

## ACT Integrated Palliative Care Pathways Standards: Service Self Assessment Tool

The self assessment tool is based on the ACT *Integrated Multi-agency Care Pathway for Children with Life-limiting or Life-threatening Conditions*, and aims to identify the aspects of best practice within a local area. The stages of the audit are:

- **Stage One** - Assess service provision against standards and goals;
- **Stage Two** - Produce and implement an action plan aimed at achieving best practice;
- **Stage Three** - Review achievements towards best practice;
- **Stage Four** - Disseminate improvements and or review action plan.

This audit provides a process of considering current practice and enables the identification of good practice and areas of practice which need further development.

NB. The Goals and Standards listed below correlate to those in ACT's *Integrated Multi-Agency Care Pathway*. You can purchase a copy of this Care Pathway by calling ACT on 0117 922 1556 or visiting the ACT website: [www.act.org.uk](http://www.act.org.uk)

Goal Number	Goals and Standards	Were these goals and standards achieved?				
● <b>Breaking News</b>	<i>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 both for the child and family in language that they can understand.</i>	Yes, always	Yes, most of the time	Yes, sometimes	Rarely	No, never
A1	Is diagnosis shared with parents during face-to-face discussion?					
A2	Are private settings available for breaking bad news?					
A3	Is bad news given to parents together or with a relative/friend to support?					
A4	Is written material provided?					
A5	Is an interpreter used where needed?					
A6	Is developmentally appropriate information available for children?					

Goal Number	Goals and Standards	Were these goals and standards achieved?				
● <b>Discharge home</b>	<i>Every child and family diagnosed in the hospital setting, should have an agreed transfer plan involving the hospital, community services and the family, and should be provided with the resources they require before leaving hospital.</i>	Yes, always	Yes, most of the time	Yes, sometimes	Rarely	Never
B1	Is a lead professional identified in hospital and community?					
B2	Are GP's 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 and hospital and community services available?					
B7	Are home visits arranged pre discharge?					
B8	Is shared medical care planned?					
B9	Are essential resources available?					
B10	Are transport needs addressed?					
B11	Are carers trained before transfer?					
B12	Are clear communication lines agreed?					
B13	Are families provided with a 24 hr contact number?					
B14	Are Keyworkers identified before discharge home?					
● <b>Assessment</b>	<i>Every family should receive a multi-agency assessment of their needs ASAP after diagnosis or recognition, and should have their needs reviewed at appropriate intervals.</i>					
C1	Are needs assessed ASAP following diagnosis/recognition?					
C2	Are multi-agency coordinated assessments carried out? Including an identified school.					
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 the father and siblings?					
C6	Do processes respect individuality and ethnicity?					
C7	Are transport needs considered?					

Goal Number	Goals and Standards	Were these goals and standards achieved?				
● <b>Assessment</b> (continued)	<i>Every family should receive a multi-agency assessment of their needs ASAP after diagnosis or recognition, and should have their needs reviewed at appropriate intervals.</i>	Yes, always	Yes, most of the time	Yes, sometimes	Rarely	Never
C8	Is information gathered and recorded systematically?					
C9	Does the procedure ensure non-jargon based language is used?					
C10	Does the process address confidentiality and consent?					
C11	Is assessment information available to families?					
C12	Is the lead role clear to the family/other professionals?					
C13	Do assessors have appropriate skills and local knowledge?					
● <b>Care Plan</b>	<i>Every child 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.</i>					
D1	Is a Key worker identified?					
D2	Is the Care Plan available to 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	Does the Care Plan address carers' health issues?					
D12	Has a Community Children's Nurse been allocated to the child and family?					
D13	Are aids/equipment available for home and school?					
D14	Does the Care Plan 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?					

Goal Number	Goals and Standards	Were these goals and standards achieved?				
<b>● End of Life</b>	<i>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.</i>	Yes, always	Yes, most of the time	Yes, sometimes	Rarely	Never
E1	Are professionals open and honest when end of life is approaching?					
E2	Does early joint planning take place?					
E3	Are care plans reviewed and agreed?					
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/spiritual support available?					
E8	Are family choices able to be supported with resources?					
E9	Are the child and family given a choice in the place of care?					
<b>● Post Death</b>						
F1	Are families given time and privacy with their 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 family members considered?					
F5	Is fully informed consent given for post mortem examinations?					
F6	Are professional contacts informed immediately about the death?					
F7	Is bereavement support available for as long as needed?					
F8	Are sibling's bereavement needs supported?					
F9	Are staff needs recognised?					

ACT is the only organisation working across the UK to achieve a better quality of life and care for every life-limited child and their family.

ACT, Orchard House, Orchard Lane, Bristol BS1 5DT. Telephone: 0117 922 1556 Fax: 0117 930 4707 Email: [info@act.org.uk](mailto:info@act.org.uk) Website: [www.act.org.uk](http://www.act.org.uk).  
Registered Charity No: 1075541 Company Registration No 3734710

