

department for

**education and skills**



*National Service Framework for  
Children, Young People and  
Maternity Services*

## Long Term Ventilation



*Change for Children  
- Every Child Matters*

<b>Policy</b>	Estates
HR/Workforce	Performance
Management	IM & T
Planning	Finance
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<b>For recipient's use</b>	

# Children requiring long-term ventilation

## Introduction

The National Service Framework (NSF) for Children, Young People and Maternity Services has been published alongside supporting material which includes a series of exemplar patient journeys. Whilst it is not the role of the NSF or the exemplars to provide detailed clinical discussion on individual childhood conditions or aspects of pregnancy or childbirth, exemplars illustrate some of the key themes in the NSF.

Several factors influenced the selection of exemplar conditions, for example: large numbers of children and families affected, significant cause of illness and distress, wide variability in standards of practice or service provision, and suitability for highlighting the NSF themes. Such themes include the importance of responding to the views of children and their parents, involving them in key decisions, providing early identification, diagnosis and intervention, delivering flexible, child-centred, holistic care, which is integrated between agencies and over time and is sensitive to the individual's changing needs. It is also acknowledged that not every child with the same condition will follow the same journey or have the same type or severity of condition as the one which is illustrated.

The primary audience for the exemplars is professionals from a broad range of backgrounds including education, NHS, social services and the voluntary sector (although they could also be of interest to parents and older children). The exemplars may be useful in a number of ways, for example, to:

- highlight further references, which relate to evidence in the NSF and elsewhere, including key clinical guidelines;
- stimulate local debate and assist multi-agency partners to re-evaluate the way they collaborate on, commission and deliver children's services, for this and other conditions, to the benefit children and their families;
- provide an aid to examining and improving local clinical & non-clinical governance;
- provide a multi-disciplinary training tool for staff working with children and young people to raise awareness of specific issues and stimulate discussion;
- canvass the views of children and families on specific children's issues (eg via focus groups), provide a non-threatening mechanism to open discussion, such as good and 'not so good' aspects of the current service, and
- provide a starting point or template for debate, prior to development of new local strategies for managing complex childhood conditions.

## The Care Pathway

The Care Pathway, for the discharge, management and community support for children with long term ventilation needs, describes three stages: the discharge process; living at home; growing up and transition.

The care pathway should be used in conjunction with “From Hospital to Home: Guidance on Discharge Management and Community Support Needs of Children using Long Term Ventilation” published by Barnardos (June 2005), the production of which has been funded by the Department of Health and which contains core principles underpinning the organisation and delivery of care, hints, tips and tools for adapting and using the Care Pathway locally.

A PDF form of this guidance is available on Barnardo’s website at [www.barnardos.org.uk](http://www.barnardos.org.uk) and on the website of the UK Working Party for Children Using Long-term ventilation at [www.longtermventilation.nhs.uk](http://www.longtermventilation.nhs.uk).

The UK Working Party’s website also contains links to best practice policies, procedures and clinical documentation, a list of professionals throughout England, Scotland, Wales and Northern Ireland who can be contacted for advice, and a bulletin board for posting queries. The purpose is to share information and provide an electronic document store from which many of the documents referenced can be downloaded and adapted for local use.

The care pathway described below provides, in the first column, a commentary on a child’s life stages and events, in the second column a cross reference to themes within the National Service Framework for Children, and in the third column, cross references to policies, evidence and links – which are provided within Barnardo’s document “From Hospital to Home”.

# Long-term ventilation

## Rachel's journey through care

Rachel was born at term in good physical condition (normal Apgar scores) in the local hospital. After four hours, Rachel's mother Anna noticed that the baby looked grey and appeared to have stopped breathing. She was resuscitated and transferred to the neonatal intensive care unit for assisted ventilation and observation. Rachel was diagnosed at one month of age with Congenital Central Hypoventilation Syndrome (CCHS). This condition is sometimes referred to inappropriately as Ondine's Curse. She was subsequently transferred to the children's intensive care unit within the same hospital for further medical management and preparation for discharge home.

Anna is 20 years old and currently on maternity leave. She works as a clerical officer. Her partner David (Rachel's dad) is a shift worker. They have one other child – Peter, aged 2 years. They rent their current house from a housing association, and the house is in a rural area 10 miles from the hospital; they own a small family car. David's family live out of the area, while Anna's parents live locally but are both in full-time employment.

## The discharge process

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p><b>Diagnosis and stabilisation</b></p> <p>Rachel remains in the neonatal intensive care unit for several weeks while extensive investigations are undertaken to determine the reason for her dependence on the ventilator.</p> <p>Because of the length of Rachel's stay Anna is discharged home after one week, so she can carry on caring for their 2-year-old son, Peter: Anna and David visit Rachel every day and participate in her care as much as possible. The nursing staff help Anna to introduce Peter to the play staff so Anna is able to spend more time caring for Rachel during these visits.</p> <p>The consultant neonatologist and named neonatal nurse meet with Anna and David regularly, so that both feel well informed about what is happening. The hospital social worker also meets with Anna regularly to offer support.</p> <p>At the age of 1 month, Rachel is diagnosed as having Congenital Central Hypoventilation Syndrome (CCHS). The neonatologist communicates the diagnosis to the parents using the 'Right from the Start Template'. The information is given in a sensitive and empathetic way, recognising how difficult it is for Anna and David to have this diagnosis confirmed. The neonatologist understands the need for them to have sufficient time for the consultation. Anna and David also need time with the hospital social worker and nursing staff to talk and clarify their understanding. With Anna and David's permission, Rachel is referred to a children's respiratory consultant within the same hospital.</p>	<p>Standard 7 – appropriate hospital care</p> <p>Standards 1 and 3 – timely access to treatment and high-quality child- and family-focused care</p> <p>Standards 6 and 7 – access to appropriate care and staff trained in the care of children, and specialist care available as appropriate to the needs of young children</p> <p>Standards 2 and 3 – parents receive information and support to enable them to care for their child</p>	<p>See Bibliography A for definitions, key policy documents and service specifications</p> <p>See Bibliographies H and J for references concerning 'breaking bad news', CCHS, other treatment modalities</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p><b>Transfer of care to the respiratory consultant and children's intensive care unit</b></p> <p>The neonatologist, respiratory consultant and named neonatal nurse meet with Anna and David to discuss the diagnosis and future plans. The respiratory consultant informs Anna and David that Rachel appears to be at the more severe end of the CCHS spectrum and is therefore likely to need mechanical ventilation for periods of the day, as well as overnight, for the rest of her life.</p> <p>The respiratory consultant recommends that Rachel has a tracheostomy formed as this will make the process of ventilation for Rachel much easier. With Anna and David's consent, Rachel is transferred to the children's intensive care unit for ongoing medical management and preparation for discharge home. Rachel is also referred to an Ear, Nose and Throat Consultant who arranges to form a tracheostomy.</p> <p>Anna and David are given written information about this condition and the implications it may have for both Rachel and her family. Information is also given on Contact-a-Family, so they can find out more about relevant support and groups that provide additional information.</p> <p>Rachel will spend several months in the children's intensive care unit. The nurses use their expertise to assess the developmental and support needs of Rachel and her family and ensure that her plan of care reflects these needs.</p>	<p>Standard 6 – timely and appropriate advice and services</p> <p>Standards 6, 7 and 8 – early intervention to aid recovery and rehabilitation</p> <p>Standard 2 – parents receive appropriate information</p>	<p>See Bibliographies J and M for guidance on involving children and their families</p> <p>Contact a Family helpline 0808 808 3555 CCHS family support e-mail: <a href="mailto:cchssupp@hotmail.com">cchssupp@hotmail.com</a></p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p><b>Referral to community nursing team</b></p> <p>The respiratory consultant anticipates at an early stage that community nursing services will be required to facilitate Rachel's discharge and manage her ongoing care. Anna and David give permission for Rachel to be referred to the community nursing team that has specialist knowledge and experience of discharging and caring for children receiving long-term ventilation (LTV) in the community. Following referral, the community nursing team identifies a 'key worker' who will be responsible for co-ordinating Rachel's discharge and ongoing care management.</p>	<p>Standard 6 – timely and appropriate advice and services</p> <p>Standard 8 – key worker to co-ordinate care</p>	<p>See Sections 3.1.7 and 3.1.8, and Bibliography E on the policy and practice of key and multi-agency working</p>
<p><b>Meeting the community nursing team</b></p> <p>The key worker who is a nurse from the children's community team, arranges with the family, and named children's intensive nurse, a time to meet and discuss in more detail the implications of LTV in the community. At this informal meeting Anna and David are able to ask lots of questions about what will be involved. The key worker gives the parents lots of information about the process and leaves them with some written information including a parent-focused preparation pack for children requiring LTV and a booklet that includes a variety of scenarios of the experiences of living at home with a child with long-term care needs.</p> <p>The key worker also introduces Anna and David to the Early Support Programme and takes them through the Family Pack, discussing with them ways this may be used to assist them as they learn to care for Rachel and work with the variety of professionals and agencies.</p> <p>Anna's mother also attends a follow-up informal meeting where she is given the opportunity to ask questions. Rachel's grandmother provides Anna and David with some support and has some questions of her own.</p>	<p>Standard 8 – co-ordinated family-centred services</p> <p>Standard 6 – children's community teams</p> <p>Standard 2 – receiving information</p>	<p>See Bibliographies J and M for source material on involving children and families</p> <p><a href="http://www.earlysupport.org.uk">www.earlysupport.org.uk</a></p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p data-bbox="225 645 376 891"><b>Thinking ahead about funding and obtaining a preliminary funding agreement</b></p> <p data-bbox="416 360 916 607">Anna and David are now aware that it will be necessary to involve professionals from other agencies to ensure that Rachel's needs are met in the most appropriate way. The key worker arranges a date for the first multi-disciplinary team meeting at a time when Anna and David can attend.</p> <p data-bbox="416 645 916 1240">The key worker recognises that it is obvious from the outset that Rachel's requirement will be for a level of provision above the core service provided for children, so the key worker undertakes to flag this need to the Primary Care Trust and local authority commissioners. This provides an early warning that a fully costed multi-agency care package proposal will be sent to them in writing within two weeks of the assessment of Rachel's needs being undertaken. The key worker also flags the need for the funding to be agreed in principle at an early stage. In Anna and David's area, plans are being developed for pooled budgets but these are not yet concluded.</p> <p data-bbox="416 1279 916 1451">Anna and David are informed that funding will be applied for following the formal assessment of need, but told that they do not need to be concerned by this process and it will not delay the discharge plans.</p>	<p data-bbox="959 360 1150 465">Standard 8 – multi-agency packages of care</p> <p data-bbox="959 645 1134 750">Standard 8 – supporting complex needs</p> <p data-bbox="959 788 1150 893">Standard 8 – key worker to co-ordinate care</p>	<p data-bbox="1209 645 1422 920">See Sections 3.1.3–3.1.6 for information and advice concerning obtaining funding, and Bibliography L on economic issues</p>
<p data-bbox="225 1491 360 1626"><b>Trialling equipment suitable for home use</b></p> <p data-bbox="416 1491 916 2051">Anna and David are informed that specialist equipment for Rachel's long-term ventilation needs to be purchased. The children's respiratory consultant and key worker will work with company representatives to trial equipment that would be suitable for home use. It is important to find equipment that meets her ventilatory requirements, and is portable and easy to use in the community. The expertise of the specialist community nursing home care team streamlines this process. Rachel's other equipment needs (such as a pram to carry her equipment, appropriate bedding, etc) are assessed and documented by the key worker, occupational therapist and physiotherapist.</p>	<p data-bbox="959 1491 1174 1727">Standard 2 – parents enabled to have equipment and skills to ensure optimum life chances for children</p>	<p data-bbox="1209 1491 1430 1767">See Sections 3.1.13 and 3.1.14 for information and advice concerning equipment, and Bibliography G on equipment and adaptations</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p><b>Thinking ahead about housing</b></p> <p>As issues around housing can take a long time to resolve, while trialling Rachel's equipment and thinking about her likely care needs, Anna and David and her key worker start considering the suitability of their home which is rented from a housing association. Anna and David fear that their two-bedroom house will not be big enough.</p> <p>The key worker anticipates the issue of the suitability of the family home at an early stage and refers them to a children's occupational therapist for an assessment of their housing which will be undertaken as part of the multi-disciplinary assessment of need (see 'Assessment' below).</p>	<p>Standard 8 – key worker to co-ordinate care</p>	<p>See Section 3.1.15 and Bibliography G for advice, source material and links concerning housing</p>
<p><b>First multi-disciplinary/ multi-agency meeting</b></p> <p>Before the meeting, the key worker encourages Anna and David to write a list of any questions they want to ask at the meeting. By the time of the multi-disciplinary meeting, they have already had the opportunity to meet a number of professionals from a variety of agencies and disciplines. At the meeting Anna and David indicate that they now have a much more realistic idea of what is going to be involved in caring for Rachel at home. They state that they feel able to take on the care required if given appropriate support. All professionals at the meeting also agree this would be the best course of action for Rachel.</p>	<p>Standards 1 and 8 – co-ordination and planning; access to targeted services</p> <p>Standards 6 and 3 – taking account of the family's unique needs and their views</p>	<p>See Sections 3.1.1–3.1.11 on planning the discharge process, and Bibliography B for source material and useful links</p> <p>See in particular Section 3.1.11 on managing a multi-agency meeting</p>
<p>Initial impressions of the extent of Rachel's needs are discussed, as are how the family members perceive they will meet these needs, including any gaps that they feel they will need help with. Key areas of consideration are that: Rachel is a second child and her sibling is at a pre-school stage; there is a lack of space in the house; and David's shift patterns will mean he is not available for regular hours to help.</p>	<p>Standard 8 – multi-agency planning</p>	

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Anna has already stated her intention not to return to work but this will create financial pressures for the family. Rachel's condition is severe and she will require ventilation both during the day and at night for the foreseeable future. This will mean she will have to have someone trained in caring for her tracheostomy and able to attach her to her ventilator; recognise the signs of deterioration and be able to respond by following protocols, and provide care for her while she is being ventilated, as well as when she is not ventilated. It was agreed that this person does not always need to be a qualified nurse but that, following training by a healthcare professional, unqualified carers, Anna and David and other willing family members could take on this role.</p> <p>At the meeting, the role of the 'key worker' from the community nursing team, concerning Rachel's discharge and home-based care, is clarified with all parties involved. The key worker will be the main link between Anna and David and other professionals who may need to be involved. Ways of working together are identified and agreed. A regular series of meetings with a small core group of professionals is arranged with the family, with a remit to progress the discharge plans and to support the key worker's role.</p> <p>Permission is given by Anna and David for information to be shared confidentially between different professionals to minimise duplication and repetition. Anna's mother attends the meeting to give Anna and David support, she also has some questions of her own.</p>	<p>Standards 6 and 1 – co-ordinated programme of action; long-term care</p> <p>Standards 6 and 8 – information-sharing and integration of services</p>	

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p><b>Assessment</b></p> <p>The assessment continues with the key worker leading the process. The formal assessment covers Rachel's care needs, the family's needs, taking due regard for Anna and David's views, as well as Peter's needs. It also covers a housing assessment carried out in partnership with the family, social services occupational therapist and the key worker who provides specialist knowledge about the particular needs of long-term ventilated children.</p> <p>The Framework for the Assessment of Children in Need and their Families, is used as a basis for the assessment, with health professionals adding on a specialised assessment relating to Rachel's technological care needs.</p>	<p>Standards 8 and 1 – assessment and early identification of child and family needs for multi-agency packages of care; supporting complex needs</p>	<p>See Section 3.1.1 on assessment, and Bibliography B for source material and useful links on assessment</p>
<p><b>Housing assessment</b></p> <p>The family's two-bedroom home is assessed as being too small to accommodate Rachel's needs for space and equipment. She will need a bedroom of her own so that Peter is not disturbed by the carers and machinery that will be needed while she is asleep. The bedroom also needs to be large enough to accommodate a comfortable chair for her carer to sit in during the night, ideally placed away from her direct bedside but within listening distance so she can be attended to promptly.</p> <p>The house will also require enough electric sockets for all Rachel's equipment, space for her equipment in the family living area so Rachel can be fully integrated with her family, as well as some dry storage area for her supplies and spare equipment. Other factors that will need consideration include access to the house so that Anna and David, and the carers will be able to get the two children and equipment easily in and out of the house, as well as dealing with all the routine things required for two small children. Ideally the house will have an outdoor area or garden. All other principles and</p>	<p>Standard 8 – children have access to a range of appropriate services and help to enable them to be included in the community</p> <p>Standard 3 – quality and safety</p> <p>Standards 5 and 6 – comprehensive and integrated local services</p>	<p>See Section 3.1.15 for advice on housing, and Bibliography G for source material and useful links concerning housing</p>

Journey	Children's NSF theme (England)	Policies evidence, and links
<p>requirements relating to disabled children and housing need to be also applied to Rachel's case.</p> <p>With Anna and David's permission, the key worker asks the local authority social worker, who is aware of the family's needs, to contact the housing association that owns the family home and request that it finds suitable housing for the family as soon as possible. The social worker will keep the key worker informed of progress and maintain direct contact with Anna and David to ensure their views are accounted for.</p> <p><b>Risk management</b></p> <p>A key part of the assessment process is a risk assessment relating to all aspects of Rachel's care. This is a difficult concept for Anna and David to understand, so the implications, underlying principles and process are explained to them in full by the key worker, so they can feel fully informed and involved, but not unduly concerned by the process. They understand that the main concern is for the ultimate safety of Rachel once she is at home. Local practice is followed to complete and document the assessments that are made, and necessary control measures are planned and put in place.</p> <p>Review dates and ongoing plans for risk assessments are documented as new aspects of care for Rachel are implemented. The experience of the key worker and links she has with others who are specialists in this field of work help in ensuring a pragmatic and safe approach to the plans for Rachel's discharge and care at home.</p> <p>One of the initial risk assessments detail the control measures that are necessary to enable Rachel, Anna and David to leave the intensive-care environment for short periods, for the appropriate equipment and back-up including battery power to be ascertained and for the training and</p>	<p>Standard 3 – quality and safety of services</p>	<p>See Sections 3.1.19–3.1.21 for advice on assessing and managing risks, and Bibliography D for source material and links concerning risk management and clinical governance</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>level of competence of those accompanying her to be agreed and documented.</p> <p>Anna and David are reassured that the need to ensure Rachel's safety is balanced with trying to achieve an ordinary life for her and her family. Their concerns and views about how this could be achieved are listened to and discussed, as their contribution to the risk assessment is an essential part of the process in order to develop and maintain the objectives of safety and an ordinary childhood and family life. Anna and David contact the CCHS Family Support group and find some tips from other parents about how they have overcome specific issues. For example, they investigate the use of an intercom system between themselves and the carer at night, to ensure the carer can call for help if required without coming into their bedroom.</p> <p><b>Prepare and submit proposal for a preliminary funding agreement</b></p> <p>All elements of the assessment are documented after Anna and David agree them. The key worker and social worker work with Anna and David, using the information about Rachel's condition and her expected progress, to decide on what level of support they will need to enable them to care for Rachel at home. David is particularly anxious that Anna has enough help while he is out at work and they are both keen for Peter not to feel left out and to have time to be with him also.</p> <p>In making the decision about what type and amount of support they need, Anna and David find it helpful to have a range of options suggested to them that include the positive aspects as well as the challenges that they are likely to face. They agree on the need for a carer each night and additional support during the day.</p>	<p>Standard 8 – multi-agency planning</p> <p>Standard 3 – robust commissioning</p>	<p>See Sections 3.1.3–3.1.6 for information and advice concerning obtaining funding, and submitting a proposal, and Bibliography L on economic issues</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>The key worker undertakes the task of putting together the joint assessment and care-package proposal, having incorporated views from all the people involved in Rachel's care using locally agreed criteria for application for continuing healthcare and social services funding. This includes costs of employing care staff as well as key pieces of medical equipment, spares, disposable items and maintenance costs that will be required on a regular basis.</p> <p>The proposal is brought to the hospital and discussed at a meeting with Anna and David before a final draft is sent to the Primary Care Trust for funding to be agreed. The proposed care package is based on recruiting a team of non-professional carers to be trained specifically in Rachel's care. These carers will assist Anna and David in caring for Rachel in the home setting and other settings that Rachel may access as she grows up.</p> <p>The initial agreement is to provide a carer for the family for 9 hours every night and for 5 hours during the day on the days that David is out at work. The amount of short-break care will be flexible and agreed once the family is established at home but will be provided by the same team of carers, to ensure continuity for Rachel. Social services makes a financial contribution to funding the short-break aspect of the care package.</p> <p>An action plan is agreed at the end of the meeting with Anna and David, which is documented and includes specific actions and responsibilities for actions with timescales among those at the meeting. Wider sharing of these notes and plans is also negotiated. Anna and David are happy with the content of the proposal and do not wish any changes to be made. They are aware that there will be flexibility built into any package that is devised so minor changes can be made later.</p>		

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p><b>Funding agreed</b></p> <p>The key worker has already flagged up the need for an agreement in principle for funding with the Primary Care Trust, so it is expecting the proposal when it arrives.</p> <p>The proposal is then forwarded to the appropriate commissioners following local practice with a summary sheet and covering letter requesting that the decision regarding funding and future care provision be communicated to the key worker. The commissioners agree to the request for funding within one week. Now that the funding has been confirmed the key worker can begin to advertise for care staff.</p>		
<p><b>Training parents</b></p> <p>Rachel is now recovering from having a tracheostomy formed and is established on the equipment she will be using at home. The named children's intensive care nurse and the key worker work together to develop a training plan for Anna and David to follow to enable them to become confident and competent in all aspects of Rachel's care. Anna's mother also agrees to undertake this training so she can offer as much support to Anna as possible.</p> <p>The training programme is structured around Anna and David's availability to be at the hospital which is dependent on work and childcare commitments. Anna's mother and a family friend provide invaluable support by looking after Peter so that Anna and David can both visit Rachel on most days.</p> <p>The children's intensive care nurses and the play specialist work with Anna to begin to introduce some routine and developmental stimulation for Rachel into her daily care programme. The hospital social worker makes a referral to the local authority disabled children's social work team in the family's area.</p>	<p>Standard 2 – equip parents with the skills they need to ensure their children have the optimum life chances</p> <p>Standard 4 – age-appropriate services for all children</p> <p>Standard 7 – play for children in hospital</p> <p>Standard 2 – receive services to support and enable caring</p>	<p>See Section 3.1.18 for advice on training parents, and Bibliographies C and D for examples of packages and competencies</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>The key worker liaises with the social workers to ensure Anna and David are provided with useful financial advice, including information on disability related benefits, child and working tax credits, rights to parental leave and how to apply to the Family Fund. This is particularly important in view of Anna's decision not to go back to work.</p> <p>The social worker also helps Anna consider different options for childcare for Peter and arranges with the hospital play room for him to have some sessions there while Rachel is in hospital so he can continue his pre-school programme and be with Anna.</p> <p>A step-by-step approach is taken to Anna and David's training and they have a written record at all stages to support what they are being taught. A named children's intensive care nurse and the key worker oversee the training programme and have the role of assessing progress as well as the pace and timing of the programme. They also regularly check how Anna and David are feeling and negotiate a balance with them that means they do not feel pushed to take on tasks but gradually build up confidence in their own abilities to learn Rachel's specialised care. Gradually, Anna and David start caring for Rachel on their own for short periods of time, knowing at all times where and how to ask for help if they want or need it.</p>	<p>Standard 8 – flexible and sensitive care</p>	<p><a href="http://www.familyfund.org.uk">www.familyfund.org.uk</a></p>
<p><b>Discharge plan</b></p> <p>The discharge plan is made following a framework for discharge planning that has been adapted locally. This includes timescales, actions and responsibilities. The key worker provides a discharge-planning checklist that is individualised for Rachel and her family; a copy is given to Anna and David so they can feel fully involved in the process and be confident that all aspects of Rachel's discharge are being addressed and be clear about who is responsible for them.</p>	<p>Standard 7 – discharge is planned in good time in liaison with relevant agencies and professionals</p>	<p>See Sections 3.1.9–3.1.11 for advice on managing the discharge process, and Bibliography B for source material and links concerning discharge management</p>

	Journey	Children's NSF theme (England)	Policies, evidence, and links
<p><b>Agreement of care</b></p>	<p>An agreement of care between the family and the community nursing service is drawn up and agreed with Anna and David. This is a useful tool to help establish a working partnership between the family and community nursing team, and to ensure clarification of roles, responsibilities and expectations.</p>	<p>Standard 3 – services co-ordinated around family needs and taking account of their views</p>	
<p><b>Recruitment and training of home carers</b></p>	<p>Because the community nursing team already has ventilated children within its caseload, it is familiar with the recruitment and training process. Two trained but unqualified carers from the existing community nursing team identify themselves as wanting to become involved in Rachel's care and are introduced to Anna, David, Peter and Rachel on the children's intensive care unit. These carers have already undergone a robust training programme and are experienced in the care of children requiring LTV. They begin working with Rachel, initially with supervision, while the key worker works with the Human Resources department to advertise for more carers in order to fully support the family's package of care. Funding has been agreed for this and for the use of some trained staff from a bank of nurses to be used in the first stages of Rachel's time at home to support the carers' training programme at home.</p> <p>Anna and David are consulted about the recruitment process but not expected to be closely involved; they understand this is because the carers will also be working with other children in the community. They are confident that they will be able to meet and get to know newly recruited carers and be involved in their training and orientation programmes later on. Agreements are made between the community and children's intensive care nursing teams to allow community carers to start working with Rachel in hospital so they can become familiar with her individual needs prior to discharge. This is</p>	<p>Standard 3 – core competencies and skills to work with children and young people</p> <p>Standard 6 – high-quality care based on evidence-based guidelines and protocols</p> <p>Standard 3 – services listen and respond to the views of children and parents</p> <p>Standard 7 – supporting co-ordination of community-based care to keep hospital-based care to a minimum</p>	<p>See Sections 3.1.16–3.1.18 for a definition of a 'carer' and advice on the process of recruitment and training. See Bibliographies C and D for guidance and examples of job descriptions, training programmes and competencies</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p data-bbox="411 360 911 465">received well by Anna and David as they have the opportunity to get to know staff in a controlled environment.</p> <p data-bbox="411 501 930 678">Experienced carers are able to help resolve some of the practical problems that hospital staff may be unfamiliar with, such as how to load the ventilator onto the buggy for trips off the ward.</p> <p data-bbox="411 714 882 819">After an initial orientation period these carers are assessed as being competent to meet Rachel's needs.</p> <p data-bbox="225 855 339 920"><b>Day trips home</b></p> <p data-bbox="411 855 930 1346">Anna, David and Anna's mum have now all completed the training programme and are confident in all aspects of Rachel's care. They have already started to take Rachel off the ward for short trips to the playroom with Peter: Anna is now very keen to take Rachel home but appreciates that it is still likely to be some weeks before the family is re-housed and sufficient carers are recruited and trained. In consultation with the key worker, it is agreed that the family can start taking Rachel home for the day and return each evening for overnight care in hospital.</p> <p data-bbox="411 1382 930 1800">For the first few trips home the key worker accompanies Anna to help iron out any unpredicted difficulties. David is able to alter his shifts to enable him to be present as often as possible. When no family member is available the children's intensive care unit is usually able to provide a member of staff to help Anna with the journey home. The day trips home have gone without any adverse incidents and Anna's confidence in her ability to manage both of her children is growing.</p>	<p data-bbox="954 855 1166 920">Standard 3 – safe care</p>	<p data-bbox="1204 855 1417 960">See Bibliography I for clinical protocols</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p><b>New carers start work</b></p> <p>Two new carers have completed the recruitment process and are now ready to begin work. The key worker has developed the training package and tailored it to Rachel's needs. The new carers are introduced to the family and ward staff.</p> <p>Over the next few weeks they undergo both classroom-based learning and practical learning on the ward with hands-on experience of caring for Rachel while being supervised by qualified nurses. The key worker regularly checks on their progress.</p>	<p>Standard 3 – appropriately trained staff</p>	<p>See Sections 3.1.16–3.1.18 for a definition of a 'carer' and advice on the process of recruitment and training. See Bibliography C for human resources guidance and examples of job descriptions</p>
<p><b>Moving house</b></p> <p>A three-bedroom house has been offered to the family by the housing association. It is close to Anna's parents – so they accept the offer. When the family registers with a new GP practice, the key worker contacts the new local primary care team. The key worker follows up a telephone call with a letter introducing the family and suggesting an initial meeting. The same health visitor works with the new practice, which provides some continuity for the family.</p>	<p>Standards 6 and 8 – access to services and support through local arrangements and access to primary healthcare</p>	<p>See Bibliography G for source material and links concerning housing</p>
<p><b>Equipment at home</b></p> <p>All equipment and associated supplies are now in place at home; initially these were provided from the hospital but are now going to be ordered by the key worker, charged to Rachel's community budget and delivered to the local health centre which is convenient for Anna or David to collect from.</p> <p>Anna has organised Rachel's bedroom with plenty of storage space, space for care staff and room for Rachel to play. Anna and David are becoming both excited and anxious about Rachel's impending discharge. The key worker introduces Anna to another local mum whose child is receiving LTV. Although the children's needs are different, Anna finds this contact very reassuring.</p>	<p>Standard 8 – access to appropriate equipment</p>	<p>See Sections 3.1.13 and 3.1.14 on managing equipment and disposable supplies, and Bibliography G for source material and links</p>

	Journey	Children's NSF theme (England)	Policies, evidence, and links
<b>Final discharge meeting</b>	<p>All preparations are complete, so a final discharge meeting is arranged to check that everyone involved (Anna and David, professionals and carers) is still happy with the arrangements, and to tie up any loose ends.</p>	<p>Standard 7 – discharge is timely and staged to meet needs of family</p>	<p>See Section 3.1.1.1 on managing an effective discharge meeting</p>
<b>The first night home</b>	<p>A trial run is arranged for Rachel to stay at home overnight with a qualified children's community nurse and a trained carer providing the night-time cover. Anna and David are reassured that they have 24-hour access to speak to either medical or nursing staff from the children's intensive care unit, as well as the support and back-up from the community nursing team.</p> <p>This first night home goes well so it is agreed to discharge Rachel home into the care of Anna and David with support from the community nursing team.</p>	<p>Standard 2 – specialist services provide timely and appropriate support to enable parenting</p>	<p>See Section 3.1.2.1 on written procedures and protocols</p>
<b>Final discharge arrangements</b>	<p>A date and time for discharge are set in agreement with Anna and David. The emergency services and utility companies are informed by the key worker of the planned discharge date; they have already been contacted and agreements about priority services to the family home have been made.</p> <p>Letters are written following phone calls confirming all the plans for discharge and follow-up to the GP, primary care team and other professionals involved in delivery of Rachel's ongoing care. Arrangements for medication provision have already been made with both the GP and local pharmacy so that the process works well for the family.</p> <p>The hospital play specialists have worked with Anna and David in preparing Peter to have his sister at home, and to understand her special needs according to his age and stage of understanding and development.</p> <p>Rachel is discharged home.</p>	<p>Standard 8 – children with complex needs have increased access to services to support their needs</p> <p>Standard 7 – importance of play and preparation for all children</p>	<p>See Section 3.1.8, and Bibliographies E on key working and B for source material and links on discharge management</p>

## Living at home

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p><b>Case management/ key working and multi-agency working</b></p> <p>Once home, Rachel receives a variety of services and resources from a number of different agencies as outlined in her care package. In order to facilitate good communication across all agencies and sectors, the team leader responsible for managing Rachel's community nursing team is designated as the key worker responsible for co-ordinating all aspects of the care package. In Rachel's case this is the same person who acted as her key worker to facilitate her discharge from hospital. The key worker continues to work in close partnership with Anna and David to enable them to take control of their family life and home as well as enabling them to have access to services at the appropriate time and be supported.</p> <p>Key working in domestic settings entails working with Rachel, Anna and David as partners in care, and includes activities such as:</p> <ul style="list-style-type: none"> <li>• managing the daily organisation of the care package on behalf of Rachel and her parents</li> <li>• liaising with all other professionals and agencies to ensure smooth and co-ordinated delivery of services with minimal overlap, thus reducing the intrusion and disruption of inappropriate telephone calls and visitors to the house</li> <li>• providing ongoing emotional, psychological and developmental support for Rachel, Anna, David and Peter, other family members and employed staff</li> <li>• developing house rules with Anna and David to ensure that professionals and parents understand each other's needs and ways of working</li> <li>• developing and implementing policies and procedures to ensure the safety of everyone in the home (health and safety, risk management, child protection)</li> <li>• organising the maintenance/replacement of equipment</li> </ul>	<p>Standard 8 – key worker to co-ordinate care; child-centred approach, family/holistic context</p> <p>Standards 2 and 8 – the child and family receive services and support to ensure optimum life chances and inclusion</p> <p>Standard 6 – high-quality care for children with long-term conditions and their families</p>	<p>See Sections 3.1.8, 3.2.1–3.2.5 for advice concerning the role of the key worker at home, and Bibliography E for sources and links on key and multi-agency working</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<ul style="list-style-type: none"> <li>• ordering disposable equipment and supplies</li> <li>• organising medicines and other pharmacy products</li> <li>• helping Anna and David to co-ordinate hospital, clinic and therapy appointments and ensure minimal overlap</li> <li>• facilitating an annual reassessment of the care package (more frequent if necessary) to ensure that as Rachel grows up her care package is flexible and responsive to her changing needs.</li> </ul> <p>Anna and David begin over time to build relationships with members of the multi-disciplinary community support team around Rachel. The core team of professionals works with them to pay attention to both Rachel's health, social and developmental needs and their own needs as individuals and a family unit, in particular their emotional needs and desire for an ordinary family life.</p> <p>Initially the family is delighted to be at home and everything seems to run very smoothly; Anna and David feel confident in their training and the abilities of the professionals and carers who are supporting them. However, after about 6 months, Anna wonders why she is feeling a bit low and finding it difficult to be tolerant of some members of care staff. In discussions with the key worker and other parents she is in contact with through the CCHS Family Support Group, she comes to realise that this is a normal reaction once the euphoria of getting Rachel home has passed and the reality of caring for Rachel and Peter becomes clear. Anna is made aware of the availability of counselling and psychology services if she should feel this may be helpful at any time.</p> <p>The key worker visits the family home regularly, negotiating the times with Anna</p>	<p>Standard 8 – flexible and sensitive care</p> <p>Standards 3 and 8 – services listen and respond to families and are co-ordinated around their needs</p>	<p>See Sections 3.2.3 and 3.2.5 concerning the impact on family life, and Bibliography H for source material and links concerning the roles of parents in domestic settings</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>for her convenience, and has telephone contact with the family in between. This ensures that Anna and David are kept fully informed about all actions being taken by the key worker. They appreciate knowing both about actions that are being progressed as well as areas where progress is very slow. They feel fully involved and informed while not having to take on the stress of chasing up services. The key worker's honesty, openness and clarity are respected by Anna and David who feel this supports them in developing an effective and supportive relationship with their care team. In turn they undertake also to try and communicate with the care team in a constructive way.</p> <p><b>Ongoing recruitment and retention of carers</b></p> <p>One of Rachel's employed carers gives four weeks notice of leaving to take up a new post elsewhere. The key worker ascertains that the carer felt bored and deskilled working at night with a child who mostly slept through the night. Other carers express similar sentiments. The key worker actively initiates a number of steps to improve the job satisfaction and stimulation of carers, including opportunities to:</p> <ul style="list-style-type: none"> <li>• work with other families in the community</li> <li>• update their competencies</li> <li>• rotate to the local NHS Trust to update/enhance skills</li> <li>• undertake distance learning modules at night, and</li> <li>• attend relevant conferences and professional updates.</li> </ul> <p>In addition, the key worker facilitates a recruitment campaign to ensure that Rachel's care team is as described in the care package. In the interim, an agency/ bank nurse is employed, trained and assessed to work within Rachel's team.</p>	<p>Standard 8 – key worker co-ordinates care</p>	<p>See Bibliography C for source material and links concerning human resources</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p><b>Short breaks and holidays</b></p>	<p>Rachel's care package contains some additional flexible hours so that Anna and David can engage in their own educational or social activities. One of the carers who knows Rachel well and in whom Anna and David have confidence, is assessed as competent to provide this respite care during the evening. Anna and David work with the key worker to ensure that this goes smoothly. Anna's mother comes to look after Peter and provide some back-up for the carer.</p> <p>Towards the end of her first year at home Anna and David want to go on holiday to a hotel in another part of the country for a week. They discuss this with the key worker and a plan is worked out to make all the necessary arrangements. The commissioners are contacted and it is agreed that a carer can accompany the family on holiday, so that the family can have some rest also. A carer agrees to go with the family for four nights; Anna and David will cover the other nights' care themselves, with the help of Anna's parents. The family applies to the Family Fund to pay for the carer's separate accommodation and the carer has a subsistence allowance for food. This arrangement is achieved through careful negotiation with the family to ensure that there is clarity about roles and responsibilities for the carer, and to ensure Rachel's safety in an unfamiliar environment.</p> <p>Before the family goes on holiday, the key worker liaises with the community children's nursing service in the locality of the hotel to ensure that they are aware of Rachel's needs, and provide Anna and David with a contact point for help if they should need it while they are there. Rachel's consultant also makes contact with a lead consultant at the local hospital to provide appropriate back-up.</p>	<p>Standards 8 and 2 – services are organised around the needs of the family and support and enable them to care and parent their children</p> <p>Standard 3 – services work with families to ensure high-quality care and take account of their views</p> <p>Standards 6 and 8 – families supported in the self-care of their illness and have access to appropriate services</p> <p>See Section 3.2.7, and Bibliography M for advice and source material on play, leisure, short breaks and family support</p>

	Journey	Children's NSF theme (England)	Policies, evidence, and links
<p><b>Medical reassessment and follow-up</b></p>	<p>Rachel is regularly reassessed at a multi-disciplinary clinic specifically for children on long-term ventilation, with a staff including:</p> <ul style="list-style-type: none"> <li>• a children's respiratory consultant</li> <li>• a community paediatrician</li> <li>• a children's speech therapist</li> <li>• a children's dietician</li> <li>• a social worker</li> <li>• a children's occupational therapist.</li> </ul> <p>This clinic provides Anna and David with an opportunity to discuss all aspects of Rachel's care with the relevant people at one appointment, which they find invaluable. It helps those delivering her care to ensure a consistent approach that meets with the family's wishes and needs.</p> <p>Rachel continues to see the speech therapist on a regular basis as she learns to talk with her tracheostomy. Anna and David and her carers are trained by the speech therapist to assist Rachel in the required techniques for communicating on a daily basis.</p> <p>Rachel also requires regular sleep studies either at the hospital sleep lab or at home. Her carers, and Anna and David, are trained to use the monitoring equipment at home to prevent her having to attend hospital. However, not all the investigations can be done at home and when Rachel needs to go for a routine sleep study in hospital, arrangements are made for her carers to accompany her so that she receives continuity of care and to minimise the effects of the hospital admission on her.</p>	<p>Standard 8 – children with complex needs receive co-ordinated family-centred services</p> <p>Standard 2 parents receive information and support</p>	<p>A protocol for the follow-up and ongoing monitoring of ventilated children written by Professor Peter Fleming can be found in Bibliography J</p>
<p><b>Emergency readmission to hospital</b></p>	<p>Rachel has a protocol in place in case of the need for emergency readmission to hospital. Twice during her first year at home, Rachel requires readmission to hospital with an acute chest infection. The agreed protocol enables Anna and David and the key worker to seek advice early from the GP and subsequently from the respiratory consultant at the regional hospital. Rachel is transferred by paramedic</p>	<p>Standard 7 – children receive care in hospital that is integrated and co-ordinated and delivered in an appropriate setting</p>	<p>See Section 3.2.6 for advice concerning returning to hospital</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>ambulance to hospital before her condition deteriorates too far.</p> <p>Anna and David have a parent-held record that summarises the key points regarding Rachel's diagnosis and treatment plan.</p> <p>Each time Rachel is readmitted to the children's intensive care unit, she has an acute respiratory infection, which means she becomes medically unstable, and beyond the scope of her home carers' skills. On admission to hospital her care is transferred to the intensive care unit qualified nursing and medical staff. Her care team is redeployed to work with other children and families and some carers take annual leave. Anna and David miss the familiarity of the carers who know Rachel, but understand that the level of care they would be able to provide would not meet Rachel's current acute care needs.</p> <p>As Rachel begins to recover, a few members of her care team arrange to visit Rachel in liaison with Anna and David and the key worker. When Rachel is recovered from her acute chest infection and is considered to be medically stable, she is once again discharged home to the care of Anna and David and her home-care team. Her discharge is organised by her key worker.</p>	<p>Standard 1 – parent-held child record</p>	
<p><b>Multi-agency care plan reviews</b></p> <p>Rachel and her family's practical and support needs are continually reassessed and evaluated in partnership with them in recognition of their need for varying levels of care and support at different times during Rachel's life. For example, when Rachel's grandmother becomes unwell for a period of time and is unable to help Anna with her weekly shopping trip, it is agreed that the family can have extra short-break care hours, to enable David and Anna to do the shopping together without having to worry about the children. Once Anna's mother is better, the original arrangements are re-established.</p>	<p>Standards 8 and 4 – children and families receive ongoing appropriate support and age-appropriate services to meet their specific needs as they grow up</p>	<p>See Section 3.1.7 and Bibliography E for source material and useful links on multi-disciplinary working</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>Rachel's multi-agency care plan reflects services working together to accommodate the peaks and troughs experienced by the family. It is a working document that is shared and details all the professionals and services that are required. It ensures access to services that are timely, appropriate information about services, and reassurance for Anna and David that their needs have been understood and considered.</p> <p>A proactive approach to Rachel's care, and reviews at regular intervals, ensures that both Rachel's stability and other factors impacting on the family's ability to cope and manage differing thresholds are considered and planned for as well as possible.</p> <p><b>Education</b></p> <p><b>Nursery</b> By age three, Anna and David feel that she is ready and would benefit from attending a nursery school in order to meet more children of her own age. Rachel begins to attend a local authority nursery school once agreement is reached between the local education authority, nursery and health service commissioners about the provision of appropriate support being available to meet Rachel's needs within the pre-school setting.</p> <p>Initially, Rachel attends nursery for two mornings a week; this increases to three full days over time. In order to accommodate her increasing need for daytime care while at nursery, her care package is adjusted to provide a carer to cover her nursery hours and transport time to and from nursery.</p> <p>Rachel's key worker liaises with the nursery to provide information for staff regarding Rachel's needs and helps the nursery manager to undertake an assessment of risk using the principles of risk assessment applied to all aspects of Rachel's life. A healthcare plan is developed by the key worker in partnership with Anna and David to provide details of the care she will</p>	<p>Standards 8 and 4 – children and families receive ongoing appropriate support and age-appropriate services to meet their specific needs as they grow up</p> <p>Standard 9 – partnership working for children with psychological and special educational needs</p> <p>Standards 3 and 8 – integration between education/social and health needs; sharing of information, continuity and co-ordination of care</p>	<p>See Section 3.2.8 and Bibliographies A and F for key policy documents and best-practice guidance concerning supporting Rachel through early years and school</p>

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p>require in nursery. This is used as the basis for training the nursery staff and her carers. As the key worker is a healthcare professional, they are able to fulfil both these roles to facilitate Rachel's pre-school attendance, with the full co-operation of the nursery staff.</p> <p>As Rachel requires a mid-morning or mid-afternoon sleep, and therefore ventilation, and she is still not old enough to care for her tracheostomy safely, it is agreed by the nursery and all agencies involved that the home carers who already know Rachel well will be funded to accompany Rachel to nursery. An honorary contract, which addresses insurance concerns, is agreed with the carers. Anna and David feel pleased and confident with this arrangement that will provide continuity and the appropriate level of expertise for Rachel's care to be delivered safely. She takes her own equipment into nursery with her on a daily basis and a trolley is made to assist with access to the nursery and for movement around the building.</p> <p>The nursery will provide training for the carers relevant to the setting to enable them to support Rachel appropriately with her learning. Emphasis is put on integrating Rachel into the nursery setting and arrangements made to allow her 'space' away from the carers, but so that they can observe her and ensure she receives appropriate medical help if and when she needs it.</p> <p>The key worker gives an information and awareness session about Rachel's needs to the nursery staff so that they can be supportive of the approach required for her care. The risk assessment has identified a need for designated staff to be trained in first aid and emergency resuscitation techniques and the key worker works with the nursery manager to identify appropriate staff to deliver this training, and staff to attend the sessions.</p>	<p>Standard 8 – children with complex needs are fully included and enabled to lead ordinary lives</p>	

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p><b>Primary school</b> At age five, Rachel starts primary school full-time. Careful multi-agency planning and risk assessment is undertaken with the key worker taking a leading role to ensure the smooth transition of Rachel into school. A ventilator is not required as Rachel no longer requires ventilation during the day. Her care package is gradually reduced as a member of the school support staff already contracted to provide support for children with health needs takes over from her own carers whilst at school. A plan is put in place for the assistant to gradually learn about her care and eventually support Rachel and another child in the same class.</p> <p>The assistant is trained to care for Rachel's tracheostomy and in all emergency procedures. Initially Rachel's carers who accompanied her to nursery work alongside the assistant as they gain confidence and competence in performing Rachel's care. Once the support assistant is assessed as competent by the key worker, the carers move on to work with another child although they remain in contact with Rachel as they do some night-time care for the family.</p> <p>Rachel progresses well in school and continues to have joint reviews of her education, health and social care needs. Her healthcare plan is updated regularly as her needs change and she becomes more independent. She adjusts well to life in school and integrates well with her peers who both support Rachel and accept her additional support needs.</p> <p><b>Secondary school</b> At age 11 years Rachel transfers to her local secondary school. The principles of risk assessment are applied again and support assistants identified for training, although their role is now more supportive of Rachel in delivering her own care for her tracheostomy. In Rachel's area the majority of the children who she</p>		

Journey	Children's NSF theme (England)	Policies, evidence, and links
<p data-bbox="413 365 925 539">knows from primary school will be attending the same secondary school as her. This helps Rachel as she feels she is in familiar company, even though teaching and support staff, and other routines differ.</p> <p data-bbox="225 577 354 678"><b>Change to mask ventilation</b></p> <p data-bbox="413 577 911 819">Rachel, Anna and David, and her children's respiratory consultant talk about a planned changeover from tracheostomy to mask ventilation. Rachel is keen for her tracheostomy to be closed so that she can be more independent, and plans for this are started.</p>	<p data-bbox="954 577 1185 786">Standards 3 and 8 – integrated co-ordinated care, which is flexible to changing needs and circumstances</p> <p data-bbox="954 824 1185 965">Standard 4 – respecting and involving young people in their care</p>	<p data-bbox="1208 577 1382 714">See link to the Expert Patient Programme in Bibliography M</p>

## Growing up and transition

	Journey	Children's NSF theme (England)	Policies, evidence, and links
<p><b>Adapting the care package over time</b></p>	<p>As Rachel grows up, her care package requires adaptations as her needs change. Her key worker organises an annual reassessment that involves Rachel, Anna and David, and relevant service managers. The minutes of meetings and an agreed plan of action are circulated to Rachel, Anna and David, and all relevant agencies.</p>	<p>Standards 3 and 8 – integrated co-ordinated care, which is flexible to changing needs and circumstances</p>	
<p><b>Developing self-care strategies and independence</b></p>	<p>As Rachel matures, she increasingly asks to see professionals by herself as she wants to become more independent. Anna and David find this transition difficult at times as they feel they are beginning to lose control over Rachel's care, although they recognise the importance of her taking responsibility for her own health needs.</p> <p>The change to mask ventilation has made a big difference to Rachel's life and she grows in confidence and enjoys her independence. Rachel wants increasingly to go out and enjoy varied social opportunities with her friends. Risk-management policies are adapted as Rachel matures and wants more independence, and to go out more at night. The roles of her carers are adjusted so that Rachel can attend social activities such as clubs and live music events. The key worker provides Rachel (and Anna and David) with important health promotion advice about the specific increased dangers to her health of smoking and illegal drug use.</p> <p>As Rachel is highly dependent on ventilation, she still requires some assistance from carers at night – but their hours are reduced in line with Rachel's wishes. In addition, Rachel says that she no longer wants her carers to sit in her bedroom at night. Discussions are initiated with the housing association and the local authority housing department about Rachel's future housing needs. Ideally Rachel would like a separate room for her carers with an</p>	<p>Standard 4 – respecting and involving young people in their care; flexibility of services as young people develop into adulthood</p> <p>Standard 8 – promote inclusion of disabled children and young people</p>	<p>See link to the Expert Patient Programme in Bibliography M</p>

	Journey	Children's NSF theme (England)	Policies, evidence, and links
<p><b>Transitions through education</b></p>	<p>interconnecting door to her room to allow her some privacy.</p> <p>Rachel achieves good examination grades at school and, as she approaches the age of 16 years, she discusses with her parents and careers advisor at school the options for her future education. Rachel decides that she would like to go to university after completing her A levels. Rachel wants to go to a local university so that she does not have to leave home or change her carers with whom she has a good relationship. Rachel, Anna and David contact the local university disability support office and an advisor helps Rachel to submit her application and identify her support needs at university.</p>	<p>Standard 3 – integration between education/social and health needs</p> <p>Standard 4 – growing up, young person increasingly involved in decisions</p>	<p>See Bibliography F for guidance on supporting young people through education</p>
<p><b>Direct payments and welfare payments</b></p>	<p>Rachel's social worker explains that she may be able to receive Direct Payments rather than services for her support needs from the age of 16 years. Rachel is provided with a video to take home which explains the advantages and disadvantages of the Direct Payment scheme.</p> <p>Rachel will also be able to access different welfare payments as she passes certain birthdays and depending on whether she is still in full-time education. Her social worker advises her, directing her to the Department of Work and Pensions website for additional information on welfare payments, and provides assistance as needed in identifying options.</p>		<p>See Bibliography L for guidance on Direct Payments</p> <p><a href="http://www.dwp.gov.uk">www.dwp.gov.uk</a></p>
<p><b>Transition to adult services</b></p>	<p>Until now Rachel has been cared for by a specialist children's long-term ventilation service and a team of community children's nurses. When Rachel is 15, the children's respiratory consultant suggests that it may now be the right time to think about transferring her care to a local adult service. The process of transition is planned carefully by the respiratory consultant and key worker along with Rachel and her parents so that at age 16 years she transfers to adult services.</p>	<p>Standard 4 – smooth transition to adult services</p> <p>Standard 8 – transition into adulthood</p>	<p>See Sections 3.3 and 3.4, and Bibliography K for best-practice guidance and literature concerning transition</p>



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