the young person's behalf at an earlier age will need to be explained, discussed and even justified as the young person begins to take responsibility for his or her future. Donnez et al. give a useful review in this area,[21] and guidance for management of the effects of cancer therapy on the reproductive functions of young people has recently been published.[22]

The majority of patients will be fertile following treatment. However, counselling patients and families appropriately can be difficult given the varied nature of the treatment.[23] The majority of female cancer survivors will have normal reproductive function and would be expected to have a successful pregnancy, although, of course, they will be subject to the same complications of pregnancy as the normal population. Female survivors of childhood cancer who are able to become pregnant but who have had radiation-induced damage to the uterus carry an excess risk of preterm delivery and a low birth weight baby.[24] Chemotherapy does not in general appear to be associated with adverse pregnancy outcomes, but for the minority of young women who have received significant cytotoxic insult to the reproductive organs and yet still manage to conceive, pregnancy must be considered a high-risk condition and these patients should be managed by a multidisciplinary specialist team. For females who experience a premature menopause, egg donation may be an option, although, again, consideration of the health of the uterus is important and these patients require specialist support from the obstetric team.[24]

Advances in techniques of assisted reproduction, particularly intracytoplasmic sperm injection, have provided a treatment option to enable men with oligozoospermia to achieve fatherhood.[19]

Looking to the future

The impact of pregnancy on a young person's own health is less relevant unless there have been significant late effects of treatment, such as uterine damage secondary to radiotherapy or cardiac damage secondary to certain cytotoxic drugs. Young women who have been exposed to such drugs should alert their obstetrician early in pregnancy so that appropriate monitoring of cardiac function can take place. The likelihood of any relapse and the length of remission should be considered both in terms of the ability that the young person may have to care for the child/children and the delay or modification in therapy that might be necessary. With some of these issues in mind, young people may feel a sense of pressure to find a partner and have children at a younger age.

Type 1 diabetes mellitus

Genetic counselling

This is not a particular issue from the point of view of the DM itself, but there is an increased risk of congenital abnormalities in the baby if DM is poorly controlled in pregnancy. This is discussed in more detail below.

Bringing up fertility issues

Type 1 DM can result in significant short- and long-term morbidity to both mother and offspring if management during pregnancy is suboptimal.[25] Evidence suggests that optimisation of diabetic control prior to conception may be crucial in terms of improving outcomes, particularly in order to reduce the risks of fetal congenital malformations.[26] Pre-pregnancy counselling is, therefore, advocated where a pregnancy is planned. It is important that this information is provided in a neutral and supportive fashion. Diabetic women who feel that their doctors discourage pregnancy

may be more likely to have an unplanned pregnancy than women who have been reassured they could have a healthy baby.[27] This will be relevant to some girls in their late teenage years wishing to start a family at a relatively young age. It is also relevant to the way younger adolescent females are provided with age-appropriate contraceptive advice.

Looking to the future

Diabetes is more difficult to control in pregnancy, requiring supervision from a diabetologist with expertise in this area. Physiological changes unique to pregnancy provide a background for the development of diabetic ketoacidosis, a medical emergency.[28] The obstetric provider must be alert to other attendant risks such as hypertension in the mother and the risk of still birth.[29] Macrosomia, which potentially complicates delivery, is difficult to prevent, except perhaps by using management strategies that seek to limit wide fluctuations in blood glucose over a 24-hour period.[26] There are additional challenges in the peri- and post-partum periods. Neonatal hypoglycaemia can largely be prevented by tight control of maternal blood glucose during labour and delivery.[26,29]

The majority of young people with DM cope well in caring for their children, but good control is required, particularly to avoid hypoglycaemic attacks. Diabetic parents may also worry about deterioration of their overall health in the longer term.

Renal disease

The underlying disorder resulting in chronic renal failure and the treatment required will influence the weight given to the different aspects of fertility considered in Table 1. For example, a young girl with steroid-resistant nephrotic syndrome may be more in need of genetic counselling than patients with diseases that do not run in families. Renal failure is also associated with hyperprolactinaemia, which will impair both male and female fertility.

The issue of fertility will be different for a young person on dialysis compared to someone who has a well-functioning transplant.[30,31] Becoming pregnant is often difficult for patients on dialysis, whereas transplant recipients should find it easier to conceive. However, the pregnancy can have adverse consequences on transplant function, and offspring are often premature and of low birth weight.

Genetic counselling

Several chronic renal conditions are hereditary and have life-long implications; other conditions are sporadic and syndromic and often render patients infertile.

Bringing up fertility issues

Young people with chronic kidney disease are less likely to mature normally and may remain dependent on parents or carers for longer. Fertility issues can be overlooked, generally in view of the overarching health problems associated with renal disease. However, chronic kidney disease has a significant impact on sexual and reproductive health. It is more appropriate for the clinical team to provide the right information at the right time in response to patients' needs, rather than assuming that patients will not want to know about their own fertility.[5]

Infertility in men and women with chronic renal disease may be a culmination of many factors, including poor body image, loss of libido and the impact of uraemia on ovulation, spermatogenesis and androgen production. A renal transplant improves female sexual function and fertility but requires careful supervision of the mother's health and immunosuppressive regimen before and during pregnancy.[2,7,30,31]

Looking to the future

The majority of women with renal disease who become pregnant will have surviving infants, although the mothers are at increased risk of deterioration in renal function and hypertension, and there is a greater likelihood of pre-term birth.[7,32] Those on dialysis rarely become pregnant and have a high frequency of fetal loss and neonatal death.[7,32] Transplant recipients may be at increased risk of complications if they conceive within one to two years of renal transplantation,[31,33] and guidelines are being developed on the timing of pregnancy after transplantation.[2] Caring for children may be difficult for mothers and fathers who require ongoing treatment, such as regular dialysis.

WHAT'S NEXT?

Sex education for young people is usually delivered within school programmes and/or by parents or carers. In addition to such basic education, young people with chronic illnesses will require further information that is specific to themselves and their illness and its management. Such specialist information will not be covered in the standard programmes and is unlikely to be known by those delivering the education. Moreover, parents and carers will not necessarily have the specialist knowledge required to enable the young person to be fully informed. Likewise, paediatricians caring for these young people may be less familiar with the specific reproductive health aspects of care and concentrate more on the illness itself.

There is clearly a need for education and training in the area of reproductive health during the time of transition from childhood to adulthood for both patients and the health professionals who care for them. For patients, such information should be offered at an appropriate time in reponse to their individual priorities and needs. Determining when this will be is a skill that the health professionals will need to develop. Information should cover the aspects outlined above with emphasis on the most relevant issues for that particular specialty area, supplemented by individual counselling and education for each patient. Involvement of a specialist with expertise in sexual and reproductive health would be particularly helpful. It is important that awareness is raised within teams caring for young people with chronic illnesses so that this important aspect of care is addressed in a timely fashion, allowing young people to make fully informed decisions about their reproductive health.

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SECTION 2
Guidance for specific medical conditions

- Cystic fibrosis
- Chronic renal disease
- Type 1 diabetes
- Childhood cancer survivors

"They tell you it's going to be your responsibility to look after yourself and make sure you get your tablets down you"

1. Cystic fibrosis

SUMMARY

Increasing life expectancy and complexity of care in cystic fibrosis (CF) require that robust protocols for transition from paediatric to adult centres are developed.

Evidence and experience support the following:

- 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 the 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 transfer is usually begun at the age of 15 and often 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 and understanding to develop trust in the adult team and to adjust to the adult model of care.
- Transition coincides with other major life changes, and patients commonly rebel against their CF treatment just as they are asked to take responsibility.
- Gradual empowerment of patients to take control of their treatment is appropriate and welcomed by most, but causes anxiety in others 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”.

BACKGROUND

The *National Service Framework for Children, Young People and Maternity Services*, published by the Department of Health in 2004, covers transition issues in the broader sense to include social care, education and employment. The Royal College of Paediatrics and Child Health recommends that in general, young people should be not transferred fully to adult services until they have the necessary skills to function in an adult service and have finished growth and puberty rather than at a set age. In the UK, services for CF patients are developing rapidly, influenced by the Cystic Fibrosis Trust initiative to define more precisely the appropriate standards of care and models of centre-based and shared care which should be used when managing paediatric and adult patients with CF.

Against this background, the present document concerns itself with the disease-specific issues facing CF patients and their families around transition.

Rapid improvements in life expectancy for patients with CF in the past 20 years have resulted in the novel situation that there are now more adults than children with the disease. In Sweden, of those born with CF after 1991, an estimated 95% will survive their 25th birthday.[1] With median life expectancy in the late 30s, it is now the appropriate expectation that children with CF will make the transition to adulthood and to adult healthcare. Alongside this demographic change, CF carers have developed protocols to smooth the transition of care from paediatric to the newly emerging adult CF services.

In addition, the number and complexity of available treatments have increased markedly, and the value of multidisciplinary management is now well established. Besides chronic respiratory infection and pancreatic insufficiency, increasing numbers of adolescent patients need care for CF-related diabetes, liver problems, enteral tube feeding and referral or follow-up for lung transplantation. Together, these factors necessitate the development of carefully structured transition arrangements to ensure the orderly transfer of care from paediatric to adult services.

Transition is a very stressful time for patients, families and carers alike, for a variety of reasons, some of which are outlined below:

Patient concerns

- Developing trust in unfamiliar carers
- Accepting an unfamiliar care environment – most adult CF units are embedded in adult respiratory wards, populated by sick elderly patients
- Fear of change
- Fear of exposure to new infections
- The need to take responsibility for one's own health
- Care interferes with school/college/life
- The need to deal with change without the support of healthy peers (stigmatisation) and CF peers (contact between patients denied for infection control reasons)

The timing of transition also coincides with important developmental changes that face any adolescent with health problems, adding more stress to the process:

- Relationships/fertility issues ("What do I tell my boyfriend/girlfriend?")
- Resentment at disease intrusion
- "Rebellion" against parents, carers, disease

An assertion of independence frequently leads to a period of non-adherence to health advice with associated disease deterioration.

Parental concerns

Transition poses special challenges for parents who have invested years in delivering optimal care for their child:

- The need to develop trust in a new adult CF team
- Loss of contact with trusted paediatric team (almost a "bereavement")
- Loss of control over their child's illness
  - New team
  - Adult model: patient now responsible for own care
  - Feelings of helplessness when patient rebels or stops self-care

Practical/logistical issues

Optimal patterns of care are different for adults and children with CF. Paediatric care is often delivered locally and always with major parental involvement. Adult care is best delivered from large centres, and is based on patients taking responsibility for their own care. Issues include:

- Explaining the merits of large adult centre care
- Travel – adult centres are few and far between
- Role of the parent in clinic – balancing patient encouragement against the exclusion of family
- Particular obstacles to transition for remote/rural locations – joint paediatric/adult clinics may not be practical

In the following sections, these issues will be developed with a review of the background literature, a description of possible models of best practice and specific advice in particular problem areas.

LITERATURE REVIEW

"Transition" in CF has been defined as "a purposeful, planned preparation of (paediatric) patients, families and caregivers for transfer of the patient to an adult program".[2]

Issues of importance in transition are:

- Is there an ideal age for transition?
- What criteria can be used to evaluate readiness for transition?
- What factors are most significant for satisfaction with transition?
- How can patients and families be best prepared for transition?

Brumfield[3] carried out in-depth interviews with six young adults with CF (19–34 years) asking them to describe their experiences during transition. Areas identified as important were:

1. **A close relationship with the paediatric doctor and familiarity with the paediatric team**, leading to the perception of transition as a "huge step". A positive attitude of the paediatric doctor to adult care was important in raising confidence about the transfer.

2. **Elements of a transition programme**
   a) Orientation tours of the adult clinic
   b) Written and verbal information
   c) Presence of a familiar face at the adult clinic
   d) Introduction to the adult doctor who will be managing care
   e) Role of parents. Although independent issues have been emphasised for patients with CF, all but one of the patients interviewed emphasised the importance of the role of their parents in supporting their self-management in CF.

The researchers concluded that participants who were happiest with the transition process, or had the developmental maturity to cope with the change in care, were the most satisfied with the adult care they were receiving.

Flume[4] surveyed the perception of transition programmes among 291 adult and paediatric members of CF care teams. This American study found that more than 50% of patients did not meet the adult team until the time of transfer. The typical adult team consisted of a nurse, nutritionist, social worker, pulmonologist (i.e. respiratory physician) and a respiratory therapist (in the UK setting, a physiotherapist). Team members believed age was the key criterion for transfer to adult care, with an expectation that CF patients would be transferred by the age of 21 years.

A parallel study by the group[5] examined patients' perceptions of transition. This survey of all adult members of the International Association of Cystic Fibrosis had a response rate of 334 (26%), so it may be necessary to be cautious of generalising its results to all CF patients. It found patients confirmed the team members' view that they commonly first met the adult CF staff at the time of transfer, and that

they believed age had been the most important criteria in transition. The study asked patients to rate the importance of a transition programme prior to entering adult care. Patients rated transition programmes as "moderately" important. They reported no significant concerns about transferring from paediatric to adult care. From the patients' perspective there did not appear to be a standard programme of transition, but patients thought such a programme was desirable.

A South African study by Westwood[6] of 47 adolescents and adults with CF found that transfer between 16–18 years was seen as the preferred option, and 90% felt that transition clinics were useful. As in other studies, respondents wanted an opportunity to meet the adult CF doctor before transfer. Westwood's adolescent participants' concerns with transition included: "what to do if I don't like the adult CF clinic", "not knowing what to expect", and concerns about how much the adult CF clinic would know about CF. The majority of participants thought it would be helpful to have a transition clinic.

For the adolescent (pre-transition) and adult (post-transition) groups the most important functions of a transition clinic were the opportunity to meet the new doctor and the provision of information about the clinic. The adults (who had made the transition) were more likely (80% versus 46% of adolescents) to rate as important the opportunity for the adult doctor to learn about them and the provision of information about CF in adulthood. The greater importance that they placed on these functions of transition is a reminder that the benefits of some aspects of transition may only be recognised in hindsight.

Parents in Westwoods' study had similar opinions to their children about what areas of autonomy were important to be dealt with in transition, such as making decisions about treatment and being responsible for self-care, although parents were somewhat more likely to be concerned about the adolescent having responsibility for making their own clinic appointments (24% of parents versus 8% of adolescents). Parents were much more likely than adolescents to want information about complications in CF in adults (90% versus 38%) and new developments in CF treatment (80% versus 38%). Parents were more likely than adolescents to see the transition clinic as an opportunity for the doctor to learn about their child (71% versus 46%) and as a place where their own worries about the transfer could be dealt with.

Boyle[7] identified having to leave previous caregivers and concerns about infection as the main preoccupations of moving to adult care in a study of 60 American CF patients and their families. The survey was carried out before and one year after transition. It found that patients who had not met the adult team had significantly higher levels of concern about having to leave their paediatric physician and about possible decline in the quality of care. Patients identified the best age for transition as between 15 and 25 years, with the median age as 18 years.

Parents in Boyle's study were likely to express fear that transition to the adult programme would prevent them from being involved in their child's care.

Conway[8] has questioned the suitability of transfer being delayed until 18–21 years. He comments that the paediatric setting is not appropriate for discussion about "adult" life events such as pregnancy and marriage, and considers that emotional and social development is hindered if the concept of transfer is not gradually introduced from the age of 14 years and concluded by 16–18 years. He recommends the ideal as a "transition" or "adolescent" clinic, usually attended from 14 years, where a mixture of paediatric and adult staff manage the patient, and full transfer to the adult clinic within two to four years.

David[9] argues for a transition target of 18–19 years, on the grounds that this is the usual school leaving time and often linked to moving away from home to attend university.

Byron and Madge[10,11] outline two models of transition: the transition clinic as described by Conway, with a transition age group around 16 years, and the adolescent clinic, for patients 14–19 years old. There is, of course, a third model, where patients transfer from paediatric to adult care with a transition programme (e.g. home visit by members of the adult team, prior visit to the adult clinic) but do not have a formal clinic. Byron and Madge[10,11] describe the Great Ormond Street model of two transition clinics per year, which includes members of the adult team. The Great Ormond Street team aims to transfer patients by 16 years. A further review of transition practices in the UK context is contained in Langton Hewer et al.[12]

Conway has suggested that many developmental issues appear to be best addressed in an adult setting. His judgement that 18–19 years is undesirably late for transition in most cases is supported by the results of Zack,[13] who found that patients wanting to discuss sexuality issues were significantly younger than those not wanting discussion in this area, and Fair,[14] who found that adult men with CF had rarely had discussion about fertility before the age of 16 years but said this would have been desirable. Women preferred 16–19 years. Sixty-eight percent of men and 59% of women had had no discussion of fertility/pregnancy before the age of 20 years.

CONCLUSIONS

Transition programmes based on formal clinics over several months or years are feasible in large clinics, but may be pragmatically difficult in smaller clinics where only a small number of patients move to the adult clinic each year. From the studies carried out so far there is no clear evidence that long-term, formal transition clinics over one to two years are necessary. However, it is clear from the studies that adolescents and their parents are more likely to be satisfied with transition if they have contact with the adult doctor and team who will care for them, that adolescents and their parents want the opportunity to visit the adult

setting, and that they want information on the adult clinic (specifically, written information). This can be provided by a transition programme, which is not identical to a transition clinic.

There is no objective evidence as to what individual characteristics predispose to a "good" transition. The studies do suggest that carers may underestimate adolescents' readiness to move to an adult clinic. The question of the appropriate age for transition is difficult. Most of the American studies have been carried out in settings where transition has not been made until late adolescence or even early adulthood. However, the results of the UK studies, and hints from the US studies, suggest that transition should be made earlier than the 18–19 years suggested by David.[9] Patients want information and support on issues of adult development and sexuality in early adolescence, and transition at the age of 14–16 years, as suggested by Conway,[8] seems appropriate. Finally, the studies also suggest that transition in early adolescence should not mean the exclusion of parents from discussion and participation in their child's care, as typically both adolescents and parents want joint discussion – although, of course, this may vary individually. The studies show the importance of transition for parents, and the need for transition to address the concerns of parents about their child's care and their participation in that care.

BEST PRACTICE

The following guidance is based on telephone surveys or direct communications with major UK CF centers. It is consistent with the evidence base above and represents a consensus view of current best practice in the UK healthcare environment.

Principles guiding transition

- At the point of transfer the young person is comfortable and confident about meeting the adult CF team and is able to report accurately and ask questions about his or her condition.

- Anxieties and other problems with respect to psychological well-being will be recognised and appropriate steps will be taken to address them well before the point of transfer.

- At the point of transfer the young person has sufficient knowledge of CF to recognise important symptoms and respond to them.

- At the point of transfer the young person has a framework and information available to work towards achieving an active and healthy life dependent on disease severity.

- Transfer to the adult clinic is not associated with any surprises and is perceived as an accomplishment by the patient and their families.

Experience supports the idea of a three-stage process of transition:

1. **The paediatric team identifies patients**, introduces the topic and provides information to patient and family. The timetable for transition is agreed and comprehensive patient information is sent to the adult centre.
2. **A series of joint clinics takes place**, during which the patient meets the adult team who take an increasingly prominent role in successive visits.
3. **A final handover** to the adult team.

The role of the paediatric team in preparing patient and family

Planning is essential. The paediatric team should discuss and prospectively identify patients who should be preparing for transition. In larger centres, moving a cohort of up to six patients through transition together, in a planned sequence of clinics (the "moving walkway" model), can be helpful as patients and families can support each other.

Paediatric centres should liaise with their local adult centre to develop a transition protocol with accompanying documentation (a checklist) and work through this.

Box 1 indicates the important aspects of preparing a CF patient and family for transition from the paediatric setting.

Preparation by the adult team

- Create a patient-friendly brochure describing the adult CF service to be given to patients by the paediatric team.
- Facilitate informal visits to the adult centre by patients and families.
- Liaise closely with the paediatric team to ensure smooth advance planning of each sequence of the joint clinics.
- When interacting with parents in the transition setting, explicitly acknowledge the difficult challenge of transition for parents – this is helpful in "building bridges".
- For patients with complex additional needs (e.g. renal, liver or CF-related diabetes), ensure, by liaison with colleagues, that subspecialty transition is co-ordinated to be simultaneous with CF clinic transition.

Joint paediatric and adult review

- Immediately before joint clinics, a meeting between paediatric and adult teams is helpful to go over the case summary and recent annual review documentation. Some centres give a copy of the transfer document to patient and parent.
- Hold joint clinics, starting at the paediatric site, every three to six months (the UK average is between three and five joint appointments during the transition process).
- Visits to the adult centre should be offered before the first appointment at the adult centre.
- Later joint clinics ideally occur at the adult centre, attended by paediatric staff.
- Good information-gathering is important – do not have the patient repeat the same information to many different professionals, as this can devalue a complex clinic.
- To help patients and families manage the stress of transition, support from a clinical psychologist should

BOX 1 Preparation of the patient and family by the paediatric team

Start the transition process at the age of 13–14 years, with the final transfer at 16–18 years, dependent on physical and emotional stability. The paediatric team is best placed to judge when patients are ready to commence transition and should be flexible regarding actual age, within reasonable limits.

When the topic is first raised, give patients and parents a definite timescale over which the team expect transition to be completed. This helps to foster concordant expectations in all concerned.

Agree with the adult centre at least a year in advance the dates for the next round of joint transition clinics; this ensures key staff are available when needed.

Ensure the start and end dates of the planned transition process are known to, and agreed by, all staff, patients and families from the outset.

Give written information describing the adult centre and the process of transition.

Make the patient and family aware that the adult centre will have the same ethos of care, but that there will be differences in management, which should not be perceived as negative.

A patient questionnaire ("quick quiz") may help to determine the level of understanding of the condition.

Ask parent and child to complete a questionnaire on views about transition – this informs planning of programmes and identifies concerns prospectively.

Arrange an assessment by a psychologist to look at maturity, level of understanding, specific fears and so on with the patient and parent.

Start to see patients in the clinic on their own for part of the consultation from the age of 13–14 years, and talk to parents about why this is a desirable step.

If giving intravenous antibiotics, start to teach the patient self-administration, making up nebulisers etc. – this encourages patient empowerment.

Discuss medication, what the patient is taking and does he or she know what each is for (one centre listed medications and asked patients to write down what each was for).

Offer parents an evening meeting to discuss transition (not always well attended!).

Offer visits to the adult centre and/or joint home visits with adult/paediatric CF nurses.

Identify a trusted adult who can challenge and support the patient through transition, act as an advocate and help and encourage the individual to develop self-advocacy skills.

Open discussions on sex education, genetics, careers, smoking and alcohol – adolescents will see their relevance in relation to the transition to adult care.

Clear documentation in the care record that all of the above is discussed, when and by whom – this avoids tedious duplication.

Complete comprehensive annual review, including quality of life assessment prior to transfer.

For patients with complex additional needs (e.g. renal, liver or CF-related diabetes), ensure, by liaison with colleagues, that subspecialty transition is co-ordinated to be simultaneous with CF clinic transition.

For patients nearing lung transplant referral, involve the adult service in any interaction with the lung transplant centre.

Ensure that the adult team receives a full written case summary and the results of the annual review well in advance of meeting the patient.

be available and offered as required during this phase of transition.

- Continue with the "transition theme" (seeing the adult team only) for 6–12 months. One centre continued to invite the paediatric CF nurse along to these clinics.
- Continue to involve parents in treatment decisions with a gradual and agreed shift of emphasis towards patient responsibility.
- Parents should be given the opportunity to feed back to paediatric and adult teams their experience of the transition process once it is complete, for example by questionnaire.

Involvement of primary care

- Notify the GP early of the plan for transition and the timing.
- Ensure the GP receives contact information for the adult service.
- Ensure the GP receives clinic letters from each joint transition clinic.
- In remote/rural areas where isolated patients need to make the transition, the GP will have a larger role in ensuring that the information regarding transition reaches the patient and in communicating with paediatric and adult centres to ensure concerns of the patient and parents are addressed.

Other helpful points

- Paediatric and adult centers should prospectively identify any major differences in practice (e.g regular versus "as required" antibiotics) and discuss and explain these in advance with patients and families.
- Where possible, it helps if the same professionals from the adult team see the patient through the transition process.
- It is common for transition to coincide with, or be closely followed by, the need for adolescents to leave home and go to college/university. This often means involvement of an additional distant adult care team. Early identification of this need and clear communi-

cation of all clinical information with the extended team is then crucial.

PROBLEM AREAS AND POSSIBLE SOLUTIONS

1. Failed or refused transition

When patients refuse the transition process they are left in an increasingly inappropriate care environment, which may impair their development and leave them open to increased stigmatisation ("he's still going to the children's hospital"). The paediatric care model that emphasises the major role of parents becomes increasingly inappropriate.

Reasons for failed transition may include a reluctant paediatrician who has emotional attachments to the patient/ family, and may not have confidence in the adult centre to provide an appropriate level of care.

For patients, the physical environment of adult centres is often a problem. Décor plays a huge role for young people. Transferring from the children's hospital, where accommo-dation is brightly decorated and welcoming, to a conventional adult ward that is often shared with older and very sick people can be difficult. Some units for CF have been fortunate to be able to decorate a small number of rooms for the use of younger patients who respond well to this. Leisure facilities such as DVD players, laptops and internet access to contact friends can be very beneficial to those that have to use inpatient facilities. There is no evidence that such comforts encourage inappropriate use of inpatient facilities – most young patients have better things to do!

A minority of patients remain reluctant to transfer despite all encouragement. A number of strategies may help in this situation, but a helpful approach is to deformalise and "demedicalise" the process in the short term. Joint home visits where the patient is visited by a trusted member of the paediatric team together with a nurse specialist from the adult team are often useful in breaking the ice. Patience is needed, and contact can progress in time towards informal visits to the adult centre, again in the company of a trusted member of paediatric staff. The realisation that friends have made successful transitions may also help. At all times it is essential that patients and parents are given clear guidance about where to seek help in time of need, to avoid the patient "falling between two stools".

2. Exceptions to normal transition

Early transfer: This is rarely appropriate. Where patients move to a new area at the age of 13–14, transfer to the children's hospital in that area may seem disruptive, but in practice most adult units cannot accept patients before the age of 16, so normal mechanisms of transition should be followed.

Late or no transfer: This may be appropriate in the case of a patient who is terminally ill (perhaps also attending a hospice), for whom there is little benefit to be gained from the added stress of transition and change to an unfamiliar team.

"Sibling delay": Families with two CF children may request, for logistical reasons, that the elder child delays transition until the younger is ready. For small age gaps this may be appropriate, but with larger gaps care becomes increasingly inappropriate for the delayed child, and separate transition is preferable.

3. Not adhering to treatments

It is not uncommon for adolescents to stop doing treatments around the time of transition. Young people may feel they have been given too much responsibility too quickly and decide to test the barriers to see how far they can get away with things, particularly with a new team that does not know them. That is one reason why it is important that both the adult and children's teams are involved at the transition clinics, so the adult team gets to know the young person before he or she moves up altogether.

Research in the area of paediatric transplantation indicates that non-adherence to treatments following a transplant correlates with immaturity rather than chronological age,[15] a history of previous risk-taking behaviour, broken homes and childhood abuse.[16] The social and developmental context of each patient must therefore be considered when non-adherence is detected.

Differences in drug protocols between paediatric and adult centres confuse the parent and young person alike. In paediatrics there is a heavy reliance on the use of proactive IV antibiotics, yet many adult clinics use IVs in response to symptoms. Parents may worry when they are offered a less intensive drug regimen that their child will be more prone to infection. Units need to identify this issue early and counsel patients that directed treatment in response to symptoms is equally effective and is empowering to patients.

4. Not coming to hospital

Not coming to hospital during and after transition is a very difficult situation for all concerned. Home visits by CF nurses often help to support patients and find out why they are not attending. Sometimes it is the hospital itself that the young person is frightened of. If there is no way that they will attend a particular adult unit, attendance at another unit may be offered where this is practical. In England, choice is an important part of the Department of Health's policy. More commonly, patients are not psychologically ready for transition, and allowing more time and support for adjustment will eventually result in a successful transition.

Other strategies

Sometimes it is the practical issues of moving hospital that can be the most daunting for patients, after they have got to know the children's hospital so well. A transition DVD that young people can take home with them and watch at their leisure, showing the new hospital, where to park, where the clinic/ward is situated, may be of help to some. This has been done in other units and is highly successful.

Ample time must be scheduled in transition clinics to allow conversation and discussion with the young people and

their families about what is ahead and what the changes will mean.

Patient involvement and communication is a major factor in making a successful transition, and transition discussions should normally start around the age of 12–13 years, so that when transition is actually initiated for each individual everyone involved is fully aware of what is happening. Transition should be age-appropriate for each individual, and this can be accomplished by a careful selection of each transition cohort.

It is very important through the transition process that the parents are also highly involved and not shut out once their children reach the adult unit. There has to be some give and take, particularly at the beginning when parents/guardians are still fairly involved as they will still have a significant role to play in the medication routine at home.

KEY MESSAGES

1. **Early, open communication is paramount:**
   - Between the paediatric team and patients and parents preparing for transition. This communication should start early, around the age of 13;
   - Between the paediatric and adult teams to hand over the complex clinical and psychosocial information required for transition;
   - Between the adult centre and transition patients and parents to allay anxieties and make patients feel welcome.

2. **Structured programmes work best**, where all involved parties agree to an orderly sequence of planned visits, knowing well in advance what to expect, and progressing steadily towards transition. The age of 15–16 years is the UK norm for transition in CF.

3. **Even with careful planning, transition is a stressful time for parents and patients.** Parents experience the loss of a trusted source of support. Patients often want to exercise an increasing amount of independence, which threatens parents with further loss of control. Parents and patients need time to establish trust in the new adult team. Multidisciplinary support, patience and a willingness to listen to the concerns of patients and parents are crucial elements for success.

4. **With careful forward planning, ample support and appropriate collaboration** between adult and paediatric teams, most patients see transition to adult care as a positive "rite of passage".

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2. Chronic renal disease

SUMMARY

- **Transition is a difficult period 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.**
- **An awareness of the developmental stages of adolescence can allow a transition programme to be tailored to meet the needs of young people. It is important to start early and prepare young people for the move to adult services. This involves educating them about their illness and treatment, promoting independence, addressing issues such as adherence and providing information about the unit to which they will be transferred and allowing them to meet their future carers. This should be done with forward planning and with an identified key worker to accompany the young person through this process.**

BACKGROUND

Many of the principles and issues for young people with chronic diseases who require transition to adult services have already been discussed in this document. This chapter will focus on patients with chronic renal disease.

There are 13 paediatric nephrology units in the UK (details can be found at www.bapn.org.uk). Each serves a population of between three and six million: Glasgow is the designated paediatric nephrology centre for Scotland (population 5.3 million). Units see patients with many different types of kidney problems. Some patients will have minor symptoms and recover completely; others may develop renal failure or be troubled by significant symptoms for many years. This chapter will concentrate on patients who have significant renal involvement and/or kidney failure; however, it is important to appreciate that many of the patients who do not fall into this category will still require transfer to adult services, and the issues and principles of transition can apply equally to that group.

Kidney failure or chronic kidney disease (CKD) is usually progressive; once renal function has declined, progression is often inevitable, although the rate of deterioration can be variable. Once the renal function has fallen to less than 15% of normal, end-stage renal failure is reached (ESRF) and renal replacement therapy (RRT) is required, either by way of a renal transplant or dialysis. Data for all children and young people receiving RRT are collected on a yearly basis by the British Association for Paediatric Nephrology (BAPN) Registry, part of the UK Renal Registry, which is held at Bristol. The latest data show that about 40–50% of children have a congenital structural problem as their cause of renal failure and the rest "acquire" renal disease during childhood. The advent of more frequent and detailed antenatal scanning means that many children with congenital (usually structural) renal disease are detected very early in life. These children will spend many years under the care of paediatric nephrology departments. The majority of young people who "graduate" onto adult services will have CKD, be receiving dialysis or have already had a transplant. However, there will be other patients whose renal function is relatively normal but who require ongoing care into adulthood, e.g. patients with nephrotic syndrome or other conditions such as IgA nephropathy or tubular problems. These patients may be symptomatic or may have the potential to develop renal failure in later life.

The issues for patients with CKD in childhood are poor growth, poor appetite, polyuria, a restrictive diet, numerous medications as well as hypertension and proteinuria. As patients get older many of these problems persist, but new issues become more prominent, such as pubertal development, and later on fertility, as well as the risk of cardiovascular morbidity. The focus of medical management may therefore be changing at the time when patients are transferred to adult services.

Advancing CKD requires RRT. Dialysis (both haemodialysis and peritoneal dialysis) can provide some of the same functions as the kidneys, but it does not match native kidney function. Renal transplantation can provide a better degree of function and allows for a more normal quality of life. For most children with CKD, this is the ultimate aim of management as it allows better growth and energy levels, and a more normal lifestyle. For some children it is possible to receive a renal transplant without first having to undertake dialysis; this is called pre-emptive transplantation.

The management of CKD involves dietary restrictions, numerous medications (either orally or by subcutaneous injection) and a fluid allowance, whether that be a fluid restriction or a minimum intake. These measures tend to become more strictly enforced as renal function worsens and

may be very restrictive by the time dialysis is required. Management after transplantation involves different medications, different dietary restrictions and usually requires a significantly increased fluid intake. For children and young people who have not undergone dialysis, the immediate post-transplant management can be overwhelming.

One of the greatest concerns in adolescent renal transplantation is adherence to medication. Graft survival in adolescents is excellent at one year, but the survival rate at five to six years is poorer than all other paediatric groups except the zero to one year age group.[1,2] Studies have shown that non-adherence in the adolescent groups (>12 years) varies between 20–53%, while in the younger group non-adherence varies between 3–17%.[3–5] In one study graft loss was 40% when adolescent patients were transferred to the adult centre.[6] This non-adherence has been identified as causing graft rejection in 12% of the adolescent transplant recipients, which is four times greater than for adults.[7]

Significant differences exist between paediatric and adult services. Paediatricians adopt a family-centred approach using a multidisciplinary team to look at the overall development and functioning of the child; adult services tend to concentrate on the patient and their medical needs. For patients with CKD, there are also differing emphases on some aspects of medical management between paediatric and adult services. Perhaps the most obvious of these is the approach to the management of cardiovascular risk.

There are also other areas of difference. Most adult centres will involve patients' general practitioners in the management of their illness, while paediatric units tend to manage their patients themselves or with the help of local paediatricians. This is because many renal diseases are uncommon in children, and most GPs will have little experience of them.

There may also be practical reasons why services are provided differently at adult centres. Renal disease is more common in adulthood, so units will be much busier. Staff–patient ratios are lower, as children – especially young children – require more attention and looking after. Routine investigations may be different, and there may be differences in the way results are relayed back to patients, although the increasing use of Renal Patient View, where patients can access their results securely on the internet, may overcome this last issue. Patients are less likely to see the same doctor at each visit, and responsibility for attendance will be placed very much with the patient. As part of the preparation for moving, these differences can be explained beforehand, but some allowance has to be taken of the fact that adolescence is a developmental stage. Healthcare needs to be tailored to take this into account.

Renal diseases that start in childhood have different aetiologies to those that start later. Patients who have serious renal diseases presenting in infancy or early childhood are now surviving longer, and some adult nephrologists may not be familiar with certain diseases (e.g. cystinosis).

Data from the Scottish Renal Registry (SRR) report that from 1990–2005 (inclusive), 133 patients under 18 years of age commenced RRT in Scotland. Of these:

- 51 patients have only been in the adult service;
- 38 patients have only been in the paediatric service;
- 41 patients have had care transferred from paediatric to adult service (2.5 patients/year);
- 3 patients' details are unclear.

Sixteen of these patients have died (six patients who were only in the adult service, six patients who were only in the paediatric service and four patients who underwent transition of care). Morbidity is more difficult to assess, but is currently being looked at. The high mortality rate among young people and adults on RRT needs emphasis, and perhaps a different approach for the management of young adults is needed.

These data emphasise that the numbers of patients transitioning between one paediatric and several adult services within Scotland is relatively small and suggests the need for an individualised approach within each adult unit.

While this review focuses on the transition of patients between services, it is also clear that there are a considerable number of young people who are treated only within the adult service. These adolescent patients will have many of the same issues as patients who present earlier and then move over to adult services.

Renal failure, particularly in infancy, may adversely affect cognitive function, development and the normal maturation process. Furthermore, the chronic nature of renal disease means that many children and young people require repeated admissions to hospital and therefore miss out on education and vocational training opportunities.

Adolescent development

Adolescence itself can be seen as a period of transition, as one moves from childhood to adulthood, with the change in social roles and responsibilities such a move entails. Herbert[8] calls adolescence a "biosocial construct", which starts with puberty and the accompanying physical and sexual maturation and ends when the person achieves some definition of independence, usually associated with an individual's culture. Adolescence is also the period when young people develop and demonstrate capacity for logical, abstract, reflective and flexible thinking and reasoning.[9,10] Such a combination of cognitive, physical and sexual development leads to a shift in priorities and focus for young people as they consider their place in the world and start to develop a self-identity. This focus on one's own thoughts and insights, which occurs directly as a result of developing cognitive capacity, leads to what has been termed '"adolescent egocentricity". As a result, young people can become over-concerned with their own internal processes and fail to take account of others' perspectives and viewpoints, for example, believing no-one has ever experienced such distress or unfairness as them.[11]

As noted above, one of the key tasks of adolescence is the development of a sense of self-identity.[12] This involves

increased identification with peers and conformity to peer culture, which, contrary to popular belief, for most young people can be achieved without complete rejection of familial relationships.[11]

New evidence about brain maturation also suggests young people have not yet developed the type of thinking that requires looking into the future to ascertain the impact of their current actions.[13,14] This may, therefore, increase the likelihood of risk-taking behaviours, including non-adherence to medical or dietary regimes. Adolescents can appear very mature but, when put into a stressful situation, may revert to a less mature state.

While we must be cautious not to stereotype all adolescents, it can be helpful to acknowledge that this time is a difficult period for young people. Being aware of the many physical, cognitive, emotional and neurological changes that occur as part of the normal developmental processes and that can impact significantly on young people's behaviours can help place these behaviours in context. Keeping such awareness in mind can help engagement with young people, if one adapts interactions accordingly.

LITERATURE REVIEW

Reviewing the literature pertaining to the transfer of patients from paediatric nephrology to adult services suggests that this is a problematic time for these patients. Data from the UK and North America show that the survival rate of renal transplant patients is worst in the adolescent group, despite this group being the "easiest" technically compared with younger patients. Much of this chapter relates to ESRF, particularly renal transplantation, as much of the literature refers to this group of patients. The principles, however, can be applied to other groups of renal patients.

Five-year graft survival of patients transplanted between the ages of 14–17 years is the poorest of all paediatric groups and is worse than in older patients who would be expected to have additional co-morbidity such as cardiovascular disease. It is difficult to be absolutely certain of the cause for this, but there is evidence to suggest that non-adherence is a major factor, although there may also be other reasons. A report published from Nottingham[15] highlighted that transition at this critical age is a contributing factor, but, perhaps surprisingly, graft survival in UK patients transplanted between the ages of 18–23 years is also poorer than might be expected.[16] As the majority of these patients are likely to be transplanted in adult units and have their ongoing care in the same institution, clearly there are other important factors to consider. Again, this stresses the need for a different approach to the care not only of adolescents but also of young adults. A return to dialysis at this age can be devastating in disrupting education and training, restricting lifestyle and reducing well-being. It will also reduce fertility. As well as dealing with the medical issues, it is important to recognise the ongoing developmental needs of young adults, which are biological, psychological, social and vocational.

Watson reported the outcomes for 20 young people who transferred from paediatric services to one of three different adult units between July 1985 and December 1997.[6] Patients were a mean age of 14.3 years, with a range from 9.6–18.1 years at the time of transplantation and a mean age of 17.9 (15.7–20.9) years at the time of transition. Eight of the 20 patients lost their grafts within 36 months of transfer; in only one patient was the graft loss not unexpected. Of the seven grafts that were lost, three were lost within the first 12 months after transfer, three within 12–24 months and one at 31 months after transfer. All had had stable function previously. Was it possible to predict who would lose their grafts? Of these seven patients, two had been transplanted pre-emptively in late adolescence and four had had low levels of ciclosporin prior to transfer, suggesting non-adherence. One patient had acknowledged non-adherence was an issue for her six months prior to transfer. Five of the patients had adverse psychosocial factors including parental mental ill health, parental violence and divorce, sexual abuse and juvenile crime. One of the patients had been in foster care. These patients were transferred earlier in the study period than those patients whose grafts survived. At the time of reporting, two other patients had lost their grafts, but this was after more than seven years of follow-up in the adult centre; the other patients all had functioning grafts.

Watson emphasised the need for vigilance in transferring paediatric patients to adult services, the need for patient education and support and an awareness of the psychosocial circumstances of the patient and their family. The role of the family in providing support for patients while they go through the turbulent times of adolescence is crucial. Watson has also highlighted the role of the multidisciplinary team in preparing patients for transfer and for being involved in the timing and actual process of transition. He emphasised the role of the youth worker and the usefulness of workshops and residential weekends to discuss certain aspects of transition.[16a]

A personal account of transition and its difficulties has been published by a transplant patient who talks about the issue of non-adherence and lack of trust after transfer.[17] This patient discussed his alarm at the prospect of transfer to an unknown environment and team, as well as feeling unimportant at being discharged so easily, as he perceived it, from paediatric services. These feelings, plus negative side effects of medication and a general frustration at having always to follow advice, led the patient to decide to experiment with reducing medication intake. It would appear this was done in a very controlled, thoughtful manner. Unfortunately, because of his lack of trust in the adult nephrology team, the patient did not feel able to discuss any of this with his doctor or other staff so that non-adherence was hidden for some time. Ultimately, this patient sadly lost his graft. Even sadder is the realisation that this may have been avoided if transition had been handled differently.

Remorino and Taylor[18] published the results of a client satisfaction questionnaire given to patients who had transferred from paediatric to adult services at Guy's Hospital, London, during 2000 and 2001. The paediatric

unit has a transition programme, and patients were offered the opportunity of attending the transition clinic. Eleven out of 18 patients responded; all were aged more than 17 years at the time of transfer. Seven patients reported the timing as "right for them"; of the other four, three would have preferred a later transfer. Nine out of 11 thought their transfer was "OK" or better and two thought it went "badly" or "really badly". There was no difference between those who attended the transition clinic and those who did not. Suggestions for an easier transition were requested as part of the survey. These included:

- A visit to the adult centre before transfer (n=4)
- Contact with someone who had been through the system before (n=5)
- An adolescent-only clinic (n=8)
- An alternative time for the clinic (n=2)

Physicians were also asked about patient adherence; results were available for 16 patients. One patient improved, nine were the same and six were worse. This was no different for those attending the transition clinic and those who did not. Patients considered stable and adherent before were not necessarily the same after transfer, and vice versa.

Much of the available literature refers to transplant patients. However, Bell[19] has published the findings of a survey assessing the current status of transition practices for chronic dialysis patients in North America and Europe. Just under half (47%) of the units surveyed had a fixed cut-off age for transfer, which ranged from 17–22 years. One third of the units had a transition programme in place. In 95% of units, nurses were involved in co-ordinating the programme, social workers in 68% and paediatric nephrologists in 58%. When considering skills for independent functioning, such as obtaining prescription medication and making appointments, fewer than 20% of centres reported at least 60% of their adolescent patients as being independent. In 31% of programmes, less than 10% of patients were able to carry out these functions. Patients on peritoneal dialysis (PD) seemed to be more independent than those on haemodialysis as 48% of centres reported that more than 60% of PD patients were able to perform their own PD set-up.

The presence or absence of a transition programme did not affect the outcome. Being able to choose an adult dialysis centre was more common in North America (87%) than Europe (36%), which is presumably related to geographical constraints. Most patients (83%) were able to visit the unit prior to transfer. A third of paediatric units were unaware if there were support services available for patients with developmental delay or adherence issues, despite the fact that many units had an adult dialysis programme linked to their own. Most centres without a transition programme at the time of the survey perceived the need to develop one.

It is clear that the presence of a transition programme per se is not sufficient. However, a transition programme designed specifically to address some of the issues outlined above may be the easiest way to tackle these issues.

Bell describes the aim of transition as "co-ordinated, uninterrupted health care that is patient centred, age and developmentally appropriate, flexible and comprehensive". This approach should enhance an adolescent's sense of control; promote skills in self-care, communication and decision-making; and maximise life-long functioning and potential. Many centres are failing to provide such an approach at present.

There are numerous articles in the literature relating to non-adherence post renal transplantation. Rates of more than 50% have been reported, with results being worst in adolescents. The consequences can be severe. In a study from France,[20] of 54 paediatric patients (32 males) with non-adherence resulting in rejection, most were aged 14–20 at the time of diagnosis of rejection. Half of these patients returned to dialysis, four died and only seven completely recovered. In this series, 25% of all graft losses from rejection were due to non-adherence.

Other studies have suggested a higher rate of non-adherence in adolescents than in either paediatric or adult renal transplant recipients. There are different definitions of non-adherence and different ways of demonstrating it and this is discussed in more detail later. The cost is high, with non-adherence being cited as a cause of graft loss in 14% of paediatric renal transplant recipients.[21] It is more common the longer patients have been transplanted and with the perception of good health.[22] A longer experience with chronic ill health may have a beneficial effect on adherence, although more recent reports suggest better outcomes with pre-emptive grafts.[21] Adherence is lower with living related transplantation, which may be due to rebellion against a sense of gratefulness or obligation to the donor.[23] Treatment-related factors are also important. Side effects of medication, especially cosmetic side effects, are particularly troublesome for teenagers, as are complex regimens and having to take large numbers of tablets.[21] The set-up of the healthcare services is also important as is the relationship to the healthcare providers.

BEST PRACTICE

One of the definitions of transition describes it as "the multi-faceted, active process that attends to the medical, psychosocial and educational/vocational needs of adolescents as they move from child-oriented to adult-oriented lifestyles and systems".[24] There is general consensus now that transition is a process and not a unique event.[25] Minimising transition to a transfer between services without addressing all of the psychosocial and developmental issues associated with it will be a barrier to successful transition.[26] The challenge, therefore, is to provide comprehensive, integrated and co-ordinated services across complex healthcare systems and settings.

The elements of an effective transition programme include:[27]

- Developing a transition policy that is agreed by both the paediatric and adult unit;

- Developing a pathway to support the preparation for, the active transfer to and integration into the adult healthcare system
- Preparation and education
- Co-ordination of transfer process
- An interested and capable adult service
- Administrative support
- Primary care involvement

Adequate preparation and education naturally requires the assessment of young people and their families and should comprise a number of factors, including:

- Their knowledge of illness and treatment[28]
- Family factors and perceptions
- Cognitive abilities
- Health locus of control

Conversely, potential barriers to successful transition to adult services include:[26]

- Paediatric anxieties about the quality of adult provision and attachment to patients
- Adult provider concerns about managing young people
- Lack of preparation of the young person in terms of self-care and overall expectations of the adult unit

Outcome studies with adult renal patients in Manchester highlighted a number of key points. Most young people found transition difficult but recognised it as inevitable; they reported the most helpful coping strategy was a full understanding of their illness and being involved in medical decision-making. Other key messages were that early planning is vital and opportunities for generic health discussions, including sexual health, would have been useful.[29,30]

Bristol services[31] have a long-established transition programme which developed out of an initial stakeholder analysis and was founded on the expert patient model. Bristol services now have clearly defined operational policies and pathways with a planned programme that includes identification of a key worker, annual transition interviews and joint complex care meetings when required. An initial audit of the programme gave the following feedback from young people:

- "Start early enough for us to make informed choices about when and how… no surprises… make it clear you're talking to us about growing up and moving on"
- "Provide information in lots of different ways, arrange meetings with other young adults who experience it as well as staff"
- "Treat us as individuals… we're not all the same just because we're the same age"

The other key points to consider in developing transition programmes are age and stage of development, as discussed above. The key focus of middle childhood is integration with one's peer group and successfully developing skills that enhance and enable future progression. Moving into adolescence, the key focus involves effective separation from parents, development of independence and of realistic vocational goals, mature level of sexuality and realistic and positive self-image. Young adult survivors of CKD often experience difficulty negotiating life tasks such as living away from home, engaging in intimate relationships and establishing employment. Chronic illness such as CKD can be conceptualised as a "disruptive event" that may result in a biographical shift from seeing oneself as "normal" to seeing oneself as "abnormal".[32] This biographical disruption can thus impact on a variety of developmental life tasks, and young people need to be helped to integrate positively and develop a realistic and positive self-identity.[33] Transition is an ongoing developmental process requiring regular attention.

Adolescent renal patient adherence and concordance – medication

One of the greatest concerns in adolescent renal transplantation is adherence to medication as discussed above. There has been a change in emphasis from adherence to concordance. Concordance is an agreement reached between the adolescent and medical/healthcare professionals on the understanding of treatment and the patient's own beliefs. This leads to an individual approach for the patient. This individual approach in the adult setting is difficult to achieve due to the numbers of patients attending clinics and the number of different medical staff the adolescent patient may see.

Non-adherence can be considered as accidental omission of medication that is infrequent. If patients have no immediate medical consequences of their missed dose this may lead to more missed doses and eventual graft rejection. This is known as a drug holiday, where drug omission has become more intentional.

Reasoned non-adherence is defined as a belief that adolescents think the drug is too strong or the side effects are altering their body image. This leads patients to reduce the dose or frequency of their medication.

Improving medicine adherence is a complex problem with no universal answer. Rianthavorn et al.[5] have produced a nine-point basic guideline:

1. Direct approach to the adolescent on a personal level.

2. Establish shared responsibility between the medical team, parents and adolescents.

3. Ensure patients have appropriate knowledge about medicines to follow directions given to them.

4. Provide pre-transplant education about transplant and medication that will be taken, e.g. dosage schedules, proprietary and generic names of medicines and their side effects.

5. Discuss medication regimes and enquire about any side effects at all clinic visits. Any problems arising should

not be dismissed, as adolescents are less likely to raise the problem again.

6. Use medication regimes that are the least intrusive as possible, e.g. dosing intervals twice daily. Use medicines with the least side effects that may cause problems for this group, e.g. acne, hirsutism.

7. Link the time of taking medicines with a patient's daily routine.

8. Monitor the results of medication by taking drug levels of immunosuppressants as an adjunct to adherence. Check if prescriptions are regularly collected.

9. Follow a multidisciplinary team approach as adolescents can develop good rapports with different health professionals.

However, for each patient it is important to assess the individual factors that are operating to influence adherence. These will include motivation to change, cost-benefit analysis and other factors, which have been explored in more detail above.

Clinical pharmacists, as part of the multidisciplinary team, have specific training in direct patient care in the area of medication therapy, and it has been shown that they improve patient adherence in non-transplant patients.[34–36] Chisholm et al.[37] compared the adherence rates of adult renal transplant patients who had a clinical pharmacist providing direct care with those who did not. At one year post transplant, the mean adherence rate was 96.1% for the clinical pharmacist group and 81.6% for the non-intervention group ($p<0.001$).

In Scotland, clinical pharmacists are involved in the inpatient setting in adult centres, but few are involved in transplant clinics and none in transition clinics. As adherence is a major cause of graft loss, the use of clinical pharmacists in transition clinics as part of the multidisciplinary team may improve graft survival.

There is also evidence that depression is associated with non-adherence.[38] Paediatric and adult renal services should have access to a mental health professional familiar with assessing and managing depression in patients from the relevant age group with chronic medical conditions. Some of these patients may benefit from formal psychological treatment, for example with cognitive behaviour therapy. Others (probably a smaller group) will require treatment with antidepressant drugs, and prescribers need to be familiar with prescribing in renal failure/on dialysis/after transplant.

Adherence/concordance is increasingly considered in decisions about listing adult patients for transplant. It is much less likely that adolescents would be unlisted or suspended for adherence reasons, given the scope for change, but the incentive of joining or remaining on the transplant list can be a powerful tool for identifying the reasons behind non-adherence and thereby improving it. This is skilled work, and for adolescents it often requires joint work with family members, in addition to the patients themselves. Renal units should ideally be able to call upon mental health professionals, probably psychologists in most cases, who are familiar with the issues to undertake such family work, as required.

Adolescent renal patients' adherence and concordance – dietetic issues

As already stated, the management of CKD involves changing dietary restrictions and a fluid allowance, whether that be a fluid restriction or minimum allowance. As renal function worsens, dietary restrictions increase. By the time of dialysis the advice is often complex, involving many food groups, depending on blood results. Appetite may also be poor at this point and enteral feeding may be necessary.

Management post transplant involves very different dietary restrictions and an increased fluid intake. Appetite usually increases and this, combined with medication, may cause weight gain and body image issues.

During childhood, parents tend to manage dietary and fluid allowances, and the patient may only pick up certain aspects of advice. As the advice changes, the patient and, indeed, the parents may have misconceptions and find it difficult to make the recommended changes.

There is no single renal diet – dietary advice has to be tailored to the individual.

RECOMMENDATIONS

1. Conduct an early initial assessment of knowledge, attitude, adherence and health beliefs.

2. Complete an individual dietetic plan to improve knowledge and give goals; to be reviewed regularly throughout the transition.

3. Promote partnership to share responsibility for care gradually with patients/parents.

4. Promote confidence and independence in dealing with the multidisciplinary team.

5. Ensure age-appropriate literature is available.

6. Use DVDs, emails and text messages to communicate with young people.

7. Listen to and acknowledge young people's concerns and ideas.

Dietitians have been an integral part of the multidisciplinary team within paediatric nephrology units, but a more recent development has been the appointment of designated paediatric renal dietitians in smaller paediatric units in

Scotland. This network should aid the transition process as these paediatric renal dietitians know the patients well and can liaise with adult colleagues locally.

EDUCATIONAL AND VOCATIONAL ISSUES

As mentioned above, cognitive function may be affected by renal failure, especially renal failure that has persisted throughout childhood. Missed schooling and opportunities, along with lowered expectations, often mean that these patients underachieve. The provision of appropriate education services in hospital and during convalescence is important, as is access to the internet and a quiet place to work during inpatient stays. Liaison with the base school is required, and appropriate careers advice needs to be given. This is important at all stages of adolescence and needs to be carried through to the adult sector.

KEY MESSAGES

Transition should be "co-ordinated, uninterrupted health care that is patient centred, age and developmentally appropriate, flexible and comprehensive". This approach should enhance an adolescent's sense of control; promote skills in self-care, communication and decision-making; and maximise life-long functioning and potential.

1. Start early in preparing young people and families for transition, ideally around 12 years of age. Present transition to the young person and family as a natural progression that will happen at some point in the future. Begin seeing the young person on his or her own for part of the visit and gradually increase this time at subsequent clinics. Be aware of the need for some parents to be seen on their own during this process.

2. Assess health beliefs and use these as a basis for ongoing developmentally appropriate work. Regular reassessment of health beliefs is essential as this allows appropriate adaptation of intervention work as the child/young person's cognitive capacity changes.

3. Transition should be a multiagency, multidisciplinary process, ideally with a key worker identified.

4. Include regular assessment of the young person's areas of needs and particular difficulties, as well as strengths, to allow individualised planning. This should encompass health, educational/vocational, psychosocial and emotional needs, and other areas as appropriate. Assess the young person's degree of independence and ability to undertake tasks of day-to-day living and to take control of his or her own health.

5. Produce a written transition plan in the casenotes to document input required/provided. This should include explicit agreements with the young person about the process of transition, including the approximate date.

6. Provide continuous education, including written and multimedia information, from an early age about the illness and the treatment to promote understanding of the condition. Some aspects of transition are common to all patients, and it may be possible to arrange workshops to deal with the issues of transition and to promote life skills.

7. Consider greater involvement of primary care earlier in the course of the patient's illness. Many patients attend the paediatric nephrology unit or their local paediatric unit rather than their GP.

8. Provide a written summary for the adult unit (and patient) about the past medical history, including procedures and operations. Psychosocial information should also be provided to the adult unit – bearing in mind confidentiality issues.

9. Include planning for educational/vocational/careers provision within the transition process – key professionals from the base school/hospital such as an education/youth worker should contribute to plans for transition. Pupil and parents should also be given dates for reviews of progress.

10. Ask young people what would help them.

11. Ensure the availability of mental health professionals, probably psychologists in most cases, who are familiar with the issues, to undertake family work as required.

12. Provide information packs and handouts about adult services explaining what to expect, how they are run, what the expectations are of the young person attending, etc.

13. Arrange visits to the adult facilities to allow familiarisation with the set-up and with procedures that are likely to be very different from child-centred clinics. Make sure that young people are aware of whom to contact should they be unwell or unable to attend clinic or if they have questions (names and numbers). Contribute to the plan. Plan targets, success criteria and personnel responsible, and be aware of patients' expectations of their adult centre.

14. Provide joint clinics with adult services to allow the young person to get to know the new staff. Overlap clinics so that the young person has a chance of returning to the paediatric unit to discuss any difficulties/concerns in a familiar environment.

15. Review patients, particularly transplant patients, regularly during adolescence to pick up the consequences of non-adherence early. This applies both before and after transfer.

16. If possible, transfer patients at the same time as others their age or arrange a "buddy system" through which they meet patients who have transferred previously.

17. Develop a formal process to say "goodbye" to the known service and staff with whom the young person and his or her family have established relationships, at the point of transition.

18. Develop services for young adults within the adult services for the first few years after transition. These should recognise the ongoing developmental needs into adulthood, which will require the input of the multiprofessional team and wider support services within the community.

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3. Type 1 diabetes

SUMMARY

- Facilities and systems for the transition of adolescents with type 1 diabetes mellitus (T1DM) from paediatric to adult diabetes services have and are being developed in Scotland. While these are patchy across all NHS boards, due to the influence of local resources and numbers, the majority of young people are offered an appropriate service.
- The use of written guidelines is limited and the initiation of transition in the paediatric clinics by age banding should be introduced in all centres.
- Increasing the age of transition to about 18 years should be considered by more centres.
- Although local practice will vary with local circumstances, it is suggested that the National Institute for Health and Clinical Excellence (NICE) recommendations in Table 1 should form the basis for planning transition for young people with T1DM.

BACKGROUND

The most common age of T1DM diagnosis is during childhood, with 10 years being the current average in Scotland. Consequently, the practical issues of managing diabetes have to be faced by young people at the same time as they move through puberty and adolescence. With the transfer from the children's health service into the adult healthcare system, the concern is that glycaemic control appears to deteriorate, and it is accepted that young people with T1DM have specific health needs relating to the physical and socio-cultural changes of adolescence.

The National Institute for Health and Clinical Excellence and the Scottish Intercollegiate Guidelines Network (SIGN) have both produced significant guidelines on diabetes,[1,2] with the recent NICE guideline including a section on transition (see Table 1). The following comments and recommendations draw substantially on this recent relevant work.

LITERATURE REVIEW

Offering a special service for adolescents with T1DM

The most recent recommended guidelines for specialist services for T1DM come from NICE, which has systematically reviewed and published the evidence of effective transition of care as part of its guidelines on the management of T1DM in children and young people. In Scotland, SIGN plans to carry out a selective review of its 2001 guideline on the management of diabetes in the near future.

TABLE 1 NICE recommendations for the transition of care in adolescents with T1DM

• 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, and 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.

Effectiveness of young adult clinics

In the UK, a number of centres transfer young people into special transition clinics rather than directly from paediatric to the general adult diabetes clinics.[3] NICE found no studies that examined the clinical or cost-effectiveness of transition clinics. However, some studies have compared the various outcomes between children's and adult clinics.

TABLE 2 Transition services across Scotland for adolescents with type 1 diabetes

	Numbers		Specialised Transfer			Age	Guidelines			Type of Clinics				
	Paediatric Clinic	Transfers	Yes/No	Across HB	Similar	Transfer	Available	Local	Nat.	Age band	Transition	No Appoint.	Joint Clinic	Upper Age
Ayrshire & Arran*	100-200	10-20	Y	Y	N	16-18	N	N	N	N	Y	>4	Y	>18
Fife	100-200	10-20	Y	Y	Y	12-16	N	N	N	N	Y	>4	N	>20
Forth Valley	100-200	10-20	Y	Y	Y	12-16	N	N	N	N	Y	>4	Y	>18
Glasgow	>200	>20	Y	N	N	12-16	N	N	N	Y	Y	1	N	
Grampian**	100-200	10-20	Y	Y	N	12-16	N	N	N	N	Y	>4	N	>20
Highland***	100-200	10-20	Y	Y	N	16-18	N	N	N	Y	N		N	>18
Lanarkshire	>200	10-20	Y	N	N	16-18	N	N	N	N	N		Y	>18
Lothian	>200	>20	Y	Y	N	12-16	Y	Y	N	Y	Y		Y	>18
Tayside	>200	10-20	Y	Y	N	>18	Y	Y	N	Y	Y	1	N	>18

*Royal Alexandra Hospital: Different arrangements for Inverclyde (5-10 transfers per year, no joint clinics) and Oban & Lochgilphead (> 5 transfers per year), no joint clinics
**Orkney and Shetland: No specific arrangements (>5 transfers per year at 18 years age)
***Western Isles: No specific arrangements (>5 transfers per year)

A survey investigating the transfer of young people from children's to adult clinics in the Oxford region showed that the age of transfer ranged from 13.3 to 22.4 years (mean age 17.9 years).[4] The rate at which clinic attendance occurred at least every six months dropped from 98% at two years before transfer to 61% two years after transfer. A letter of transfer was identified in the clinical records for 86% of the young people, and the attendance rate at the first appointment in the new clinic was 79%.

Another study from the UK National Children's Bureau examined young people's knowledge of adult clinics before transfer, preparation for transfer and how young people felt about the move.[5] Young people who were attending an adolescent or transition clinic seemed to have little knowledge about the clinic they would be going to in the future. Of the young people attending adult clinics:

- 35% had discussed the change beforehand;
- 16% reported having had a choice about the move;
- 84% felt they were ready to move;
- 40% felt they were well prepared by staff for the move;
- 79% were not pleased to move.

A Canadian survey examined the experience of young people with T1DM during the period of transfer from paediatric to adult care.[6] The mean age at transfer was 18.5 years, and this was lower than the age of transfer suggested by the patients (18.8 years): 21% of patients felt they should have been transferred earlier, whereas 65% felt they should have been transferred later. After transfer, 13% had no regular contact with adult care services, 3% had contact with a family physician and the remainder had contact with an endocrinologist or a diabetes clinic. Thirty-three per cent of patients felt they had a problem with the transition from paediatric to adult care. Twenty-seven per cent experienced a delay of more than six months between their last visit to the paediatric clinic and their first visit to the adult clinic. (In 17% of patients this delay was longer than a year.)

A Finnish study examined glycaemic control in young people one year before and one year after they were transferred from a paediatric clinic to an adult clinic.[7] The mean age of transfer was 17.5 years, and the mean HbA1 level improved from one year before transfer to one year after transfer (11.2% versus 9.9%).

Where to and when to transfer?

An Australian survey of young people with T1DM found that patients wished to be treated in a range of care places: 72% in a public hospital, 43% by a private specialist and 14% by general practitioner only.[8] Also, they had differing views on the age of transfer: 6% felt that transfer should occur before the age of 17 years, 49% felt that transfer should occur between the ages of 17 and 20 years and 45% felt that transfer should occur at any age up to 25 years.

A UK survey of young people in Exeter showed that the average age of transfer was 15.9 years (range 12–20 years), and 27% offered some reason for transfer of care.[9] The patients thought that it would be more helpful to visit the young adults' clinic before transfer than for a nurse or physician from the young adults' clinic to visit the paediatric clinic. The young people thought that the staff in the paediatric clinic assigned more importance to school progress and family relations than did staff in the young adults' clinic but less importance to exercise, avoidance of complications and blood glucose. The paediatric and young adults' clinic staff did not differ in their assignment of importance to diet, insulin management or privacy.

How to transfer

The UK National Service Framework for Diabetes states that transfer of young people with diabetes from paediatric services to adult services often occurs at a sensitive time in relation to the young person's condition and personal life.[10] The culture change that occurs at transition is found to be unacceptable by many young people, and young people's attendance rates at adult clinics are often low. Sensitive and skilled care at transition can assist in achieving good diabetes management, with a consequent avoidance of complications. A multidisciplinary approach is particularly effective for young people at transition. Young people with T1DM who are preparing for the transition to adult services should be informed that some aspects of diabetes management will change at transition.

BEST PRACTICE

NICE summed up its recommendations for transition of care in seven points (see Table 1). The recommendations are broad and assume that each individual young adult will receive a personalised care package from a multidisciplinary team who are experienced in the issues of teenagers in their respective cultural setting.

A recent review[11] of the provision of services for children and adolescents with diabetes in the UK did not specifically assess the transition process, but did show continuing improvements in the organisational structure of services for older children. NICE recommended that paediatric diabetes care teams should organise age-banded clinics for adolescents and young adults jointly with their adult colleagues: 71% of hospital clinics surveyed in 2005 (n = 119) have age-stratified clinics, of which 63% have an adolescent clinic and 48% have joint clinics with adult colleagues. This is a marked change from surveys in the previous 15 years. From the limited evidence base, the recommendations were weighted based on the NICE criteria. NICE strongly suggested that further research is needed to investigate young people's experiences of transition from paediatric to adult services for people with T1DM.

Forming a transition service

The Scottish Study Group for the Care of the Young with Diabetes (SSGCYD) is a joint paediatric and adult physician group. It has no specific government remit but is highly regarded as a body with a particular interest in diabetes and adolescence. Table 2 shows the current transition services across Scotland for adolescents with T1DM, documenting the current practice in the NHS boards across Scotland. Data were collected from a survey through the members of the SSGCYD in April 2007.

Undoubtedly, adolescents are a special group and require a different clinical service compared with young children.[12] Several issues, however, should be considered in establishing a transition service:

- The children's team needs to communicate with and be comfortable working closely alongside the adult team.
- 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, to their mutual convenience.
- A paediatric and adult consultant should be named to have overall responsibility for the organisation of the transition.
- Agreement should be made on the culturally designed and influenced:
  - venue;
  - age range;
  - position 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;
  - work and diabetes;
  - extreme sports and diabetes.
- It is important to ensure that emergency management is shared through both the paediatric and adult services. Particular attention should be given to ensuring good lines of communication between all healthcare professionals involved with this group of patients.

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

- Start 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 the paediatric and adult services about the patients;
- Design an audit system to test the effectiveness of the transition service.

KEY MESSAGES

1. Facilities and systems for the transition of adolescents with T1DM from the paediatric to the adult diabetes service have and are being developed in Scotland. While these are patchy across all NHS boards, due to the influence of local resources and numbers, the majority of young people are offered an appropriate service.

2. All children and young people with T1DM in Scotland should continue to be cared for by specialist teams (paediatricians, specialised nurses and dietitians) based in each NHS board. Each team operates within a local regional managed clinical network for diabetes at NHS board level.

3. Increasing the age of transition to about 18 years should be considered by more centres.

4. The use of written guidelines is limited and the initiation of transition in the paediatric clinics by age banding should be introduced by all centres.

5. Transition services will inevitably be influenced both by local resources and geography, together with personal practice. Although local practice will vary with local circumstances, it is suggested that the NICE recommendations in Table 1 should form the basis for planning transition for young people with T1DM.

Diabetes subcommittee

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4. Childhood cancer survivors

SUMMARY

- The number of long-term childhood cancer survivors continues to increase, and they are at risk of developing late complications of their successful cancer treatment. It is therefore essential that they receive regular, long-term monitoring.
- At present, health surveillance practice varies, with many paediatric oncologists following up their long-term survivors of childhood cancer, particularly those who have had significant treatment exposure, in a paediatric environment long into adulthood. This is neither appropriate for the patient nor practical for the paediatric oncologist co-ordinating the patient's care.
- Current services need to be redesigned to ensure age-appropriate long-term follow-up for the expanding population of childhood cancer survivors.

BACKGROUND

The five-year survival rate for children with cancer is currently about 75%. Consequently, the population of long-term survivors continues to increase steadily. In Great Britain, more than 26,000 people, constituting one in 715 of the young adult population, are childhood cancer survivors.[1] They are at risk of developing late complications of their treatment. Increased mortality has been reported by the North American Childhood Cancer Survivor Study, where 20,000 long-term survivors had a standardised mortality ratio of 10.8, of which about 20% was due to treatment-related late complications.[2]

Treatment-related morbidity is diverse and may give rise to endocrine dysfunction (including growth impairment, infertility, hypothyroidism), cardiovascular disease, pulmonary and renal complications, cognitive impairment, educational problems, neuropsychological difficulties and social problems. It has been reported that two thirds of childhood cancer survivors have one or more chronic health problems, while 40% have suffered at least one life-threatening/ disabling event, and 25% of survivors have at least five chronic health problems.[3,4]

It is clear that multidisciplinary long-term follow-up of these patients is essential to monitor, diagnose early, treat, and, where possible, prevent morbidity.

Current problem

Survivors have traditionally been followed up in paediatric oncology clinics, often jointly with paediatric endocrinologists, neurologists and clinical oncologists, long into adulthood. This is not only an age-inappropriate environment for these patients, but also an unsustainable situation for paediatric oncologists, as the population of long-term survivors increases and ages.

Ideally, once long-term survivors reach adulthood they should be transferred into the appropriate adult late effects services. At present, such a service does not exist and it is difficult to identify which physician should take on this role. In a busy and overstretched tertiary oncology healthcare service, medical oncology consultants are unlikely to be in a position to take on this responsibility, and may well feel inadequately trained in caring for childhood cancer survivors.

In current practice, the only adult specialist services supporting the long-term follow-up of these patients in hospital are adult endocrine clinics. However, as we have highlighted, many of these survivors have a number of chronic problems and require a clinician specialising in late effects to co-ordinate their care and ensure all their needs are met. The most feasible solution to this problem is for the development of a late effects clinic as a hospital-based service in an adult environment, with the paediatric/ adolescent oncologist and nurse specialist co-ordinating the patient's care and involving various adult specialists as required. One of the criticisms of this approach is the lack of clinicians trained in looking after adult survivors of childhood cancer. In some areas throughout the country the late effects service is supported by a GP with an interest in the long-term follow-up of cancer survivors. Adopting this model would ensure that the needs of the adult patients were met and there was appropriate surveillance for late effects of childhood cancer.

In order to ensure age-appropriate long-term follow-up for the continually expanding population of childhood cancer survivors, it is necessary to redesign our services based on the current recommendations detailed below. This will optimise the use of existing resources and ensure age-appropriate care for survivors.

We envisage that the late effects oncology nurse specialist will play an important role in this transition phase. There

is no late effects nurse specialist at present to support these services, but developing this role will be a priority of the newly established managed clinical network for children and teenagers with cancer in Scotland (Children and Teenagers Scottish Cancer Network, CATSCAN).

LITERATURE REVIEW

Guidelines for long-term follow-up

Awareness of the need to develop a service for the long-term follow-up (LTFU) of childhood cancer survivors is reflected in the recently published guidelines from NICE, SIGN and the Children's Cancer and Leukaemia Group (CCLG).

NICE

The approach proposed by NICE is contained in the guidance *Improving outcomes in children and young people with cancer*.[5] It involves a LTFU multidisciplinary team (MDT), including a lead clinician with expertise in LTFU (usually an oncologist, but not necessarily paediatric), a specialist nurse, an endocrinologist, a GP, an allied health professional (e.g. social worker) and a psychologist. The guidance also recommends that a "key worker", probably the specialist nurse, should be identified for each patient to co-ordinate the care.

SIGN

Based on the limited evidence available, SIGN developed an evidence-based approach to LTFU.[6] The long-term risks depend upon the underlying malignancy, the site of the tumour, the type of treatment and the age at time of treatment. Risk-based levels of follow-up were described by the CCLG Late Effects Group in 2001 and subsequently incorporated into the SIGN guidelines.[6,7] Three levels of follow-up, assigned at five years out from treatment, have been recommended (see Appendix A). With increasing time from the end of treatment, the risk of developing therapy-related side effects will change and patients can be reassigned an intensity of follow-up at 10 and 15 years off treatment, by which time most survivors will be independent adults.

CCLG

The CCLG Late Effects Group recently published a practice statement, *Therapy-based long-term follow-up*, which is designed to inform and guide clinicians responsible for the LTFU of childhood cancer survivors.[8] The practice statement recommends follow-up assessments and investigations based on the treatment the individual has received and complements the recommendations made by SIGN. In addition, the CCLG has developed a website, www.aftercure.org, for survivors of childhood cancer.[9] This website provides helpful information on the importance of LTFU, fact sheets on therapy-related late effects, health promotion and guidance on education, employment and other social issues. This resource should be introduced to patients in the LTFU clinics, with ongoing support from the patient's key worker or nurse specialist.

Implementation of guidelines

The implementation of guidelines varies throughout the country and, given the therapy-based approach, LTFU will also vary considerably for the different patient groups within each centre. However, there are common strands to LTFU that are applicable to all survivors, including health education and psychosocial support. Currently there is a tendency towards hospital dependency for LTFU, often in age-inappropriate settings. This culture is felt to be potentially detrimental to patients, in terms of discouraging independence, rehabilitation and empowerment, in addition to inappropriate use of overstretched resources. Stratification of patients according to the risk of late morbidity will maximise the use of NHS resources and provide age-appropriate care as locally as possible. With increasing time from completion of treatment, it is hoped that the majority of adult survivors will be independent and take responsibility for their own health, with healthcare support provided by their GP. Furthermore, primary care professionals must also be made aware of the needs of this population and optimum communication between the GP and LTFU MDT will be essential.

BEST PRACTICE

Transition issues and practical options

Once patients are five years out from treatment they are described as long-term survivors of childhood cancer and can be assigned a risk stratified level of follow-up according to the SIGN guidelines (Appendix A). Stratification of the follow-up level will identify three groups of patients: level 1, 2 or 3. During childhood, patients in the level 1 group will form only a very small minority. It is anticipated that most children will continue to require follow-up in the hospital setting, either in nurse-led or paediatric oncology-led clinics, until they are ten years off treatment or reach adulthood.

Between five and ten years post treatment, patients and parents will be educated about any potential cancer or therapy-related problems the child may experience in the future. Patients/parents will also be provided with an "aftercure" patient treatment summary card and advised of the "aftercure" website. A patient treatment summary will also be sent to the patient's GP.

Assigning a level of follow-up for patients of transition age (16–18 years)

Patients aged 16–18 years can be reassigned a level of follow-up.

Level 1

For patients assigned level 1 it is recommended that they are followed up by postal questionnaire or telephone interview by the late effects specialist nurse. Although the risks of developing late sequelae are small for these patients, a number of them will require ongoing surveillance by the GP.

The primary care team is likely to play an increasing role in the long-term follow-up of childhood cancer survivors. Primary care services may already be stretched, but GPs are

used to meeting targets and ensuring guidelines are implemented. Good communication between the hospital services and primary care will be essential. Early involvement of general practitioners in the LTFU MDT will establish collaborations between the two teams and enable GPs to become familiar with the surveillance programme. The feasibility of a shared care model between cancer paediatric oncology cancer centres and primary care doctors to deliver survivor-focused risk-based healthcare was tested successfully by a Dutch group.[10] The study showed that patients would see their family doctor for LTFU: the family doctors were interested in sharing survivors'care and family doctors would return the necessary medical information needed for continued follow-up.

The late effects nurse specialist will play an important role in preparing patients for the step towards independence. However, educating the patient to take responsibility for ongoing surveillance is unlikely to be sufficient in many cases. Completion of a health status questionnaire (with the assistance of the late effects nurse specialist) may provide an opportunity to prompt patients to attend their GPs for review.

Level 2

A number of patients will be at risk of developing treatment-related side effects, which can be monitored for and managed by a late effects nurse specialist in a hospital clinic. Once the patients reach adulthood, this clinic would be more appropriately based in an adult environment. Patients in this category could also be appropriately managed by the primary care doctor, following communication and guidance from the paediatric oncology team.

Level 3

Many patients will have received treatment that is associated with a significant risk of developing late side effects, which may or may not be evident by the time a patient is 16–18 years old and will require ongoing hospital-based follow-up: these patients are assigned level 3 follow-up. Children who develop treatment-related side effects, particularly endocrine or neurological problems, will be seen by an endocrinologist or neurologist, as part of a paediatric joint late effects clinic. Upon reaching adulthood, those patients who have already developed therapy-related complications can be transferred to the appropriate adult specialists.

However, for many patients, complications may not yet be evident or there is a risk of complications other than endocrine or neurological problems which will not generally be screened for in a specialist adult clinic. Hence there is a need for multidisciplinary LTFU of all level 3 patients, co-ordinated by a clinician with an understanding of the late effects of childhood cancer treatment. Management of adult survivors should take place in an adult environment with ongoing support from the paediatric oncologist and late effects nurse specialist.

Over the next few years it is our objective to set up a late-effects clinic for adult survivors in an adult setting, run by the paediatric oncologist, with a late effects nurse specialist, a GP with an interest in late effects, a clinical oncologist and an adult endocrinologist. From these clinic reviews surveillance can be co-ordinated and patients referred to adult physicians of the appropriate specialty when problems are detected.

Assessing the burden of late effects in long-term survivors of childhood cancer

In order to improve our understanding of treatment-related side effects and help develop protocols to minimise toxicity, lifelong monitoring of health and well-being of all long-term survivors will be necessary. We propose to do this by asking all long-term survivors to complete a health and well-being questionnaire every one to two years. For patients followed up by their GP, this will be done by post and supported by the late effects nurse. For patients attending hospital clinics, the late effects nurse will co-ordinate and assist with the completion of questionnaires.

Barriers to long-term follow-up

There are many potential barriers to the successful performance of LTFU. One of the most fundamental is a lack of knowledge among both the long-term survivors themselves and non-specialist physicians caring for them.

The role of the late effects nurse specialist

The role of the late effects nurse specialist needs to be further defined. We believe the late effects nurse specialist should play an integral role in the multidisciplinary team's LTFU of childhood cancer survivors. This will include:

- Identifying and contacting patients lost to follow-up
- Running 'nurse-led' clinics for level 2 patients
- Patient education
- Transitioning patients into adult services
- Co-ordinating postal and telephone interview follow-up of level 1 patients
- Co-ordinating and supporting the completion of health status and well-being questionnaires
- Developing and maintaining a late effects database

The late effects nurse specialist will play a key role in educating patients/parents during the transition period and ensuring that patients are not lost to follow-up.

KEY MESSAGES

- Survivors of childhood cancer are at significant risk of developing late complications following the successful treatment of their cancer. Increasing awareness of the late complications of therapy dictates vigilant LTFU of these patients with early intervention, treatment and appropriate counselling.

- There is little evidence available to define the optimum follow-up for long-term survivors and there is a wide variation in when survivors are currently discharged from follow-up. Multidisciplinary LTFU of childhood cancer survivors is essential to ensure that patients are followed up efficiently in age-appropriate environments.

- As patients approach adulthood, clinical risk stratification of follow-up will enable adolescents to be transitioned into the appropriate pathway for ongoing follow-up. The late effects nurse specialist will play a key role in supporting and co-ordinating the care of each patient as they progress through this transition period.

  It is important that the survivors themselves should have a clear understanding of the goals of LTFU, in particular those that require active survivor involvement (e.g. health promotion), in order to optimise its benefits. The active involvement of survivors, by discussing the aims of LTFU rather than simply seeking passive agreement to attend clinics and undergo investigations, may promote meaningful engagement in strategies to improve their future health.

- In the UK, strategies are being developed to define a comprehensive programme for follow-up. There is little evidence to guide these strategies, and current best practice is that all survivors should be followed up for life. In addition, data is being centralised to evaluate the late effects of childhood cancer therapy in the expectation that future treatment protocols may be modified where possible.

Childhood cancer subcommittee

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APPENDIX A Suggested levels of follow-up for long-term survivors of childhood cancer[6,7]

Level	Treatment	Method of follow-up	Frequency	Examples of tumours
1	• Surgery alone • Low-risk chemotherapy	Postal or telephone	1–2 years	• Wilms' stage I or II • LCH (single-system) • Germ cell (surgery only)
2	• Chemotherapy • Low-dose cranial irradiation (<24 Gy)	Nurse- or primary care-led (after appropriate training)	1–2 years	• Majority of patients (e.g. ALL in first remission)
3	• Radiotherapy, except low-dose cranial irradiation • Megatherapy	Medically supervised long-term follow-up clinic	Annual	• Brain tumours • Post BMT • Any Stage 4 patients