

‘How to’ guide: moving on to adult care services - young people with life-limiting and life-threatening conditions

Based on the ACT Transition Care Pathway

Introduction

This guide outlines the key issues for young people with life-limiting and life-threatening conditions. It sets out what the main barriers are, an overview of good practice and a range of practical ideas and resources.

Key issues and principles

This pathway was developed in response to

- growing evidence of the unmet needs and growing numbers of young people living with a life-limiting condition into adult years (estimated to be 6-10,000 young people in the UK).
- growing evidence of the poor outcomes for young people with complex and life-limiting conditions.

Research conducted with young people with life-limiting and life-threatening conditions is consistent. It shows that the issues they face are the same as those affecting all adolescents and young adults in the United Kingdom. They are concerned with relationships, friendships, sex, fitting in and being different, being independent, going out, experimenting with alcohol, and with their desire for privacy. All of these are natural concerns but more difficult to achieve with conditions requiring a high level of nursing input, such as help with mobility or with feeding. In addition to the desire to be treated first and foremost as a young person, other issues that relate to their palliative care needs present important challenges. Research evidence again shows consistently that service provision differs between different locations and even within the same locality. These differences are accentuated when a child has outgrown paediatric services and the young person may need to enter services designed for older adults or the elderly.

ACT recognised the gap between policy directive and practice and developed the Transition Care Pathway to fill this gap. The ACT Transition Care Pathway was developed with parents and young people and other “grassroots” experts from the outset and it is a part of the ACT Care Pathway series. The published Care Pathway is a generic off-the-shelf version and is designed for local areas to personalise, taking into account their local culture, population needs and local service capacity.

Alongside the Transition Care Pathway, a DVD called *Talk About Change* was produced, in conjunction with The Kosh (a film production company), to provide first-hand real stories from young people of the issues that matter to them.

Barriers

Young people and their families identified the following barriers to a good transition to adult services:

- Other people taking control
- A lack of review and reflection during the transition process
- Lack of coordination
- Poor communication
- Failure to respond to cultural and spiritual issues
- Lack of emotional support
- Lack of practical support

It is also recognised that there is a lack of planning of services to meet the needs of young people, often based on a lack of knowledge about the numbers and needs of young people with life-limiting and life-threatening conditions.

How to turn it into good practice

The Transition Care Pathway recognises three phases of care:

- Recognising the need to move on
- Moving on
- End of life.

It sets out six standards that should be developed as a minimum, with the aim of achieving equality for all young people and families, wherever they live and whatever the young person's condition. The template should also be helpful to young people and families so that they can clearly identify the stages along their journey and the points at which this care could be better planned or co-ordinated. A series of key goals have been set out within each of the six standards. These goals can be worked on together across agencies and within paediatric and adult services.

The document aims to facilitate the development of care pathways for young people with all types of life-limiting and life-threatening conditions in all settings. There is a key shift in the approach that is recommended in the pathway, from family-centred care to young person-centred care. The needs and wishes of young people should be central to the planning process, whilst also acknowledging the support and emotional needs of families. Young people should be empowered to take a proactive part in the planning of their care.

Transition from children's palliative care services to adult services has been problematic in the past and for this reason ACT developed its Transition Care Pathway and an associated Audit Tool to help organisations work better together to

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improve the experiences of life-limited young people. ACT also acknowledged the difficulties in changing approaches to service design and delivery and appointed 14 part-time Transition Co-ordinators to work across each Strategic Health Authority in England and in Scotland, Northern Ireland and Wales to help to stimulate the change in services that was needed. The aim of the roles is to improve the care of young people with life-limiting and life-threatening conditions by facilitating and supporting the development of improved transition services through the implementation of the ACT Transition Care Pathway. This will mean ensuring that all key stakeholders are engaged in the process – from both children’s and adult services and across all sectors and agencies. It will also involve raising awareness locally of the needs of young people with life-limiting conditions and of the value of the care pathway approach.

Practical ideas

Think about using the audit tool which has been developed to use alongside the Transition Care Pathway to identify gaps in local service provision and help to identify priority areas for service development. The audit tool is available on the ACT website. www.act.org.uk/index.php/policy/transition-care-pathways-standards.html.

At local level consider:

- What are the must do’s?
- How can all services inter-relate e.g. Local Government, NHS and voluntary sector?
- How can adult & children’s services inter-relate
- Does this pathway fit the local pattern for care pathways?

Top tips

- Identify potential partners in taking forward a care pathway approach
- Involve your local ACT Co-ordinator in a meeting to bring all services together
- Consider the roles all agencies and services play in the transition of young people to adult services
- Identify the barriers to making transition work
- Set time aside to work together
- Involve young people
- Explore what works in other areas
- Share good practice
- Start with a “can do” attitude

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- Identify resources which could support transition activity e.g. art facilities in adult services which might be of interest to young people

Good practice ideas

- Try to get involved in training opportunities e.g. GP training
- Think about developing a transition “champions” network to share ideas
- Develop a local newsletter to share good practice and new ideas/requests for service solutions
- Look at working across traditional boundaries e.g. working with colleagues in Learning Disability services

Key policy and legislation

Better Care, Better Lives, Department of Health, 2008

End of Life Programme, Department of Health, 2007

Gold Standards Framework for Palliative Care, Department of Health 2007

Liverpool Care Pathway for the Dying Patient, 2007

Transition: Moving on Well, Department of Health 2008

Transitions - young adults with complex needs. Social exclusion unit, ODPM. 2005

Organisations and websites

ACT (The Association for Children’s Palliative Care), Children’s Hospices UK, Help the Hospices and the National Council for Palliative Care are national charities that all have a specific interest in palliative care. They have formed a Transition Partnership to coordinate and steer the work of these partner organisations in their approach to transition issues relating to life-limited or life-threatened young people and their families.

ACT: www.act.org.uk

Children’s Hospices UK: www.childhospice.org.uk

Help the Hospices: www.helpthehospices.org.uk

National Council for Palliative Care: www.ncpc.org.uk

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Useful resources

For further information about Transition Co-ordinators and their roles, please contact Katrina McNamara-Goodger katrina@act.org.uk

A trailer of The Kosh DVD *Talk About Change* can be viewed and the full version can be ordered from: www.talkaboutchange.co.uk/

Produced by ACT for the national transition support team

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See page 6 of this leaflet for more information about ACT.

To find out more about the national transition support team and the Transition Support Programme see the website.

www.transitionssupportprogramme.org.uk

Information about ACT

ACT is the only organisation working across the United Kingdom to achieve a better quality of life and care for every life-limited or life-threatened child or young person and their family.

ACT has four main strands to its work:

Campaigning for integrated, equitable and sustainable services for children and young people's palliative care services. This is achieved through lobbying, membership of national advisory groups and partnerships and the production of reports and research that highlight the needs of children and young people with life-limiting or life-threatening conditions. For example, data on the numbers of children and young people with life-limiting and life-threatening conditions has been incomplete and has hampered effective commissioning of services. The Mapping Project, led by ACT in partnership with Children's Hospices UK, will enable the collection of robust real-time data on the numbers and locations of children and young people requiring palliative care as well as the services available in each region to support them.

Working with professionals to develop best practice and disseminate the evidence. For example through supporting children's palliative care networks across the country, hosting conferences, providing training and publishing guidance documents, such as:

- *Multi-agency Care Pathway for Children with Life-limiting conditions and their Families*, which facilitates joint working between different organisations to deliver better services based on the child and family's needs.
- *Guide to the Development of Children's Palliative Care Services*, which sets out the statistics, definitions and guidance for commissioners and providers on what constitutes an effective children's palliative care service.
- *Right People, Right Place, Right Time*, an education and training framework developed in partnership with Children's Hospices UK to enable the development of an effective and sustainable children's palliative care workforce.
- *PaedPalLit*, a bi-annual summary of research in the field which is available as a printed journal or as an online search.
- *Let's Talk about Sex*, ACT guidance on sexuality, relationships and sexual health.

Empowering children, young people and their families, to have a voice in the development and provision of appropriate palliative care services. ACT believes that children and young people should be at the centre of the planning of their own care package and at the centre of ACT. A *Family Companion to the ACT Care Pathway* was published in May 2009 to provide families with an overview of the professionals and services that they are likely to encounter on their care journey and provide them with tips to gain the best from the system.

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Information giving to families, children, young people and professionals. A national helpline service is available Monday to Friday, 9am to 5pm, providing support on a range of practice innovations and information on sources of support and services across the UK. This information is also available to search online on ACT's website.

ACT website: www.act.org.uk