

## ACT Transition Care Pathways Standards: Service Self Assessment Tool

The self-assessment tool is based on the ACT *Transition Care Pathway: A Framework for the Development of Integrated Multi-Agency Care Pathways for Young People with Life-threatening and Life-limiting 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 Transition Care Pathway. You can purchase a copy of the Transition 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?				
		Yes, always	Yes, most of the time	Yes, sometimes	Rarely	No, never
● <b>Sharing Significant News</b>	<i>In cases of new diagnoses, or when revisiting a prognosis made earlier in childhood, 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 young person and family in language that they can understand.</i>					
A1	Is news shared in a face-to-face discussion in privacy?					
A2	Are families together to receive the news?					
A3	Is helpful written material provided and information conveyed in readily understandable language?					

Goal number	Goals and Standards	Were these goals and standards achieved?				
<p><b>● Approaching adolescence</b></p>	<p><i>There is no one “right” time or age for completion of transition. It should happen at the appropriate developmental stage for each young person. However it’s vital that transition doesn’t come as a surprise to young people, and that they are prepared long before they reach it. Every young person should be supported by an identified key worker to prepare for the move onto adult services from their 14th birthday.</i></p>	Yes, always	Yes, most of the time	Yes, sometimes	Rarely	No, never
B1	Is transition an actively managed process?					
B1	Is there a process for identifying young people at 14 who require transition.					
B2	Are young people listened to, involved and encouraged to ask questions, express opinions and make decisions?					
B3	Are key workers identified for each young person to take them forward to the next stage?					
B4	Are dedicated facilities used for young people when possible?					
B5	Is there good inter-agency and inter-disciplinary co-ordination across statutory and voluntary sector, and adult/paediatric services?					
B6	Are training needs of both adult and paediatric providers considered?					
<p><b>● Proactive Planning</b></p>	<p><i>Every young person with a life-limiting or life-threatening condition has a right to plan proactively for their future.</i></p>					
C1	Does transition planning continue during times of uncertainty?					
C2	Are young people and their parents helped with the transition from family-centred to young person-centred care?					
C3	Does every young person have a key worker within children’s services to facilitate continuity of care and a key worker designate in adult services to prepare the way into adult services?					
C4	Is every young person supported to consider future plans, which are supported by a full multi-agency assessment?					
C5	Does every young person have an appropriate reciprocal service identified in adult services?					

Goal number	Goals and Standards	Were these goals and standards achieved?				
<p><b>● Multi-agency Care Plan</b></p>	<p><i>Every young person has a timely multi-agency plan for an active transition process to take place within an agreed time frame. A co-ordinated care plan is developed to meet the young person's individual needs. A key worker and adult key worker designate are identified to work alongside the young person/family to facilitate this process.</i></p>	Yes, always	Yes, most of the time	Yes, sometimes	Rarely	No never
D1	Does an appropriate holistic care team take over the young person's therapy and care needs?					
D2	Are person-centred co-ordinated care plans developed?					
D3	Is appropriate funding identified to enable transition?					
D4	Is transition a planned and staged process?					
<p><b>● Multi-agency team support</b></p>	<p><i>The young person is appropriately supported in adult services, with multi-agency team fully engaged in facilitating care and support. There is confidence from the young person, family and professional perspective in the future plan and provision of care.</i></p>					
E1	Is there an overlap of the care team and resources until sustainable adult services are established?					
E2	Are young people kept out of hospital (where possible)?					
E3	Is transportation facilitated?					
E4	Is progress evaluated?					
<p><b>● End of Life Care</b></p>	<p><i>When end of life is recognised there should be a review of the young person and family's needs and goals and an end-of-life plan drawn up. This should be a multi-disciplinary/multi-agency meeting with the active involvement of the young person and family. The meeting should take place within two weeks of recognition of end-of-life approaching or sooner if the young person's death appears imminent.</i></p>					
F1	The young person's emotional, cultural and spiritual needs should be met.					
F2	The young person and family should feel reassured that pain and other symptoms will be dealt with effectively.					

Goal number	Goals and Standards	Were these goals and standards achieved?				
<p>● <b>End of Life Care</b> (continued)</p>	<p><i>When end of life is recognised there should be a review of the young person and family's needs and goals and an end-of-life plan drawn up. This should be a multi-disciplinary/multi-agency meeting with the active involvement of the young person and family. The meeting should take place within two weeks of recognition of end-of-life approaching or sooner if the young person's death appears imminent.</i></p>	Yes, always	Yes, most of the time	Yes, sometimes	Rarely	No, never
F3	The young person and family should feel reassured that their death will take place according to their wishes in their place of choice wherever possible.					
F4	Family members and other carers should be supported, informed and involved.					
F5	The young person should have the best quality of life and care to the end.					

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.

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