Standards framework for children's palliative care

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Together for Short Lives is the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them– families, professionals and services, including children's hospices. Our work helps to ensure that children can get the best possible care, wherever and whenever they need it. When children are unlikely to reach adulthood, we aim to make a lifetime of difference to them and their families.

We work closely with the organisations and professionals that provide important lifeline services to children and families. We support, lobby, and raise funds for children's hospices and a range of other voluntary organisations to enable them to sustain the vital work they do. We offer resources and training to help them maintain consistent, high quality care from the moment a child is diagnosed, until their eventual death, and to continue supporting families for as long as they need it.

Standards framework for children's palliative care – 3rd edition

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Together for Short Lives holds The Information Standard certification

Introduction

Together for Short Lives promotes a care pathway approach to children's palliative care, and has produced three care pathways which relate to different age groups, and a further one specifically focused on making choices surrounding the withdrawal of life-sustaining treatment.

Giving families real choice is key to the care pathway approach: a choice of place of care, a choice of place of death, a choice of emotional and bereavement support, and putting the child and family at the centre of decision making to produce a care plan that is right for them.

Together for Short Lives publishes four care pathways:

- *A Neonatal Care Pathway for Babies with Palliative Care Needs* (for babies)
- *A Core Care Pathway for Children with Life-threatening and Life-limiting Conditions*
- *Stepping Up (A Framework for Transition to Adult Services*)
- *A Care Pathway to Support Extubation within a Children's Palliative Care Framework*

This standards document sets out the key standards that form the back bone of these four care pathways, for easy reference. It also includes self-assessment audit tools relating to these standards, so you and your colleagues can map how your service currently performs and think about how to develop the areas where the standards may not be fully met.

Anecdotal evidence from within the sector has identified a need to develop outcome measures for children's palliative care services. We hope that this document will go some way to bridging the current gap in the measurement of outcomes and identification of gaps in service provision in the sector.

Since the publication of the first care pathway in 2004, ACT (now Together for Short Lives) has been nationally and internationally recognised as setting the standards for the care received by life-limited babies, children and young people. A number of other resources have been developed based on the standards' including *The Quality Standards for Children and Young People's Palliative Care* produced by the West Midlands Paediatric Palliative Care Network supported by West Midlands Quality Review Service. The group of children and young people covered by this document are described in detail within the relevant care pathway, but generally cover children of all ages – babies, children and young people – with any kind of life-threatening or life-limiting condition, receiving palliative care from health, social care and education services within the statutory and voluntary sector.

For further details about care pathways for life-limited and life threatened children, visit www.togetherforshortlives.org.uk/professionals/resources

Principles of good practice within Care Pathways

There are a number of overarching elements of good practice and themes which should be considered at every stage of the care pathway.

Best interest

The overriding legal and ethical principle is that all treatment decisions must be taken in the child's best interest.

Diversity and cultural issues

Culturally appropriate care which respects diversity helps maintain the quality of family centred care for all. An understanding of specific cultural and religious practices around death, dying and bereavement assists in providing culturally appropriate palliative care, identifying and supporting individual family needs and preferences and preventing assumptions that all people from the same culture or religion practice the same rituals or share the same beliefs. The Together for Short Lives *DiversityToolkit* http://www.togetherforshortlives.org.uk/professionals/resources/2438_the_diversity_toolkit is a useful resource to support professionals and organisations as they consider diversity and cultural issues in children's palliative care.

Consent, confidentiality and capacity

Confidentiality, consent and capacity issues must be addressed throughout the care pathway. A number of resources are available to support professionals, including the *Mental Capacity Act*

Communication

There should be an honest, open and timely approach to all communication with parents and carers, who should be treated as equal partners in any discussions with the care team. It is crucial to remember the importance of talking to parents and the family, giving them choices and maintaining a flexible, 'can-do' attitude to support their choice. If they choose to allow their child to die at home or at a local children's hospice, then the pathway should be followed to support the child's rapid discharge from hospital. At such times, it is vital that one practitioner is identified to take the lead, so they can act as the family's first point of contact for communication, and to ensure that information flows to all services.

Uncertainty and losses

Families often experience repeated uncertainty and losses: first the loss of the 'normal' child, followed by the anticipated loss of a child predicted to die. At times, the child may defy medical expectations and survive episodes of life-threatening deterioration, only for the family to face their death in the future. Some families may also face multiple losses with more than one child having the same medical condition. Often the only honest answer to a family's questions about how long the child will live, is simply that you don't know.

A unique bereavement journey for every child and family

Family life for everyone is affected when a child is diagnosed with a life-limiting illness, and of course, when they die. Grief is an individual concept, experienced very differently. Choice is therefore vital. It is important to ask the family what they want to ensure the whole family focus is retained while ensuring a professional approach, underpinned by theory. All types of support should be available throughout the family's journey. Sometimes a professional approach, over-reliant on theories and ideas, can lead to inappropriate support for families. For example, support groups suit some, but not all. Couple support can be helpful because of the strain the parent's relationship is under when caring for a seriously ill or dying child.

Emotional and psychological support

This is needed throughout the family's experience, from diagnosis, through end of life care and following the death of the child. Families should be enabled to access support when they want to, rather than having their needs assessed at pre-set intervals. The specific needs of siblings should be considered throughout this care pathway.

Spiritual support

Every child and family should receive spiritual support to meet their individual needs. This should begin at diagnosis and continue throughout the child's lifetime, death and during bereavement.

Multiple admissions

Children with life-limiting or life-threatening conditions often experience multiple admissions to hospital. Professionals should prepare the family for this possibility and the potential for their child being cared for in different environments, possibly different hospitals under different care teams.

Co-ordinated care

Children and their families should receive coordinated care, where services work together to deliver integrated, child-centred, life-long care to improve quality of life.

24 hour support

Every child should have a local GP and access to a 24 hour multi-disciplinary children's palliative care team for flexible support in the home, and be under the care of a local paediatrician.

Ability to respond quickly and flexibly

Some children will have a very short life expectancy and the normal planning meetings may not happen.

Parallel planning

It is often hard to predict what the future holds for children requiring palliative care. For some, periods of relatively good health are associated with the potential for an unpredictable, and potentially terminal event. For others, a period of deterioration may be observed, yet the child may have considerable time to live when the quality of their life should be maximised. Parents quickly experience the uncertainty that living with a child requiring palliative care brings, and with support, value a 'parallel planning' approach. Discussions with the child (where appropriate) and the family enable various options for care in response to a range of potential outcomes to be considered and written down in advance. Although children may be assessed as deteriorating or approaching the end of their life, it is sometimes the case that children survive these episodes. Parallel planning for life while also planning for deterioration or death allows a child's full potential to be achieved and primes the mobilisation of services and professionals where necessary. Planning for the future at times of great uncertainty can also be comforting for children and parents. These plans often include the development of an Advance Care Plan.

Advance Care Plan

Advance Care Planning (ACP) is a process of discussion between an individual and their care provider and often those close to them. The End of Life Care Strategy (Department of Health, 2008) clearly states that ACP and clarity about resuscitation decisions are essential to quality care. This is as important for children and families as it is for adults receiving end of life care. ACP may lead to actions such as advance statements about wishes and preferences, preferred place of care, withdrawal of treatment and resuscitation status. For children and families this will include decisions relating to care in the case of acute deterioration and may also address preferences for organ and tissue donation.

Care for the team around the child

Everyone who is called upon to support the child and their wider family throughout this care pathway journey will at times, find this journey emotionally challenging. Every member of the team around the child and family should receive support and an opportunity to feedback and discuss what is happening. Professionals should also have access to ongoing support and supervision.

Risk assessment

Risk assessment and risk management play an important part in ensuring that children and young people with life-limiting or life-threatening conditions can enjoy the kind of activities that many others take for granted. By identifying risks and looking proactively at risk management, professionals can be more effective in supporting families.

Centrality of child to the process

The child or young person should remain central to the care process at all times.

Respecting intellectual needs

Every individual should be treated with respect, honesty and sensitivity, with communication, information-giving and care planning recognising their intellectual needs.

Respecting language needs

Information should be provided for the child and family in language that they can understand. Appropriate translation services should be available at all times.

Respecting and valuing individuality

Every individual should be treated with respect, honesty and sensitivity, acknowledging and taking into account their individual beliefs, needs and views.

Sibling support

The physical, emotional and practical needs of siblings should be assessed and addressed as part of the family assessment, with specific information and support provided to them.

A Core Care Pathway for Children with Life-limiting and Life-threatening conditions

Standards

1	**The prognosis – sharing significant news**	Every family should receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided for the child and the family in a form that they can understand.
2	**Transfer and liaison between hospital and community services**	Every child and family diagnosed in the hospital setting should have an agreed transfer plan involving hospital, community services and the family, and should be provided with the resources they require before leaving hospital.
3	**Multi-disciplinary assessment of needs**	Every family should receive a child and family centred multi-disciplinary and multi-agency assessment of their needs as soon as possible after diagnosis or recognition, and should have their needs reviewed at appropriate intervals.
4	**A child and family care plan**	Every child and family should have a multi-disciplinary, multi-agency care plan, developed in partnership with them for the delivery of co-ordinated care to enhance family strengths and meet need. A multi-disciplinary and multi-agency team should be identified in agreement with the family and use key working principles. Wherever possible this should involve all agencies involved in supporting the child and family, including the child's community nursing team, allied health professionals, hospice, local acute and tertiary hospital services, education, social care and short break services.
5	**An end of life care plan**	Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this.
6	**Bereavement support**	Bereavement support should be provided along the care pathway and continue throughout the child's death and beyond.

Stepping Up (A Framework for Transition to Adult Services)

Standards

1	**Standard 1**	Every young person from age 14 should be supported to be at the centre of preparing for approaching adulthood and for the move to adult services. Their families should be supported to prepare for their changing role.
2	**Standard 2**	Every young person is supported to plan proactively for their future. They are involved in ongoing assessments and developing a comprehensive holistic plan that reflects their wishes for the future.
3	**Standard 3**	Every young person has an end of life plan which is developed in parallel to planning for ongoing care and support in adult services. *This standard applies to all stages of the transition journey.*
4	**Standard 4**	Children's and adult services are actively working together to enable a smooth transition.
5	**Standard 5**	Every young person is supported in adult services with a multi-agency team fully engaged in facilitating care and support. The young person and their family are equipped with realistic expectations and knowledge to ensure confidence in their care and support needs being met in the future.

A neonatal pathway for babies with palliative care needs

Standards

1	**Sharing significant news**	Every family should receive the disclosure of their baby's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided for the family using language that they can understand.
2	**Planning for going home**	Every baby and family should have an agreed transfer plan involving the family or carers, hospital, community services and hospice services. The family should be provided with the resources they require before leaving hospital.
3	**Multi agency assessment of the family's needs**	Every family should receive a multi-agency assessment of their needs as soon as possible after their baby's diagnosis or recognition that their baby's condition is life-threatening or life-limiting. They should have their needs reviewed at appropriate intervals.
4	**Multiagency care plan**	Every baby and family should have a multi-agency care plan agreed with them for the delivery of co-ordinated care and support to meet their individual needs. A key worker to assist with this should be identified and agreed with the family.
5	**End of life plan**	Every family should be helped to prepare an end of life plan for their baby and should be provided with care and support to achieve this.
6	**Continuing bereavement support**	Bereavement support should be provided along the care pathway and continue throughout the baby's death and beyond.

Care Pathway for extubation within a palliative care framework

Standards

1	**Sharing significant news**	In cases of new diagnoses, or when revisiting a prognosis made earlier, every family should receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided for the family in language that they can understand.
2	**An agreed plan of care**	Every child and family should have an agreed plan of care, including, if appropriate, a transfer plan involving the family or carers, hospital, community services and hospice service. The resources and equipment that the child and family need should be planned for and prepared before the child leaves hospital.
3	**An end of life plan**	Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this as closely as possible.
4	**Planning the extubation process**	The child and family should be kept central to the process. The family should be made aware of the roles and responsibilities of members of the care team. The child and family should receive high quality care led by skilled and competent professionals. Care transitions should be seamless and should be supported by parallel planning.
5	**Enabling end of life wishes**	The child's end of life plan should be carried out in a timely way in accordance with the parents' wishes.
6	**Continuing bereavement support**	Bereavement support should be provided along the care pathway and continue throughout the child's death and beyond.

Appendix 1 Service Self Assessment Tools

A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions

The prognosis – sharing significant news

Every family should receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided for the child and the family in a form that they can understand.

	Goals & standards	**Were these standards met?**				
		Always	**Mostly**	**Sometimes**	**Rarely**	**Never**
A1	Is prognosis shared with parents during face to face discussion?					
A2	Are private settings available for sharing significant news?					
A3	Is significant news given to parents together or with a relative/friend to support?					
A4	Is written material provided for the family?					
A5	Is an interpreter used where needed?					
A6	Is developmentally appropriate information available for children?					

Transfer and liaison between hospital and community services

Every child and family diagnosed in the hospital setting should have an agreed transfer plan involving hospital, community services and the family, and should be provided with the resources they require before leaving hospital.

	Goals & standards	Were these standards met?				
		Always	Mostly	Sometimes	Rarely	Never
B1	Is a lead professional identified in hospital and in the community?					
B2	Are GPs routinely informed?					
B3	Are community services informed ASAP?					
B4	Is a community children's nursing service available?					
B5	Is community in-reach available?					
B6	Is early planning arranged, with an agreed transfer plan that involves the family, hospital and community services?					
B7	Are home visits arranged within three days of discharge?					

B8	Is shared medical care planned?					
B9	Are essential resources including equipment available?					
B10	Are transport needs addressed?					
B11	Are carers trained before transfer?					
B12	Are clear lines of communication agreed?					
B13	Are families provided with a 24 hour contact number?					
B14	Do hospice teams visit before transfer?					

Multi-disciplinary assessment of family's needs

Every family should receive a child and family centred multi-disciplinary and multi-agency assessment of their needs as soon as possible after diagnosis or recognition, and should have their needs reviewed at appropriate intervals.

	Goals & standards	Were these standards met?				
		Always	Mostly	Sometimes	Rarely	Never
C1	Are needs assessed as soon as possible following diagnosis/recognition?					
C2	Are multi-disciplinary, multi-agency co-ordinated assessments carried out?					
C3	Are assessments carried out in partnership with the family?					
C4	Is the child/young person kept central to and included in the process?					
C5	Does the assessment include father, siblings and other relevant carers?					
C6	Do processes respect individuality and ethnicity?					
C7	Are transport needs considered?					
C8	Is information gathered and recorded systematically?					
C9	Does the procedure ensure non-jargon language is used?					

C10	Does the process address confidentiality and consent?					
C11	Is assessment information available to families as part of a family held document?					
C12	Is the lead role clear to the family and other professionals?					
C13	Do assessors have appropriate skills and local knowledge?					

A child and family care plan

Every child and family should have a multidisciplinary, multi-agency care plan, developed in partnership with them for the delivery of co-ordinated care to enhance family strengths and meet need. A multi-disciplinary and multiagency team should be identified in agreement with the family and use key working principles.

Wherever possible this should involve all agencies involved in supporting the child and family, including the child’s community nursing team, allied health professionals, hospice, local acute and tertiary hospital services, education, social care and short break services.

	Goals & standards	**Were these standards met?**				
		Always	**Mostly**	**Sometimes**	**Rarely**	**Never**
D1	Are key working principles used?					
D2	Is the care plan available to the child and family?					
D3	Do care plans include the whole family?					
D4	Is symptom management, nursing care and personal care planned for?					
D5	Is psychological care available for family?					
D6	Is benefits advice/financial information given to families?					
D7	Are flexible short breaks available for children and young people?					

D8	Is social care and support available?					
D9	Are there opportunities for play/social activities?					
D10	Is there access to appropriate education?					
D11	Do the care plans address carers' health issues?					
D12	Is a named Community Children's Nurse allocated to the child and family?					
D13	Are aids/equipment available for home and school?					
D14	Do the care plans address transition to adult services?					
D15	Are there regular updated reviews?					
D16	Are families able to request reviews?					
D17	Are professionals involved in reviewing service effectiveness?					

An End of life care plan

Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this.

	Goals & standards	Were these standards met?				
		Always	Mostly	Sometimes	Rarely	Never
E1	Are professionals open and honest when end of life is approaching?					
E2	Does joint planning take place as soon as possible?					
E3	Are care plans agreed and shared with emergency services?					
E4	Are resuscitation plans agreed, written up and communicated appropriately?					
E5	Do families have access to 24 hour symptom control?					
E6	Are symptom control staff suitably qualified and experienced?					
E7	Is emotional and spiritual support available?					
E8	Are family choices supported with resources?					
E9	Are the child and family given a choice in the place of care?					

Bereavement support

Bereavement support should be provided along the care pathway and continue throughout the child's death and beyond.

	Goals & standards	Were these standards met?				
		Always	Mostly	Sometimes	Rarely	Never
F1	Are families given time and privacy with child after death?					
F2	Are parents in control and supported in making choices?					
F3	Is practical advice and written information available?					
F4	Are the needs of siblings, grandparents and other relevant family members and carers' considered?					
F5	Is fully informed consent given for post-mortem examinations?					
F6	Are professional contacts informed immediately about the death?					
F7	Is bereavement support offered available for as long as needed?					

F8	Are siblings' bereavement needs supported?					
F9	Are staff needs recognised?					

Stepping Up (A Framework for Transition to Adult Services)

Phase 1: Preparing for adulthood – Young person age 14+

Standard 1

Every young person from age 14 should be supported to be at the centre of preparing for approaching adulthood and for the move to adult services. Their families should be supported to prepare for their changing role.

	Goals & standards	**Were these standards met?**				
		Always	**Mostly**	**Sometimes**	**Rarely**	**Never**
A1	Are young people at the centre of planning, using person-centred planning approaches?					
A2	Is parallel planning taking place?					
A3	Are initial conversations about transition taking place with the young person and their family at a time and in a place that suits them?					
A4	Has a follow-up meeting with the young person and family taken place?					
A5	Has the first multi-agency/multi-disciplinary team meeting taken place?					

Phase 2: Preparing for moving on – Young person aged 14-18

Standard 2

Every young person is supported to plan proactively for their future. They are involved in ongoing assessments and developing a comprehensive holistic plan that reflects their wishes for the future.

	Goals & standards	Were these standards met?				
		Always	Mostly	Sometimes	Rarely	Never
B1	Are young people and their parents being helped with the transition from family-centred to young person centred-care?					
B2	Does every young person have a key worker to facilitate continuity of care and prepare the way into adult services?					
B3	Is every young person being supported to consider their future plans, supported by ongoing multi-agency assessment?					
B4	Is every young person being supported to identify adult services which can meet their needs?					

Standard 3

Every young person has an end of life plan which is developed in parallel to planning for ongoing care and support in adult services. *This standard applies to all stages of the transition journey.*

	Goals & standards	**Were these standards met?**				
		Always	**Mostly**	**Sometimes**	**Rarely**	**Never**
C1	Is transition planning continuing to take place even during time of uncertainty?					
C2	Does every person have a documented end of life plan running alongside their plan for the future?					
C3	Are the young person's pain and other symptoms being dealt with effectively?					
C4	Is every effort being made to ensure that the young person's death takes place according to their wishes and in their place of choice wherever possible, with their emotional, cultural and spiritual needs being met?					
C5	Are family members and other carers being supported, informed and involved?					
C6	Is the young person receiving the best quality of life and care to the end?					
C7	Are parents able to retain their parenting role after the death of the young person?					
C8	Are siblings being supported and included in all decisions?					

C9	Are all professionals/agencies being informed of the death with the parents' consent?					
C10	Are all family members being supported according to their individual needs for as long as they need it?					

Standard 4

Children's and adult services are actively working together to enable a smooth transition.

	Goals & standards	**Were these standards met?**				
		Always	**Mostly**	**Sometimes**	**Rarely**	**Never**
D1	Are child and adult services within health working together so that there is an overlap of care planning and care provision?					
D2	Are services within all agencies engaging in planning for the specific needs of the young person?					
D3	Are ongoing reviews (at least annually) with the young person taking place?					

Phase 3 – Settling in to adult services – Young adult age 18+

Standard 5

Every young person is supported in adult services with a multi-agency team fully engaged in facilitating care and support. The young person and their family are equipped with realistic expectations and knowledge to ensure confidence in their care and support needs being met in the future.

	Goals & standards	Were these standards met?				
		Always	Mostly	Sometimes	Rarely	Never
E1	Is a key working function being provided for every young person so that all the agencies providing care and support are co-ordinated?					
E2	Are all agencies ensuring that age and developmentally appropriate services are available that address the full range of a young person's needs?					
E3	Are palliative care services providing a single clinical overview for the young person and linking with other specialists involved in their care?					
E4	Is there frequent review and communication across services about care plans and end of life decisions?					
E5	Are primary health care services, including GPs, developing a relationship with the young person and their families/carers?					
E6	Are adult services in secondary care ensuring that there is an appropriate lead clinician to take responsibility for young adults in their clinics and admissions processes?					
E7	Are short breaks or respite needs of young people and their parents/carers being					

	considered and provided for in the most appropriate setting?					
E8	Are parents being included if appropriate?					

Neonatal care pathway

Sharing significant news

Every family should receive the disclosure of their baby's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided for the family using language that they can understand.

	Goals & standards	**Were these standards met?**				
		Always	**Mostly**	**Sometimes**	**Rarely**	**Never**
A1	Is news shared in a face-to-face discussion in privacy?					
A2	Are parents together to receive the news?					
A3	Is helpful written material provided and information conveyed in readily understandable language?					

Planning for going home

Every baby and family should have an agreed transfer plan involving the family or carers, hospital, community services and hospice services. The family should be provided with the resources they require before leaving hospital.

	Goals & standards	Were these standards met?				
		Always	Mostly	Sometimes	Rarely	Never
B1	Are community services notified as soon as possible?					
B2	Is community in-reach available?					
B3	Is a transfer plan developed as soon as possible?					
B4	Is a lead CCN identified?					
B5	Are shared medical arrangements in place?					
B6	Is equipment (and supplies) provided before transfer?					
B7	Are training needs of carers considered?					
B8	Are clear lines of communication agreed?					

B9	Are home visits arranged on the same day as the transfer?					
B10	Is a 24-hour contact number provided to the family?					
B11	Is a key worker identified?					

Multi-agency assessment of the family's needs

Every family should receive a multi-agency assessment of their needs as soon as possible after their baby's diagnosis or recognition that their baby's condition is life-threatening or life-limiting. They should have their needs reviewed at appropriate intervals.

	Goals & standards	Were these standards met?				
		Always	Mostly	Sometimes	Rarely	Never
C1	Do babies and families have their needs assessed as soon as possible after diagnosis or recognition?					
C2	Are holistic and multi-agency approaches used to avoid the need for multiple assessments?					
C3	Is the assessment of needs made in partnership with the family?					
C4	Is the baby kept central to the process?					
C5	Are the needs of fathers and siblings considered?					
C6	Is individuality and ethnicity respected?					
C7	Is straightforward and jargon-free language used?					

C8	Is assessment information made available to the family?					
C9	Is there clarity in respect of the lead role?					
C10	Do those undertaking needs assessments have appropriate skills and local knowledge?					

Multi-agency care plan

Every baby and family should have a multi-agency care plan agreed with them for the delivery of co-ordinated care and support to meet their individual needs. A key worker to assist with this should be identified and agreed with the family.

	Goals & standards	Were these standards met?				
		Always	Mostly	Sometimes	Rarely	Never
D1	Does every family have a key worker to co-ordinate their plan?					
D2	Is information available to the family?					
D3	Does the plan include the whole family and take account of the baby's symptoms and personal care.					
D4	Does the plan include psychological care for the baby's siblings and parents?					
D5	Is information about how to access to benefits and financial assistance provided?					
D6	Is information about how to access flexible short breaks provided?					
D7	Is information about how to access aids and equipment provided?					
D8	Are tailored out-of-hours plans provided?					

End of life plan

Every family should be helped to prepare an end of life plan for their baby and should be provided with care and support to achieve this.

	Goals & standards	Were these standards met?				
		Always	Mostly	Sometimes	Rarely	Never
E1	Are professionals open and honest with families when it is recognised that the baby is approaching its end of life?					
E2	Does joint planning with families and relevant professionals take place as soon as possible?					
E3	Is a written plan of care for the baby and family agreed?					
E4	Are emergency services informed along with all other services/professionals involved in the baby and family's care?					
E5	Are care plans reviewed regularly?					
E6	Are end of life plans reviewed with the GP or doctor at least every two weeks?					
E7	Is there 24 hour access to pain and symptom control including access to medication?					
E8	Are those managing the control of symptoms suitably qualified and experienced?					

E9	Is emotional and spiritual support available to the family and carers?					
E10	Are families supported in their choices and goals for quality of life to the end?					
E11	Do staff involved have access to their own lines of support and supervision?					
E12	Are the needs of siblings and grandparents considered and included at the time of death and immediately afterwards as part of the end of life plan?					
E13	Is fully informed consent sought for post-mortem?					
E14	Are families informed of post-mortem findings by an informed professional that they know in a face-to-face setting?					
E15	Are professional contacts informed of the baby's death immediately?					
E16	Is practical advice and written information given about care of the baby's body, official procedures and entitlements?					
E17	Are possible heart valve donation and consent issues discussed?					

Continuing bereavement support

Bereavement support should be provided along the care pathway and continue throughout the baby's death and beyond.

	Goals & standards	Were these standards met?				
		Always	Mostly	Sometimes	Rarely	Never
F1	Is the family allowed time and privacy with their baby?					
F2	Are parents able to follow their own choices and wishes?					
F3	Is the bereavement support offered based on assessed needs?					
F4	Are the bereavement needs of siblings recognised and supported?					
F5	Are the needs of care staff considered?					
F6	Are parents provided with details of who they can contact to discuss any plans for a future pregnancy or need to make contact with a genetic service?					
F7	Are midwives sensitive to the mother's needs in future pregnancies?					

A care pathway to support extubation within a children's palliative care framework

Sharing significant news

In cases of new diagnoses, or when revisiting a prognosis made earlier, every family should receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided for the family in language that they can understand.

	Goals & standards	Were these standards met?				
		Always	Mostly	Sometimes	Rarely	Never
A1	Are parents treated with openness and honesty?					
A2	Are parents acknowledged as experts in the care of their child?					
A3	Is significant news shared in a place of privacy?					
A4	Do professionals allow plenty of time for sharing news and discussing what this means with families?					
A5	Are parents be given the opportunity to hear news together or to have another supporter present?					

A6	Are advocates and interpreters readily available to support families?					
A7	Is clear, jargon-free and readily understandable language used when breaking news?					
A8	Is there open communication between professionals and the family?					
A9	Are parents given time to explore care options and ask questions?					
A10	When sharing significant news, is helpful written material used to back up the conversation?					

An agreed plan of care

Every child and family should have an agreed plan of care, including, if appropriate, a transfer plan involving the family or carers, hospital, community services and hospice service. The resources and equipment that the child and family need should be planned for and prepared before the child leaves hospital.

	Goals & standards	**Were these standards met?**				
		Always	**Mostly**	**Sometimes**	**Rarely**	**Never**
B1	Is a key worker identified?					
B2	Is consensus between the care team and family achieved by supporting families to discuss their child's critical care plan and place of care?					
B3	Are families asked about what kind of environment they would like their child to be cared for in?					
B4	Does planning begin as soon as possible?					
B5	Where appropriate, is a clear plan for transfer agreed with the family and services?					
B6	Are families offered the opportunity for support from other family members or supporters such as religious, faith or spiritual leaders?					

B7	Is the need for parallel planning discussed with the family?					
B8	Are community based services notified as soon as is practical?					
B9	Is a lead community children's nurse (CCN) agreed before transfer?					
B10	Is the child's GP and local palliative care team informed and invited to become involved as appropriate?					
B11	Are shared medical care plans between consultants and medical services in place?					
B12	Are equipment and supplies planned for and provided before transfer?					
B13	Are clear lines of communication agreed, including on-call arrangements for contact with staff such as CCNs?					
B14	If transfer to a children's hospice is planned and time allows, does a member of the hospice team meet the family at the hospital before discharge?					
B15	Is the family informed of who will be providing 24 hour end of life care, medical support and medication?					

An end of life plan

Every child and family should be helped to decide on an end of life plan and should be provided with care and support to achieve this as closely as possible.

	Goals & standards	Were these standards met?				
		Always	Mostly	Sometimes	Rarely	Never
C1	Is a core care team around the child established?					
C2	Are families given a choice of place of care for their child, where possible?					
C3	Do professionals encourage discussion about the child and family's choices for quality of life and provide the appropriate support to make these choices possible?					
C4	Is an end of life plan agreed, shared and regularly reviewed with the family?					
C5	Are personal resuscitation plans discussed and developed?					
C6	Is organ donation and post-mortem examination discussed with the family?					
C7	Are actual and anticipatory symptom and pain management plans developed?					

C8	Are supplies of medication and out-of-hours pharmacy needs planned for?					
C9	Is future prescribing anticipated?					
C10	Are families given contact details for key professionals?					
C11	Do the family and team have access to 24/7 care including a children's palliative care specialist, paediatrician or specialist GP throughout the palliative stage of care?					
C12	Is emotional support provided for the family, including any siblings?					
C13	Are families supported to memory build and to carry out any special wishes with their child?					
C14	Are families supported to prepare and plan any special ceremonies before or after death?					

Planning the extubation process

The child and family should be kept central to the process. The family should be made aware of the roles and responsibilities of members of the care team. The child and family should receive high quality care led by skilled and competent professionals. Care transitions should be seamless and should be supported by parallel planning.

	Goals & standards	**Were these standards met?**				
		Always	**Mostly**	**Sometimes**	**Rarely**	**Never**
D1	Are the child and the family kept central to the planning process at all times?					
D2	Is an assessment of the child and family's needs made in partnership with the family?					
D3	Are family strengths and potential stress factors identified, and consideration given to how staff can help the family cope with the process, including the burden of uncertainty?					
D4	Are fathers and siblings and other key family members involved and included in care planning and provision?					
D5	Is individuality and ethnicity respected?					
D6	Is confidentiality and consent addressed?					
D7	Is consistent and systematic documentation used?					

D8	Are contact details of those who should be informed of the death of the child identified with the family, for example the school, GP or hospital ward?					
D9	Is parallel planning in place?					
D10	Is open, honest and fluid communication used throughout the process?					
D11	Is straightforward and jargon-free language used?					

Enabling end of life wishes

The child's end of life plan should be carried out in a timely way in accordance with the parents' wishes.

	Goals & standards	Were these standards met?				
		Always	Mostly	Sometimes	Rarely	Never
E1	Are families supported in their choices and goals for quality of life to the end?					
E2	Is the agreed plan for the child and family followed?					
E3	Is the family allowed time and privacy with their child?					
E4	Are parents enabled to feel in control of events before and after death and able to follow their own choices and wishes?					
E5	Are the family members and others who the family wish to have with them enabled to present?					
E6	Is emotional and spiritual support available to the family or parent carers?					
E7	Are the needs of siblings and grandparents considered and included around the time of death, and immediately afterwards, as part of the end of life plan?					
E8	Do staff involved have access to their own sources of support and supervision?					

E9	Is fully informed consent sought for a post-mortem, where relevant?					
E10	When a post-mortem is performed, are families informed of its findings by a professional they know, and who has a full understanding of the implications of the pathology report. Is this done in a face-to-face, meeting in an environment that will not generate undue anxiety?					
E11	Are earlier discussions regarding possible tissue and organ donation reviewed and consent confirmed?					
E12	Are professional contacts informed of the child's death immediately?					
E13	Is practical advice and written information given to the family about the care of the child's body, official procedures and entitlements or benefits?					

Continuing bereavement support

Bereavement support should be provided along the care pathway and continue throughout the child's death and beyond.

	Goals & standards	**Were these standards met?**				
		Always	**Mostly**	**Sometimes**	**Rarely**	**Never**
F1	Is the family allowed time and privacy with their child?					
F2	Do parents feel in control of events before and after death and able to follow their own choices and wishes?					
F3	Is bereavement support offered, based on assessed need?					
F4	Are the bereavement needs of siblings recognised and support provided?					
F5	Are the parents provided with details of who they can contact to discuss any plans for future pregnancies, including contacts with a clinical genetics service?					
F6	Are the needs of care staff considered?					
F7	Staff support is essential. Is debriefing, ongoing support and supervision readily available?					

Quality markers for children and young people's palliative care services

Together for Short Lives has set out the following Quality Markers for children and young people's palliative care services.

We suggest that provider services should work in partnership to review and develop children and young people's palliative care services in line with the proposed Quality Markers (below).

Commissioners may wish to use the Quality Markers, and an expectation of improvement against them, in their contracting processes.

Children and young people's palliative care services will:

- Have an action plan for the delivery of high quality palliative care which is reviewed for impact and progress.
- It should encompass children, young people (including those in transition to adult services) and their families.
- Implement effective mechanisms to identify children and young people with life-limiting or life-threatening conditions at any point from the time of diagnosis or recognition right through to the approach of their end of life phase.
- Ensure that the child or young person and their family's preferences and choices are documented and communicated to appropriate professionals, and that the needs of family members, including siblings, are appropriately assessed and recorded through a carer's assessment.
- Have mechanisms in place to ensure that care for children and young people is co-ordinated across organisational boundaries 24/7.
- Ensure that all children and young people who are approaching end-of-life are offered a care plan.
- Have sustainable essential services available 24/7 to all children and young people who are approaching end of life. These services should also be capable of offering home-based care at end of life, if this is what the family chooses.
- Be aware of children's palliative care and end of life care training opportunities and enable relevant workers to access or attend programmes appropriate to their needs.
- Adopt a standardised approach (for example, a care pathway approach) to care for life-limited children and young people throughout their whole care journey.
- Ensure mechanisms are in place to provide effective feedback and meaningful evaluation from parents and carers.
- Monitor the quality and outputs of children's palliative care including end of life care and submit relevant information for local and national audits.