Royal College of Nursing

# Adolescent transition care

RCN guidance for nursing staff

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The RCN Children and Young People's Staying Healthy Forum includes those members who have an interest in care aimed at promoting positive physical, mental and emotional health and wellbeing in all children and young people.

The communities linked to this forum are:

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(including independent school nurses)

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This document has been revised in 2013 to reflect a number of current political and professional issues and initiatives.

This publication is due for review in December 2015. To provide feedback on its contents or on your experience of using the publication, please email publications.feedback@rcn.org.uk

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# Adolescent transition care

## RCN guidance for nursing staff

# Contents

# 1

# Introduction: why do we need adolescent transition care?

> *"Transition is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems."*
>
> *(Blum et al, 1993)*

Young people aged between 10 and 19 account for over 12 per cent of the UK's total population in 2003 (Cencus, 2011). An increasing number of children with long-term conditions and complex care needs are surviving into young adulthood. With over 85 per cent of children with chronic illnesses (Betz, 1999) and 90 per cent of those with disabilities (Bloomquist et al, 1998) surviving into adulthood, there is a growing need for specialised care to ensure a seamless transfer and transition from children's to adult health care services. There is also a need for greater attention towards transition within mental health services for 16 to 18 year olds.

Currently, there is a lack of specific, discrete provision for transfer, in addition to the longer process of transition for adolescents. Young people report feelings of being "dumped, cut off and abandoned" as they reach the transition period (Shaw, Southwood,McDonagh, 2004). The current options for transfer are: an abrupt transfer to adult services; staying in the care of children's services longer than is really appropriate; or leaving medical supervision altogether, either voluntarily or by default.

Transition is a lengthy process and should continue on into adult care. The responsibility for ensuring effective transition does not stop when the young person is transferred to a different consultant. Joint multidisciplinary working is essential, and longer consultation times are required for adolescents working through transition than in children's or adult clinics (RCPCH, 2003).

The National Service Framework (NSF) for Children and Young People (DH, 2003; DH/DfES, 2006) recognises that transition should be a guided, educational, therapeutic process, rather than an administrative event. Effective transition must also allow for the fact that adolescents are undergoing changes far broader than just their clinical needs.

In 2003, the RCN Adolescent Health Forum commissioned a systematic literature review of 698 primary and secondary studies, both published and unpublished. To shape practice, research which is appraisable should underpin activities, such as randomised controlled trials and systematic reviews. Although there has been an increase in research into the needs of young people undertaken since 2003, there remains a lack of robust research available on transitional care and current literature on adolescent health continues to be based largely on expert opinion.

The search highlighted a multi-method review which was funded by the government (Forbes et al, 2001). The first controlled study of transitional care in a chronic illness reported on the importance of having individualised transitional care plans from both a user and provider perspective (Shaw, Southwood and McDonagh, 2004). There is a recognised need for more research specifically focussing on young people.

## About this guide

Ensuring a seamless transfer is one of the greatest challenges facing both children's and adult services. This guide should help practitioners achieve a seamless transfer using a national clinical pathway framework. It is divided into two parts: the first provides an overview of the issues to consider when planning transition services; while the second provides a practical framework for working with young people at each of the major phases of adolescence: early stage (around 12 to 14 years); middle stage (around 14 to 15 years); and late stage (around 15 to 16 years). There is also an appendix with a diagram showing the RCN clinical pathway for adolescent transition.

# 2

# Key issues

The following concerns and potential problems should be taken into account when planning provision for the transitional care of young people.

## Concerns

- For adolescents – desire for autonomy and involvement in decision-making.
- For parents/carers – empowering the young person ('letting go').
- For professionals – involving families, preparing and empowering the young person for transition ('letting go'), involving other professionals and working across boundaries.

## Potential problems and obstacles

- Lack of specialist knowledge in adult teams and lack of confidence in knowledge.
- Lack of specific service provision for young people.
- Lack of understanding and appreciation of young people's needs and issues in both children and adult health sectors.
- Professional attitudes.

## Specific issues for adolescents with disabilities

- Low parental, young person and professional expectations.
- Lack of self-advocacy skills and lack of opportunity to develop and practise these skills.
- Differing views of independence and success.
- Lack of knowledge of existing career and vocational education services (Bloomquist et al, 1998).

## Factors thought to enhance transition between services

- Leadership.
- Successful collaboration and cross-boundary working.
- Resources.
- Acquisition of skills and knowledge.
- Robust documentation and appropriate administration.

# 3

# Providing effective services

## Ask young people what they think

Adolescents themselves should be involved in the planning and delivery of health services (Oppong-Odiseng, 1997; Dodd, 1996; DH, 2006). Their precise needs will vary according to specific medical, social and cultural circumstances (Paul, 1998; Needham, 1997), and local research will be needed in order to identify and understand these.

## Continuing professional education

Nursing staff across all agencies will need ongoing training to care for adolescents at both pre- and post-registration level. Involving practitioners from all agencies will help establish local transition policies that incorporate all aspects of the wider health and social care agenda. Experienced staff members should also be given opportunities to share their knowledge of caring for adolescents with less experienced staff (RCPCH, 2003).

All multidisiplinary training should cover:

- transitional care
- young people's perspectives
- mental health issues and problems
- communication and leadership
- multidisiplinary working.

## Organisational planning and frameworks

Thorough planning and clear frameworks will provide a strong foundation for any approach to transition. Adolescent health services should form part of a comprehensive, strategic plan of care (Viner et al, 1998). All the agencies involved should work together to share expertise, carry out joint assessments and, where appropriate, pool resources. The generic nature of many transitional care issues lends itself to sharing workload amongst different agencies.

## Dedicated facilities

Encouraging young people to develop as much independence as possible, both from their families and health care staff, will help bridge the gap to adult services and to help them make informed decisions about their own care. Initiatives such as out-of-hours clinics, age-specific clinics, selfmedication, self-care and parent-free consultations can help young people begin to take responsibility for their own health care needs.

Ideally, if requiring inpatient services, young people should be cared for together and there should be locally devised policies in place to determine the case mix for admission.

# 4

# Guidance for transition planning

## Timing

Flexibility is key. Not all young people will be ready to make the transfer to adult services at the same time, and you must take into account their cognitive and physical development, emotional maturity and state of health. However, the RCN suggests that all adolescents – including those with learning disabilities or special needs – should be supported to leave children's services by the age of 18 or 19. Transition in many instances is being encompassed into service specifications and commissioning arrangements.

The Royal College of Paediatrics and Child Health states: "Young people should not be transferred fully to adult services until they have the necessary skills to function in an adult service and have finished growth and puberty" (RCPCH, 2003).

There is growing recognition of the need to provide young adult services that meet the needs of young people and young adults who have transitioned from children's services.

## Transferring care

Each young person should be allocated a named key worker with responsibility for monitoring their health, social, psychological, educational and employment needs. A key worker is a named individual whom the young person and family approaches for advice about any problem related to the young person. The key worker has responsibility for collaborating with professionals from their own and from other services to ensure co-ordination of the care of the young person (Garwick et al, 1999). Evidence suggests (Hay, Joffe and Maynard, 2003) that a dedicated transition worker can have a positive impact in most health care settings, and that young people should have a named contact within both children's and adult services.

Vulnerable young people with complex needs may benefit from the involvement of an adolescent specialist nurse, particularly where several services are involved, although this can be an expensive option. Creating such a role is a major investment, but could have a significant impact on transition. Someone in this role could support individual disciplines within specialist children's hospitals and in district general hospitals. They could also act as an adviser, source of support, educator, advocate and service developer. However, in the majority of district general hospitals the key worker will be the children's nurse specialist in, for example, diabetes or epilepsy. The role could also be undertaken by another professional such as a social worker, community nurse, GP or occupational therapist.

## Getting young people involved

The process of getting young people involved in their own care should be carefully planned, with key milestones marked out. Responsibility for decision-making should be increased gradually, and the process should be discussed and accompanied by formal documentation covering details of clinical care, a record of needs assessment, goals, and inter-agency agreements. Wherever possible, these documents should be accessible to the young person as a hand-held record. Where the young person has complex special needs, it is particularly important to involve their family too, so that they can agree to and support the proposed care package.

The RCN's own clinical pathway and associated care plan acknowledges previous work by Whitehouse and Paone (1999). More recently the concept of co-production and co-design have been successful models of engaging young people to manage their long-term conditions such as sickle cell disease. While the forum recognises that locally devised care plans are in use in some specialist units, generic documentation could help to raise the profile of transition and make it more transferable throughout health services so there are consistent standards and processes. The model in the appendix aims to make the transfer of responsibility to the young person less stressful for the young person, the family and health care team. See Appendix (page 20).

## Case management

The young person's named key worker is responsible for taking an organised approach to the transition process. The evidence from the systematic review (Hay, Joffe and Maynard, 2003) suggests that establishing lines of accountability is essential. As there can be many professionals involved in a young person's care, practitioners should be given enough time and resources to develop good working relationships with each other, especially when they are dealing with vulnerable or marginalised young people.

The transition process will take more time to establish if the young person has more than one health need. Adult services tend to be specialty focussed and input from a number of adult services may be required to achieve a holistic approach for the young person. Administration support must be available to support the use of the transition care plans.

## Auditing service provision

Key performance indicators should be established locally. These could include satisfaction surveys and an audit of whether young people and/or their parents:

- are generally happy with the service
- agree with the treatment regime and feel involved with the transition process
- attend their appointments
- feel the treatment is having a positive impact on the patient's quality of life.

When auditing the key components of transition you need to consider the availability and effectiveness of:

- a policy on transition
- a multidisciplinary education programme
- co-ordination between services
- administration and documentation.

## Care plans

### Early stage (12 to 14 years)

Aim to introduce the young person and their family to the concept of transition to adult health care, and to the need for the young person to develop their autonomy at the same time as being supported by their family. The young person should become aware of their own health and care needs, and the full implications of their medical condition. An assessment of the young person's level of understanding is as important as providing information and education about the services available. The concept of seeing a professional on their own should be gradually introduced to the young person in order to give them and their family time to adjust to this change.

### Middle stage (14 to 15 years)

Aim to give the young person and their family an understanding of the transition process and what they can expect from the adult health care system. The young person should practise their skills, gather more information and begin to set goals for participating in their own care.

### Late stage (15 to 16 years)

By now, the young person and their family should be feeling confident about leaving the paediatric system, and the young person should have a considerable degree of autonomy over their own care.

The ages indicated above are for general guidance. The young person should be encouraged to take the lead on the speed of progression with support from their key worker. Transition will proceed at different rates for each young person.

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# 5

# Transition in practice: a sample planning checklist and evidence record

The aims outlined previously can be facilitated by using a competency-based framework covering six key areas:

- self advocacy
- independent health care behaviour
- sexual health
- psychosocial support
- educational and vocational planning
- health and lifestyle.

This section provides a checklist for discussion in all of these areas at each of the three stages of transition. You can photocopy these pages and use them to record your discussions with individual young people.

## Guidance for completion

The checklists for each key area suggest some general aims and subjects for discussion, although additional areas may be identified to meet individual young people's needs. In the 'Action' section you should record any actions agreed, referrals made or information – such as leaflets – given to the young person during the discussion. In the 'Evidence' section, summarise the discussion, the advice given, and any goals set. You should also indicate the young person's level of understanding. Both you and the young person should sign the record.

### Example:

**Independent health care behaviour**

- Make sure X understands what medication is needed, and discuss any potential problems/barriers.
- Make sure X knows where to get help.
- Make sure X understands the principles of confidentiality.

**Action (examples include)**

Introduced X to ward pharmacist to discuss medication.

Gave X information sheet on inhaled steroids and mouth care, plus handout on consent.

**Evidence**

X was able to identify regular medication, and discuss likely side-effects. They were able to identify which inhalers to increase when their chest was bad.

X knows how to make an urgent GP appointment and understands the SOS admission to the ward.

We discussed the importance of the hand-held record, and the need to bring it into hospital on each visit.

X is aware of the confidential nature of the transition programme.

Signatures:

Date:

# Sample cover sheet

**Interdisciplinary transition planning checklist and evidence record for:**

Consultant

Named nurse/key worker

Specialist nurse

Dietitian

Psychologist/psychological support

Community (eg GP)

Education (eg teacher)

Other

**Early stage transition**

Start date:

**Middle stage transition**

Start date:

**Late stage transition**

Start date:

# Early stage transition

## Self advocacy

- Educate X in describing their health condition.
- Encourage X to ask questions during each visit.
- Encourage X's parents to participate.

## Action

## Evidence

Signatures:

Date:

## Independent health care behaviour

- Make sure X understands what medication is needed, and discuss any potential problems/barriers.
- Make sure X knows where to get help.
- Make sure X understands the principles of confidentiality.

## Action

## Evidence

Signatures:

Date:

# Early stage transition

## Sexual health

- Talk through the changes associated with puberty, and the implications of X's condition.
- Make sure X and their parents know where to get information about puberty, sex and sexuality.

## Action

## Evidence

Signatures:

Date:

## Psychosocial support

- Give parents an opportunity to discuss their feelings about transition and any concerns about the future.
- Talk to X about friends and supportive relationships.

## Action

## Evidence

Signatures:

Date:

# Early stage transition

## Educational and vocational planning

- Talk about X's responsibilities at home.
- Discuss any restrictions, real or imagined, that affect X's education and recreational activities.

### Action

### Evidence

Signatures:

Date:

## Health and lifestyle

- Discuss issues surrounding smoking, alcohol and street drugs.
- Discuss the possible impact on X's health condition and general wellbeing.

### Action

### Evidence

Signatures:

Date:

# Middle stage transition

## Self advocacy

- Make sure X knows how to access information about their condition, for example through support groups, the internet or condition-specific organisations.

## Action

## Evidence

Signatures:

Date:

## Independent health care behaviour

- X maintains a personal health record book to keep track of appointments, health information, medication, treatments and health care providers.
- X knows when and how to get emergency/medical help.

## Action

## Evidence

Signatures:

Date:

# Middle stage transition

## Sexual health

- A general discussion about sexual health, providing an opportunity for X to ask questions about the impact of the condition and/or medications, for example, will the condition affect fertility?
- Discuss the possible impact on pubertal development of X's condition.
- Give X and their parents the chance to meet you alone to discuss their concerns and ask questions.

### Action

### Evidence

Signatures:

Date:

## Psychosocial support

- Encourage X to join a social group, such as a club or youth group.

### Action

### Evidence

Signatures:

Date:

# Middle stage transition

## Educational and vocational planning

- Talk about school, favourite subjects, and any career plans or ideas.
- Set up a meeting with a careers counselling service.
- Explore work experience.

## Action

## Evidence

Signatures:

Date:

## Health and lifestyle

- Discuss any restrictions on mobility caused by X's condition.
- Discuss body images, and any concerns about weight gain or loss.

## Action

## Evidence

Signatures:

Date:

# Late stage transition

## Self advocacy

- Explain all the available adult care options.
- Provide details about relevant adult care providers, including the differences between paediatric and adult care.
- If appropriate, help X to choose an adult care provider and arrange visits.

## Action

## Evidence

Signatures:

Date:

## Independent health care behaviour

- X maintains a personal health record book, including appointment times, health information, medication, treatments and details of health providers.
- X meets with adult consultant/specialist nurse before discontinuing paediatric care.

## Action

## Evidence

Signatures:

Date:

# Late stage transition

## Sexual health

- Discuss X's sexual capabilities, including physical capability, fertility, safe sex and any associated genetic issues.
- Discuss the impact of their condition on pubertal development and their sexual health.

## Action

## Evidence

Signatures:

Date:

## Psychosocial support

- Encourage X and their parents to set positive goals.
- Identify any need for assistance in personal care.
- If X's condition is potentially life-shortening, identify any need for help in dealing with this.

## Action

## Evidence

Signatures:

Date:

# Late stage transition

## Educational and vocational planning

- Discuss employment options – what kind of work do they want to do? Are there any restrictions, for example, on the number of hours X can work? Is there an opportunity for a work experience placement?
- Discuss the health care benefits available, for example, the Disability Discrimination Act.
- If X plans to go to college or university, discuss the implications of this.

## Action

## Evidence

Signatures:

Date:

## Health and lifestyle

- Give X the opportunity to discuss any feelings of low mood, depression, or problems adjusting to or managing their condition.
- Ask X to identify people they can contact for help and advice.

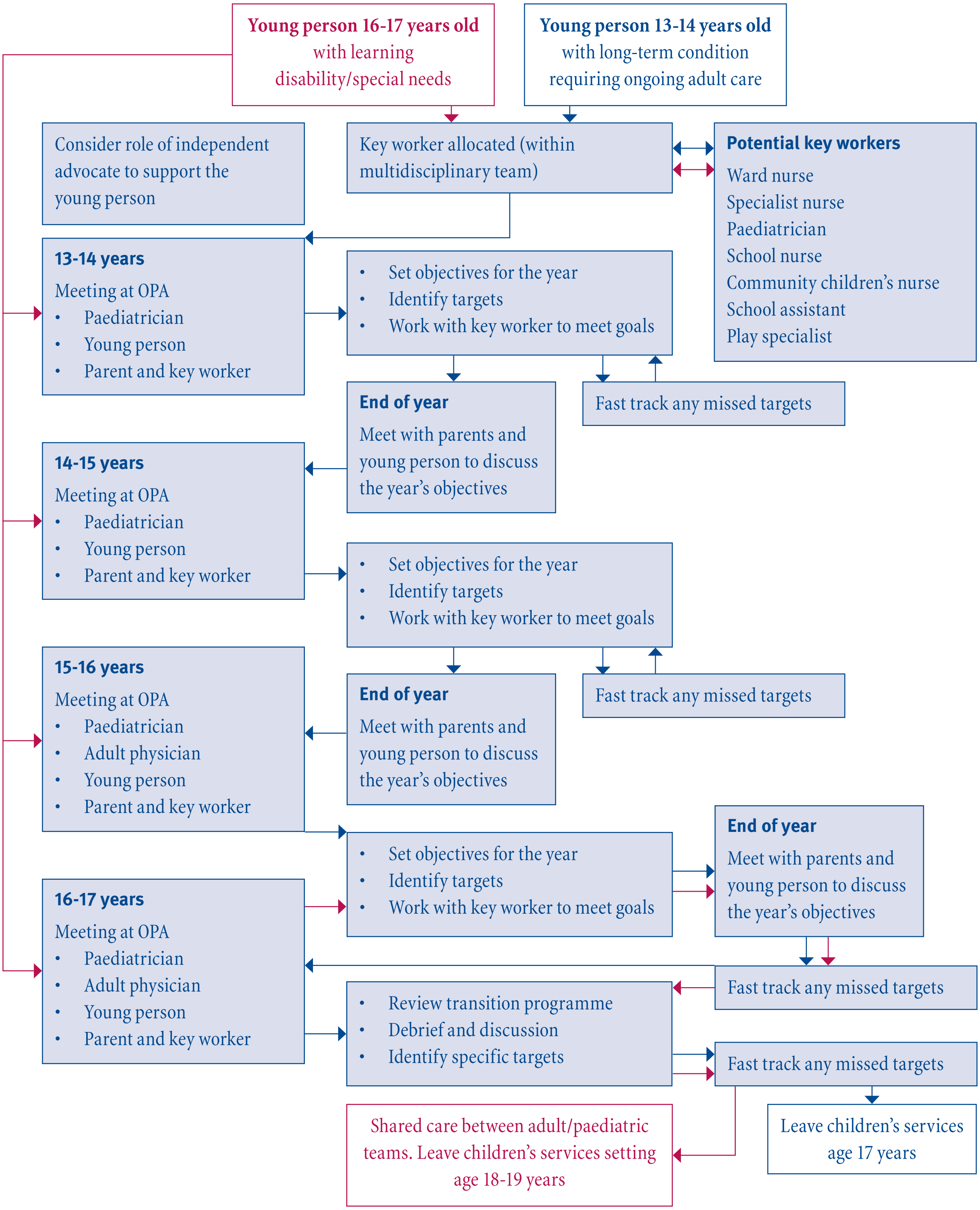
## Action

## Evidence

Signatures:

Date:

# Appendix: the RCN clinical pathway for adolescent transition



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# Useful websites

## Self advocacy/encouraging independent health behaviour

www.savethechildren.org.uk/resources/online-library – Save the Children's web pages for young people, on young people's rights around the world.

www.after16.org.uk – for young people in the UK who have an impairment or disability, with advice on opportunities and services available for when they leave school.

## Sexual health

www.brook.org.uk – sexual health advice.

www.fpa.org.uk – working to improve the sexual health and reproductive rights of people throughout the UK, providing advice, statistics and facts.

www.mariestopes.org.uk – information and advice on Marie Stopes services and local centres in the UK.

## Psychological support

www.youngminds.org.uk – information and resources on key topics to improve the mental health of all children and young people.

www.childline.co.uk – help, advice and information on policy and campaigns.

## Educational and vocational planning

www.skill.org.uk – (National Bureau for Students with Disabilities) – provides information on opportunities for young people and adults with any kind of disability in post-16 education, training and employment across the UK.

## Health and lifestyle

www.teenagehealthfreak.com – provides an A to Z on health.

## General transition websites

http://depts.washington.edu/healthtr/ – a resource for adolescents with special health care needs, chronic illnesses, physical or developmental disabilities (the adolescent health transition project at the University of Washington).

www.chs.ky.gov/commissionkids/transition.htm – Commission for children with special health care needs (Kentucky, USA).

http://hctransitions.ichp.edu/ – a research and training activity of the Institute for Child Health Policy at the University of Florida.

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