



Berkshire West
Clinical Commissioning Group

Transition and Continuing Care: A Guide for Parents and Carers



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What is Transition?

'..a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems.' *Blum RW et al, 1993*

Children and Young People's Continuing Care differs from Adult Continuing Healthcare (CHC). The legislation and the respective responsibilities of the NHS, social care and other services are different in children's and adult services.

What does this mean to us as parents/carers of a young person who is in receipt of Children's Continuing Care?

Being eligible for Children and Young People's Continuing Care does not automatically guarantee that your son/daughter will be eligible for adult CHC. When they are approaching their 15th birthday, discussions about the transition process should be started with you. This leaflet is designed to give you more information about transition before someone comes out to speak with you.

What is the difference between Children's Continuing Care and Adult CHC?

Eligibility for Children and Young People's Continuing Care is awarded if a child/young person scores 3 or more highs, and/or a Priority or Severe in the relevant domains in the Children and Young People's Decision Support Tool (DST).

Eligibility for Adult CHC is awarded if it is felt that the person has a Primary Health Need. The scores awarded in each domain does not automatically mean they are eligible. The Adult DST differs from the Children and Young People's Continuing Care DST and is made up of the domains of care (outlined below) and the four key indicators of:

- Nature
- Intensity
- Complexity
- Unpredictability

If the evidence within the DST demonstrates that the young person has a Primary Health Need, they will found eligible for adult CHC.

As with the Children and Young People's Continuing Care framework, this is subject to regular reviews.

Referral

A professional who is well-known to you/your child (this may be a paediatric nurse from Children and Young People's Continuing Care or your allocated social worker) should obtain your consent, as a parent/carer, to refer your son/daughter to adult CHC. This referral includes a Health Needs Checklist. The person referring your child will spend time with you going through and completing this Checklist. It focuses on **11 domains** of care, as opposed to the 10 domains in the Children's Assessment.

These domains are:

- Behaviour
- Cognition
- Communication
- Mobility
- Continence
- Nutrition
- Skin Integrity and Tissue
- Drug Therapies and Medications
- Psychological and Emotional
- Breathing
- Altered States of Consciousness.

Once complete, this Checklist will be 'screened' by the adult CHC team. This means that they look at the information on the checklist to decide if a full CHC assessment of your child's needs should be completed.

If they decide an assessment is not needed, the person who referred you will be notified and they in turn will contact you to let you know.

Timescale

A **formal referral** for screening at age **16** should be made to the adult CHC Team.

An **adult assessment** should be completed **by the time your child is 17 years of age**.

What happens now?

If it is decided that an adult CHC assessment will be carried out, the following process will be undertaken.

Adult CHC Process

- Your son/daughter's case will be assigned to an adult nurse assessor. Together with a paediatric nurse assessor they will come and meet with your son/daughter to obtain a **verbal report of their views of their needs**, if they are able to do so. If they are unable to do so, a verbal report of your views of your child's needs will be taken.
- **Notes/records will also be requested** from all professionals involved in your child's care. These notes (evidence) together with a record of the verbal report will be collated into an adult DST (Decision Support Tool). This is the health assessment document.
- Once a DST has been drafted, you will be sent a copy requesting feedback/comments.
- Shortly after this you will be invited to a **Multi-Disciplinary Team Meeting (MDT)** to go through the assessment.

Multi-Disciplinary Team Meeting

- The MDT meeting is in two parts. You and /or you representative will be present for the first part. The second part is a professionals meeting and discussion whereby a recommendation is made on eligibility for adult CHC.
- There is a separate leaflet explaining more about the MDT which will be given to you as required.

Frequently Asked Questions

- **What does it mean if my child is found eligible for Adult CHC?**

This means that your child's care in the community will be funded exclusively by the NHS. This could be a bespoke care package at home or one at University or in residential care. The details of the care package will be explored and discussed with your child and yourself once this eligibility decision has been made.

➤ **What does it mean if my child is not found eligible for Adult CHC?**

If it is decided that they do not have a Primary Health Need, your child's support package may be taken over by the Local Authority once they reach the age of eighteen. Your Local Authority social worker will be able to advise you further.

There may be times when the NHS makes a contribution towards a care package for particular health needs. This is known as shared care.

➤ **What do we do if we feel our child should have a full assessment?**

If you feel that your child should have a full adult assessment you need to write to the address below and state your reasons for this:

CHC Team
57-59 Bath Road
Reading
RG30 2BA
Tel. 0118 982 2900
bwccg.chcduty@nhs.net

➤ **What should we do if we feel our child should be found eligible for Adult CHC?**

You will be sent a letter explaining why they were found not eligible. Within this letter will be details as to how you can appeal this decision.

More information can be found on:

<https://www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework>

Other things to consider

➤ **Decision-making**

Please read this leaflet in conjunction with the Preparing for Adulthood leaflet attached. This will provide you with more information about decision-making once your son/daughter reaches the **age of 16**.

➤ **Future placements**

It would be wise to start thinking about what your child would like to do/where they would like to go once they reach 18. Would they like to further their education? If so, where would they like to go?

If they would like to live more independently, what would this placement look like?

➤ **Adult Services**

Which therapies that your child currently receives would they need to continue with?
(Physiotherapy/ occupational therapy etc.)

Make a list of all professionals who may need to be involved post 18.

Please make a note of any questions you may have at this stage and these can be discussed with a health professional from either Children's Continuing Care or Adult CHC.