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1 About this booklet

This booklet is produced by NHS Southwark Clinical Commissioning Group (CCG), which is responsible for NHS services for people registered with a Southwark GP. It is for parents of children and young people, and those children and young people, who are eligible for 'continuing care'.

The booklet includes information about:

- continuing care – what it is and how it works
- personal health budgets – one option for those who are eligible for continuing care
- different options for care at home – the relative advantages and disadvantages of using care agencies or employing your own staff.

If you have any questions about the information in this booklet please contact the children's continuing care nurse for Southwark, Laura Robertson (email: laura.robertson@gstt.nhs.uk, tel: 02030498299).

2 Continuing care for children and young people

Continuing care for children and young people is funding from the NHS, social services and education for children and young people with very complex health needs. Continuing care only applies to children and young people whose needs cannot be met by existing universal and specialist services. The purpose of continuing care is to meet the additional needs of children with highly complex health needs, when they are not in hospital.

The criteria for children's continuing care are set out in the Department of Health's paper 'National Framework for Children and Young People' Continuing Care'.

You can obtain a copy of this framework here:

<http://www.nhs.uk/CarersDirect/guide/practicalsupport/Documents/National-framework-for-continuing-care-england.pdf>

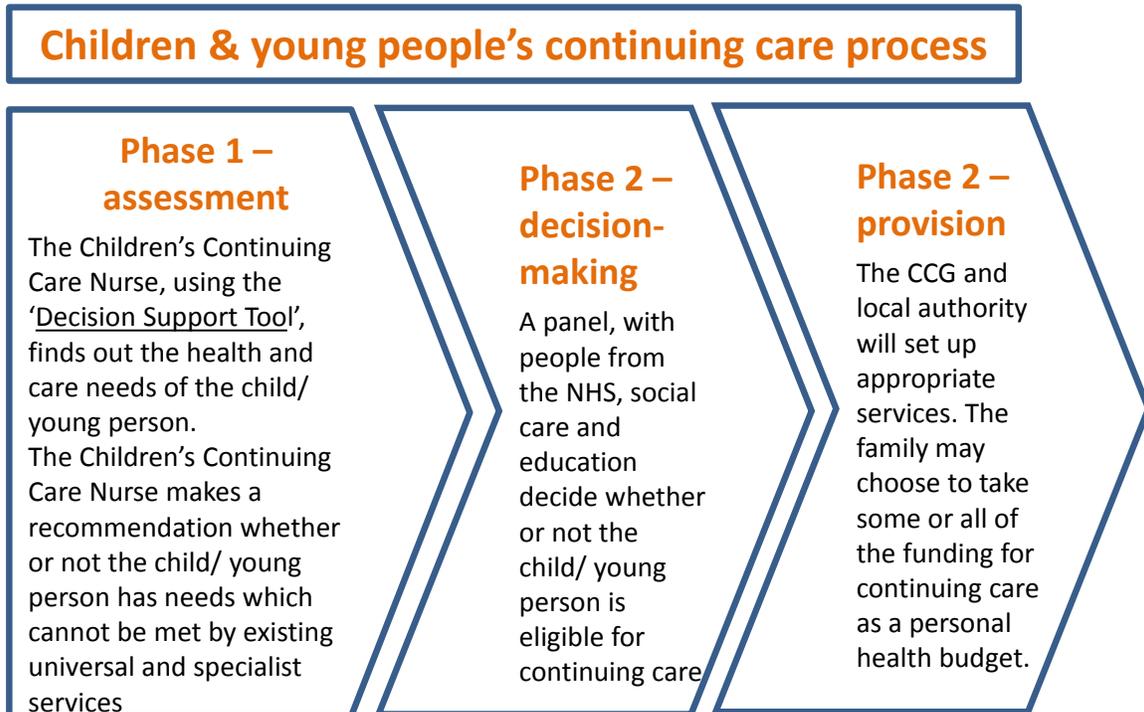
Children and young people who meet these criteria have long term, complex health needs, for example they could have a tracheostomy or be ventilated. In Southwark there are currently (in October 2015) around 30 children who have continuing care.

The framework above sets out how children and young people are assessed to see if they are eligible for continuing care and how that care is arranged. This can include funding for additional care at home or at school.

Since October 2014, children and young people who meet the criteria for continuing care have a right to have their continuing care funding as a personal health budget.

2.1 How does it work?

The National Framework mentioned on page 4 sets out in detail how eligibility for continuing care is determined and what happens if a child is eligible. The diagram below gives an overview of this process:



When working out how best to use continuing care funding, the preferences of the family must be documented and considered alongside the relative risks and benefits of any care arrangements.

2.2 Continuing care funding

Funding for health services is held by local clinical commissioning groups, and funding for social care and education is held by local councils. All three areas can contribute to a child or young person's continuing care funding. Exactly which service contributes funding and how much is available depends on the needs of each child or young person.

So, for example, if a child is less than two years old, they do not have formal educational needs and so there is no contribution from education services. Some children have complex health needs and, because of their health condition, they need additional help to access school and play with friends. In these cases, health, education and social care may all provide funding to meet the additional needs of the child or young person.

Although the funding for children's continuing care is from three areas, the child is only assessed once and there is a single contact for continuing care - the Children's Continuing Care Nurse.

In Southwark, the Children's Continuing Care Nurse assesses the child or young person, using a set of criteria, to take a view on whether they meet the criteria for continuing care. The nurse will then talk to the family to see what services and funding are needed. All of this information is then taken to a panel, the Multi-Agency Team for Children (MATCh) Panel which decides whether the child or young person meets the continuing care criteria and, if they do, what funding is allocated. The MATCh Panel members are representatives from Southwark CCG and the social services and education departments in Southwark Council.



3 Personal health budgets

All children and young people who are eligible for continuing care have a right to have a personal health budget. This means that some of a child or young person's continuing care funding can be taken as a personal health budget.

NHS England's definition of a personal health budget:

“A personal health budget is an amount of money to support a person's identified health and wellbeing needs, the application of which is planned and agreed between the individual, their representative or, in the case of children, their families or carers and the local NHS team. It is not new money but it is money that would normally have been spent by the NHS on a person's care, being spent more flexibly to meet their identified needs”.¹

Personal health budgets are not a welfare benefit and not an entitlement to a fixed amount of money. The value of the personal health budget will change to reflect changes in the needs of the child or young person. A personal health budget is NHS funding which, would have been used on a child or young person's care, which can be freed up to be used more flexibly, allowing individuals and families to have more control over the funding to meet their health and wellbeing needs in a way that works for them.

3.1 Continuing care funding and personal health budgets

Exactly what can and can't be included in a personal budget varies from area to area, as it depends on what the local authority and the local clinical commissioning group has already commissioned for children and young people. For example funding for special school places cannot be taken as a personal health budget. It also depends on the needs of the individual child or young person. In Southwark, some parents who have personal health budgets have chosen to stop using agency care and either employ staff directly or choose who looks after their child through another agency.

More information about options for children and young people with disabilities and special educational needs can be found on this website:

<http://localoffer.southwark.gov.uk/>

¹ *Guidance on the Right to have a Personal Health Budget in Adult NHS Continuing Healthcare and Children and Young People's Continuing Care*, September 2014, NHS England

3.2 Different forms of personal health budget

You do not need to take your child's continuing care funding as a personal health budget – it is entirely optional. You can choose to keep things as they are.

If you chose to take a personal health budget, it could be taken as one of three forms or a combination:

- **Notional Budget:** the money is held by the NHS and the Children's Continuing Care Nurse will arrange health and care services, working with the family to set up what is suitable
- **Third Party Budget:** the money is paid to an organisation that holds the money on the person's behalf, for example a brokerage service. This way the family can choose who they want to employ and
- **Direct Payment:** the money is paid to the person or their representative to a specifically set up bank account.

3.3 What can a personal health budget be used for and what have other families done?

Children who meet the criteria for continuing care need support with day to day activities, for example washing, eating, dressing, going to school, as well as more specific medical needs, for example chest physiotherapy.

A personal health budget can be used in a way that best meets the needs of the child/young person, within their individual family circumstances. Some families have chosen to employ their own care workers, instead of using care agencies. Others have used some of their personal health budget to buy aids or equipment which they cannot otherwise get. However you spend the personal health budget, this will need to be agreed with the children's continuing care nurse and documented in a care plan.

If you would like to talk to other families in Southwark about continuing care and using personal health budgets, please contact the Southwark Parent Carer Council (email: info@southwarkpcc.org.uk, tel: 07739 836988).

4 Home care

NHS Southwark CCG and Southwark Council support parents to care for children and young people with complex health needs. Where children and young people meet the criteria for 'continuing care', the CCG will pay for a range of services to support their parents to look after them. This includes supporting parents with their child's everyday activities, for example washing and dressing, known as 'home care'. Home care can be funded from different statutory services – so the NHS, social services and education services can all make contributions towards a child or young person's home care.

'Home care' can take different forms and families can choose to have home care in different ways, depending on the needs of the child or young person and the arrangements at home. This section explains the home care options available for families in Southwark where there is a child or young person who is eligible for 'continuing care'.

4.1 How much home care can families have?

All parents have a responsibility to care for their children, but some children, because of their health problems, have additional care needs. In this case, the CCG will pay for home care to support parents to care for their children.

The hours of care, and the qualifications and experience of staff, are based on the child or young person's assessed needs. Parental responsibility and capacity of individual parents and their particular circumstances is also taken into account. The hours and timings of the home care are then set out in a care plan, which the care agency will develop with the family.

As part of the 'continuing care' assessment, the care co-ordinator will work out an estimate of the total hours of care needed. This is translated into an amount of money – which is an 'indicative budget'. The total spend on home care has to be within the indicative budget. Within that indicative budget, families can choose the hours and workers, which must be agreed with the care co-ordinator.

4.2 What are the options for 'home care'?

Families can choose to have home care through an agency or by employing their own staff. They can employ staff directly or through a 'third party' organisation, which undertakes the administration. They can choose to do a mix of both – use some agency care and have some care from staff employed directly.

The type of worker and the hours of care will vary depending on the needs of the child or young person and the preferences of the family. However the care is

delivered, the total amount should be within the indicative budget and the CCG will meet the assessed needs of the child or young person.

NHS Southwark CCG has a list of organisations which provide home care for children and young people with complex needs – this is called the Children and Young People’s Personalised Care and Support Preferred Provider Framework (or referred to as just the Preferred Provider Framework). If you choose agency care, you can purchase it from this list of approved organisations.

Support can be provided by ‘care worker’s or by ‘personal assistants’. The two roles are different and suit different individuals or families. Care workers provide care – they help with daily living activities and carry out tasks, as agreed in a care plan. Personal assistants may carry out similar tasks to care workers but their role is different – they are there to support the individual and be there to respond to their needs. For young children, care workers may be the most appropriate role for providing day to day support, whereas with older children/ young people, may prefer to have personal assistants to provide support.

The relative advantages and disadvantages of home care through an agency or through employing directly are set out below:

	Agency	Employing care workers/ personal assistants
Advantages	<ul style="list-style-type: none"> • Must meet standards set out by the Care Quality Commission • Agencies on Southwark CCG’s Preferred Provider Framework have all been assured as being high quality • If you choose an agency from the Preferred Provider Framework, then you can select which individuals care for your child • There is less paperwork than if you choose to become an employer • Can be set up quickly 	<ul style="list-style-type: none"> • You can choose every individual who provides care to your child • If they can do the work and your care co-ordinator is assured they can work safely, then you may be able to employ people your child knows • You can organise shifts • You can choose people based on the needs and preferences of your child
Disadvantages	<ul style="list-style-type: none"> • You may not know people 	<ul style="list-style-type: none"> • Can take longer to set up

	Agency	Employing care workers/ personal assistants
	<p>who care for your child</p> <ul style="list-style-type: none"> • Agencies can have a high turnover of staff • Some agencies 	<ul style="list-style-type: none"> • Whether you employ directly or through a third party, you will need to do some paperwork • If you employ directly, you have to take all the responsibilities that come with being an employer (NHS Southwark CCG can provide advice and support with this) • If your child's needs are such that he or she needs nurses, it can be hard to find nurses who are working independently. Most children's nurses work through agencies

You can choose agency care or to employ your own staff or a mix, for example employing one person directly and also having some hours of agency care during the week.

As well as choosing agency care from Southwark's Preferred Provider Framework, you can choose to purchase home care from an agency that is not on our framework. To ensure that the care provided is safe and of good quality, we would recommend that you carry out the following checks:

- Is the agency registered with the Care Quality Commission?
- Can the agency provide recent references from clinical commissioning groups or councils?
- Does the agency have a track record in providing care for children and young people with complex needs?
- Can the agency provide the hours of care your child needs?
- Will the agency take account of your family's cultural needs?
- Will the agency give you the opportunity to meet care staff before they start working with your child and/or allow you to ask for different care staff if you are not happy with the individuals working with your family?

- Will you be involved in the recruitment of care staff who will work with your child?

4.3 Employing your own staff

If your child meets the criteria for 'continuing care', then you can have the funding for care as a personal health budget. If you choose this option, your care co-ordinator will tell you the indicative budget and you and the care co-ordinator can then work out who to employ and for how many hours, within that budget.

If you choose to employ staff, you take on the responsibilities of being an employer and must ensure that you pay tax and National Insurance and have the right insurances. It is also recommended that a Disclosure and Barring Service (DBS) check (formerly known as CRB) is carried out for anyone who works with children and young people, and that staff are appropriately trained. NHS Southwark CCG can put you in touch with organisations which can help provide support to become an employer, and we will pay for this service.

If you want to employ your own staff but do not want the full responsibilities of being an employer, NHS Southwark CCG can help to set up a third party arrangement, where another organisation acts as the employer and you select and recruit the staff.

Whilst NHS Southwark CCG wants to provide services as flexibly as possible, the CCG has clinical responsibility for the children and young people to whom care is provided and, in some cases, it may not be possible or appropriate for a family to directly employ their own staff.

4.4 What to expect from care workers/personal assistants

Whether your child has care from a care agency or from directly employed staff you directly employ, there are certain behaviours and standards you should expect:

- Care staff are polite, introduce themselves when they first meet you and let you know what they are there to do
- Care staff have identification to show who they are and if it is an agency, the organisation they work for
- Care staff work in your home and respect your house and belongings
- Care staff dress and speak appropriately
- Care staff always let you know if they are likely to be late or unable to work when scheduled
- Care staff explain to you what they will be doing and/or plan this with you.

5 Frequently asked questions

This section includes questions asked by parents, with a response from NHS Southwark CCG:

Can I use the personal health budget to be paid to look after my child?

The NHS Direct Payments Regulations, which sets the rules around how personal health budgets must be administered, states that you would not normally pay someone living in the same household to provide care. In addition, all parents have a duty of parental responsibility to their child.

We do want to support parents so, whilst we would not normally pay a parent to be a carer, we can use health and social care funding flexibly to provide support in a way that works. So, for example, before the introduction of personal health budgets we could only use health and social care funding to buy agency care, we can now use it to pay for people to help in a variety of ways. There is no more or less money spent, but the flexibility can make a big difference, for example one family did not want any help to care for the child, so the money that would have been spent on care was used to help with household tasks like cleaning.

Will having a personal health budget affect my benefits?

Personal health budgets are not a benefit – they are health and care funding to meet a person's needs at a point in time. This means they are not counted as income and do not affect any entitlements to benefits.

6 More information and contacts

If you would like to find out more about continuing care for children, please go to the NHS Choices website:

<http://www.nhs.uk/conditions/social-care-and-support-guide/pages/nhs-continuing-care.aspx>

If your child has continuing care and you would like talk to someone about the options for care and support, please contact the Southwark Children's Continuing Care Nurse, Laura Robertson: email: laura.robertson@gstt.nhs.uk, tel: 02030498299.

If you would like to talk to other parents who have children with complex health needs or disabilities, please contact the Southwark Parent Carer Council: email: info@southwarkpcc.org.uk, tel: 07739 836988.