Robbie Arnold
13 Years Old
Reynalds Cross School

Contents

If you would like to speak to someone in relation to Children and Young People's Continuing Care in Birmingham and Solihull please contact the Children and Young People's team at on 0121 2033222

As the Commissioner for healthcare across Birmingham and Solihull ICB has a statutory obligation to promote respect, equality and human rights. This is set out in various pieces of legislation including: Sex Discrimination Act 1975, Race Relations (Amendment) Act 2000, Disability Discrimination Act 2005 and the Age Discrimination Act 2006.

This leaflet will also be available electronically on:

Birmingham and Solihull Local offer websites:

https://www.birmingham.gov.uk/localoffer

https://www.solihull.gov.uk/children-and-family-support/localoffer

Birmingham and Solihull ICB website:

https://www.birminghamsolihull.icb.nhs.uk/

Children and Young People's Continuing Care

What is continuing care?

A continuing care package of support is provided for children and young people under 18 years who need a tailored package of care because of their disability, an accident or illness that cannot be met by existing universal and specialist services.

If your child/ young person is assessed for continuing care it is likely that a range of official organisations will be involved such as health, education and social care children's services. These different agencies will also contribute to your child/young persons care package if they are found to have continuing care needs.

The process for arranging continuing care is led by your ICB – they are responsible for managing local health services.

Why might my child/ young person need continuing care?

Your child/ young person may have health needs which require additional support. Some examples of these are:

- Complex Health Needs
- Specialist dressings
- Tracheostomy management
- Long term ventilation
- Peritoneal dialysis
- Total Parenteral Nutrition
- End of Life Care
- Neuro - Rehabilitation packages
- Complex challenging behaviour secondary to developmental disabilities (eg. LD and/or Autism)

Other Agencies that might be involved

All children of statutory school age should receive suitable education either by regular attendance at school or through other arrangements. Most care for children and young people is provided by families at home but some require additional support or care from different agencies. Maintaining relationships between the child/ young person, their family and other carers and professionals is an important aspect. Care and support can also be provided in various other environments including educational settings and in other community venues.

This means that a wide range of agencies are likely to be involved in the care of a child/ young person. Therefore the care needs are best addressed holistically by all agencies that are involved. For children and young people this is usually a combination of health, social care and education. It is likely that a continuing care package will include a range of services commissioned by Clinical Commissioning Groups, local authority children's services and sometimes others.

Examples of some of the members of the multi–disciplinary team (MDT) that reports and advice may be obtained from include:

- School based staff
- General Practitioner
- Learning disability nurse
- Named nurse/ Children's
- Educational Psychologist
- Child development advisors
- Health visitors/ school nurses
- Dietician
- Play specialist
- Specialist nurses
- Community Nurse
- Social Care Worker Child and adolescent mental health service
- Physiotherapists/ Occupational therapists
- Speech and language therapists

Any other person you and your child/young person feels should be consulted.

The Process

There are 4 phases in the continuing care process for children and young people:

1: **Assessment**
2: **Decision making**
3: **Arrangement of provision**
4: **Review**

The process will be led by a healthcare professional who is experienced in working with children and young people with complex health needs. Guidance says that the continuing care process should focus on the child/ young person and their family. As a young person moves towards adulthood, there should be more focus on them as an individual within their family.

If a child or young person needs immediate support, for example because they need palliative care or they have a terminal illness there is a fast track process to ensure that their care can be put in place as soon as possible.

1. Assessment looks at:

- A multi-disciplinary checklist completed first to identify if a full assessment is required.
- A multi-disciplinary holistic assessment of the child/ young person using a specific decision support tool (DST) devised by the Department of Health
- Reports and risk assessments including those from other professionals/ people involved with the child/ young person – for example health, social care and education. This should also include a 24 hour or 48 hour diary for the child/young persons care needs kept by the family or others caring over this period of time.
- The individual preferences of the child/ young person and their those of their family Including consideration of the needs of those people who provide the care.

The document used for this assessment is called the Decision Support Tool (DST), and was devised specifically for assessing children and young peoples needs.

It looks at 10 areas called ‘domains’. These are:

- Breathing
- Nutrition, Food and Drink
- Mobility
- Continence and Elimination
- Skin and Tissue Viability
- Communication
- Drug therapies and medication
- Psychological and emotional needs
- Seizures
- Challenging behaviour

Each ‘domain’ has descriptions of how the need presents. Your health assessor will support you and the multi-disciplinary team with what each descriptor means.

When assessing health needs the multi-disciplinary team (MDT) will explore the complexity, intensity and unpredictability of need and how this impacts on the child, young person and family. A holistic view will be taken which explores what is currently in place to meet need and where there are the greatest gaps and how this gap can be best met. The MDT will need to explore how this gap can be met by existing universal and specialist services or if this has been already explored what commissioned health care support can be requested from NHS continuing care if eligibility is met and agreed.

The criteria for eligibility as set out in the framework is a guide and the experienced assessor will make their recommendation, taking into account the views of professionals, parents and the young person.

2. Decision making involves a panel made up of professionals with different areas of expertise such as health and children's services. The panel will consider the assessors recommendations and make a decision about whether the child/ young person is eligible for NHS continuing care and what an appropriate package of care would be. Part of the panel's role is to ensure equity of provision and fairness across Birmingham and Solihull (BSOL).

You and your child/young person should be told the panel's decision within 5 working days of the Panel discussion. You should also be given information as to how the decision was reached.

If the panel decides a child/ young person does not meet the eligibility criteria you will be given a rationale and discussions will take place regarding how other services could meet the needs.

You have the right to appeal any decisions made and will be given information about this.

3. Arrangement of provision takes place if it has been decided that your child/young person is eligible for NHS continuing care. A provider agency, your chosen carers, your local authority, your health care team and other relevant professionals will work together to put your child/young person's package in place.
Time frames for this process are dependent on the level of support required.

The ICB is promoting the uptake of Personal Health Budgets (PHB) which offer a greater level of personal choice and flexibility.
Should you wish to have a PHB as your preferred option – your nurses assessor can discuss this further with you.
(see page 11 for more details)

4. Review is an essential part of continuing care to ensure the support being provided is meeting the child/young persons needs. The package of care should be reviewed after three months to see how the package is set up and supporting you and your child/ young person and that it is running as planned. Reviews are carried out after this at 12 monthly intervals. Guidance states that the family should get support to ensure their quality of life is maintained – this will be considered at each review.
It is recognised that all children and young people are individuals with different health responses and changes can occur at any time. A review can therefore be conducted at any time at the request of the child/young person, the family or any professional involved in your child's care.

Reviews also confirm whether or not the child/young person still has continuing care needs. It is important that you understand that if your child's health needs reduce then the package of care will be reviewed and may be decreased/ withdrawn. These decisions will all be considered by the panel after multi-disciplinary review has taken place.

All decisions in relation to Continuing Care for children and young people are based on National Guidance. Any alterations to National Guidance can affect eligibility criteria and possibly the package of support agreed by panel. Your continuing care assessor will always inform you of any changes that may affect the assessment/ eligibility at the time of assessment or review.

Link to the current framework:

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

Transition to Adult Care provision

Continuing Care for children and young people stops when a child/ young person reaches 18. For people over the age of 18 with severe and complex health needs support may be provided through NHS Continuing Healthcare for adults. This is organised differently from continuing care for children and young people and there is a different assessment process.

If your child/young person receives Continuing Care and it seems likely they will need similar support when they are an adult this should be identified in discussion with you when they reach age 14 years. At 16-17 years your young person should be referred for initial assessment for adult NHS continuing healthcare. This should again be a multi-disciplinary assessment and a decision about eligibility should be made when they are 17 years.

If you have any concerns

Following a new assessment or review if you or your child/young person disagree with any aspect of the continuing care process you are encouraged to discuss this initially with your nominated health assessor.

If this is not resolved the health assessor will refer any disputes about assessments or a change in package so that the original decision can be reviewed.

Should you wish to make a formal complaint this will need to be submitted to the Patient Experience and Complaints team at **BSOL.complaints@nhs.net**

Professional disputes

If there is dispute between BSOL ICB and your local authority or between 2 different NHS organisations this should not mean that your child/young person's support is delayed.

Children and Young People's Continuing Care Pathway

Identification of child or young person with possible continuing care needs discussion with child/young person and family

Checklist completed for referral for assessment by an appropriate health professional. Checklist is processed by the continuing care team and if possible eligibility is shown a meeting is arranged to complete the DST.

Assessment arranged : Nominated assessor, child/young person, family and MDT discussions and completion of Decision Support Document. Assessor and MDT make recommendation about needs and possible package of care.

Multi-agency Panel discussion and eligibility decision

regarding continuing care provision.

Options for package of support discussed including offer of Personal Health Budget.

Panel outcome communicated to families within 2 days of panel and followed by a confirmation letter within 5 working days.

Provider identified for package of continuing care Commissioning of package of continuing care OR contact with PHB facilitator. Training, support and monitoring agreed. Package implemented. Timescale of full implementation dependent on level of need, training and recruitment.

Review of package of support should occur at 3 months after initiation of package of support. Re-assessment of child/young

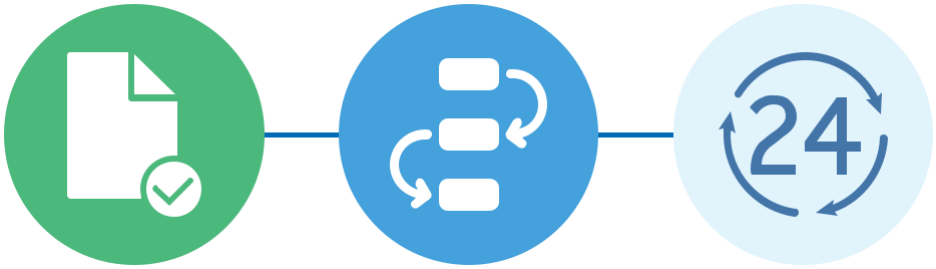
persons continuing care needs and review of appropriateness of package should be carried out annually at 12 monthly intervals or earlier if any changes in health/needs is identified. This should be completed as a multidisciplinary approach.


Birmingham and Solihull
Integrated Care System
Caring about healthier lives
NHS

Fast Track

Where a child or young person with a rapidly deteriorating condition is entering a terminal phase, they may require a fast track for immediate provision of care.

Application processed within 24 hours of submission and virtual panel decision communicated to families and professionals.



Arrangement as soon as possible of provision of care for Children/ Young People entering final days/ weeks of life

Personal Health Budget (PHB)

What are PHB's?

A PHB is one way to give you and your child more choice and control over how Continuing Care money is spent on meeting their health and well-being needs. This is about doing things differently in a flexible way with an amount of money that is calculated for you by the ICB. The calculation is based on your child's assessed needs. By working together with a healthcare professional your child can develop a personal care plan which achieves their agreed goals. It might be decided to continue with the existing care and support, do something different or a mixture.

There are three ways a PHB can be managed:

Notional budget

A sum of money is worked out on the number of hours of care awarded to meet your child's health needs. You decide how to spend this with your child and the healthcare worker will arrange the agreed care and support. No money changes hands. This is often with a recognised care provider.

Third Party Budget

An organisation legally independent of both you and the NHS holds the money for you and pays for the care and support agreed in your child's plan.

Direct Payment

You are responsible for the money spent on the care agreed in your child's support plan. You will have to show what you have spent it on but you, as your child's representative, buy and manage services directly.

To make sure that your child's personal plan is up-to-date and that the services you are using are meeting your needs and goals,

regular reviews will take place.

Hospital Admissions

If your child/ young person is admitted to hospital at any time during their eligibility to Continuing Care, it remains the responsibility of the hospital to provide medical care for your child and you as Parents to be present with them. This means the package of support for home is not transferred to hospital.

If the hospital team are unable to meet all of your child/ young persons needs they will escalate this concern to the Clinical Commissioning Group. If additional support is required the level of this will be agreed according to each individual and situation. This means that if additional support is provided during one admission it does not mean it will be required at further admissions.

This also applies when a child/young person has respite care eg goes into Acorns.

School packages

In some cases your child or young person may be eligible for a school package. The purpose of this package is to enable access to education, so as their health needs can be met whilst they are at school. If your child or young person is not attending school due to illness or other circumstances this package would not automatically be continued at home. This would be decided on a case by case basis.

Responsibilities

Parents maintain responsibility for their child or young person at all times. A child or young person can only be left alone with their carer or carers in exceptional circumstances and following a suitable risk assessment by the care provider.

Notes

Key Contacts

Health Assessor - _____

Equipment provision - _____

Package provider - _____

Local Hospital - _____

Discharging Hospital - _____

For Out of hours health support:

GP out of hours service - _____

or NHS 111 or 999 (for emergency care only)