



The Association for Children's  
Palliative Care

## The Transition Care Pathway

A Framework for the Development of  
Integrated Multi-Agency Care Pathways  
for Young People with Life-threatening  
and Life-limiting Conditions

April 2007

‘The differences between young persons and adults make a simple extension of adult palliative care to young persons both inappropriate and ineffective. Young persons are not just ‘little adults’, and care givers skilled in the care of dying adults generally lack the expertise to deal with the unique medical and psychosocial needs of young persons.’

Morgan & Murphy (2000)

Endorsed by the Royal College of Nursing



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We have not included a named acknowledgement of all the young people, as many asked ACT not to do so.

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A journey is what the family take... A pathway includes all the resources required to make that journey... Journeys have ends... They are not black and white...

Transitional care must involve young people, their families and /or carers as well as paediatric and adult care providers in health, education, social services and the voluntary sector.

McDonagh (2006)

## Foreword

The journey from childhood to becoming a fully independent adult can be a challenging one for both young people and their parents and carers. The addition of a life-limiting or life-threatening condition adds a complexity to what is already a difficult time.

The needs of children and young people as they approach this phase in their lives is compounded by the need to make a break from the comfort of familiar children's palliative care to adult services. The specific needs of young people during this transition must be recognised, and special thought should be given on how to provide for them, as well as ensuring as smooth a transition as possible.

This new ACT Transition Care Pathway draws on the strength of ACT's original Care Pathway, and provides an easy to use, clear framework for helping young people, families and professionals to adjust to, prepare for and move-on to adult services. It emphasises the importance of empowering young people to take control of their lives, and calls for an early collaboration of paediatric and adult services to improve transition.

Sadly, for many young people with life-threatening conditions, transition into adult services often coincides with a rapid decline of their condition and eventual death. ACT's Transition Care Pathway concludes with an "end-of-life" pathway, to help young people, carers and professionals to prepare for the young person's death. It aims to help young people prepare to die with dignity and for the family to have a positive memory of their life, dying and death.

In approaching transition we must develop a new approach, and where possible enable and empower young people to take the lead in mapping their future. There needs to be a significant shift towards recognising the legal autonomy of young people.

I applaud ACT's pioneering work in developing this essential resource and am delighted to offer my endorsement, and urge service providers across children's and adult palliative care, and all other statutory and voluntary agencies involved, to adopt this essential transition framework.

**Ivan Lewis MP**

Parliamentary Under-Secretary of State, Department of Health

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# Introduction

## Introduction

ACT has produced this Transition Care Pathway to provide a generic framework that can be adapted locally to plan services for young people with life-threatening or life-limiting complex conditions. In 2001, ACT identified the many distinct needs that these young people have in its report 'Palliative Care for Young People, Aged 13-24'. Much of what was identified and described in this report holds true today and as the population of young people with life-limiting conditions grows and will continue to grow, it is vital that these needs are addressed and planned for.

These young people deserve to enjoy as normal a life as possible, with the same opportunities as their peers. When the end of their life approaches they deserve to die with dignity and with their choices fulfilled where possible. This Pathway will enable young people, families, service providers and commissioners to work together in one joined-up planning process to enable this to happen.

We hope that you will find this Pathway a useful tool. If you have any comments or suggestions or would like support in its implementation, please do contact us.

# Executive Summary

## Background to developing the Transition Care Pathway

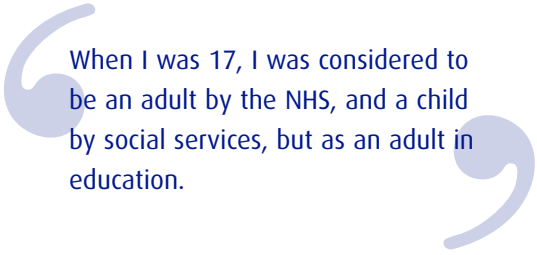
- This transition pathway was developed in response to the growing evidence of the unmet needs and growing numbers of young people living with a life-limiting condition into adult years. There is growing evidence of the poor outcomes for young people with complex and life-limiting conditions.
- ACT published a Multi-Agency Care Pathway for Life-limited Children in 2004, which set out a template for those working with all life-limited or life-threatened children in all settings. This transition pathway has been developed to complement this original pathway for children and can be used to link young people and families with all services in one joined up planning process.
- The process used in developing this pathway was similar to that used in the creation of the first care pathway. A working party was set up of representatives from both adult and children's services to develop the structure of the pathway and provide the content material. The pathway was divided into three sections: recognition of the need to move on; moving on; and end-of-life. Three chairs were appointed for each of these sections; working group members were allocated to one of these sections and there was an overall chair of the whole working group. A first draft of the transition pathway was developed and this was sent out for consultation to a wide group of experts, parents and young people for comment.
- It was felt very important to involve young people in the development of this pathway and a series of focus groups were facilitated. At these focus groups issues were raised and personal experiences were described of growing up with a life-limiting condition. This pathway contains many of the quotes and ideas that arose from these focus groups.
- Along with this pathway document a DVD called "talk about change" is being 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.

## The Transition Care Pathway

- The document provides a template to develop local care pathways based on local need and local service capacity. The planning of local pathways can be effectively undertaken by local strategic level networks as the process will inevitably involve close co-operation and co-ordination between professionals from both adult and children's services.
- The template sets out six sentinel standards that should be developed as a minimum, with the aim of achieving equity for all young people and families, wherever they live. 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 sentinel standards. These goals can be used across agencies within paediatric and adult services to work towards achieving them.
- It is acknowledged that there is wide variation in the availability of services across the country. In particular access to short break care that is appropriate for young people and to 24-hour cover in the home. The pathway and its standards aim to facilitate better planning for improving provision of these services.
- 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 part in the planning of their care.
- A vital component of the transition pathway is to ensure that there is good co-ordination of the transition process between paediatric and adult services. This pathway recommends a new key worker designate role within adult services to gradually take over the child's key worker role to ensure smooth transition.

## Executive Summary

- In the past ACT has recommended good co-ordination between professionals through multi-disciplinary working. Within adult services, the term “inter-disciplinary” is frequently used. Inter-disciplinarity is typical of palliative care which has a holistic approach with different disciplines cross-working and professionals willing to hand over to a colleague for their particular expertise. This pathway recommends that multi-disciplinary as well as inter-disciplinary approaches are taken at different points in the pathway.
- ACT’s report Palliative Care for Young People, aged 13-24 estimated that there were between 6,000 and 10,000 young people living with life-limiting or life-threatening conditions. This figure had been extrapolated from all major research studies that had been undertaken at that time. At the time of going to press, new statistics were being produced by the Department of Health that indicated the numbers of children with life-limiting or life-threatening conditions, were at the upper end of the range of 1.2 to 1.6 per 10,000, that had been suggested by ACT. It has yet to be identified how many of these will be in the 13-24 age group.



When I was 17, I was considered to be an adult by the NHS, and a child by social services, but as an adult in education.

# Part 1 | Background

## 1.1 Palliative care

### 1.1.1 Definition of Children's Palliative Care

Palliative care for children and young people is **"An active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite and care through death and bereavement."**

(ACT/RCPCH, 1997/2003)

Palliative care is an approach that improves the quality of life of patients and their families through early identification and a thorough assessment of needs. It begins at the time of diagnosis.

### 1.1.2 Children's palliative care - Supporting values

ACT recommends that all children's and young people's palliative care services are underpinned by a number of supporting values. Where palliative care:

- Is the active total care of the young person's body, mind and spirit; and support to the family.
- Begins when a condition is diagnosed, and continues regardless of whether or not a young person receives treatment directed at the disease.
- Includes assessment and alleviation of a young person's physical, psychological, and social distress.
- Adopts a broad multi-disciplinary or inter-disciplinary approach that includes the family and makes use of available community resources.
- Can be provided in tertiary care facilities, in community health centres, in residential schools and colleges, and in young persons' homes.
- Includes the provision of effective communication and information to help in decision-making.
- Provides relief from pain and other distressing symptoms, with frequent review.
- Enables access to ongoing education and employment opportunities wherever possible and appropriate.
- Respects cultural, religious and spiritual beliefs.

- Ensures that a key worker is appointed and reviewed.
- Provides practical support throughout the transition pathway.

Families who have experienced the unexpected death of a child in adolescence should also have access to a bereavement pathway.

The care team should be offered ongoing support and clinical supervision with access to ongoing training and education.

## 1.2 Introduction to care pathways

### 1.2.1 Definition of Care Pathways

Care pathways are a relatively recent concept that has developed in response to the need for services to be more patient-focused. Pathways often concentrate on the treatment and care of people with specific diagnoses. The original ACT Care Pathway (2004) takes a more generic approach and is a framework that can be used to develop local care pathways for children with all types of life-limiting or life-threatening conditions in all settings. The pathway aims to link children and families with community services, hospital based services, social services, education and the voluntary sector in one joined up planning process. This transition pathway for young people has been developed to complement ACT's original pathway document.

### 1.2.2 Principles for the Development of Integrated Care Pathways

- They must be developed and "owned" locally by a multi-disciplinary team.
- They can cross organisational and inter-agency boundaries.
- They include a plan of anticipated care for an identified group.
- They make the patient the focus and allow for variation when appropriate.
- They incorporate evidence or research-based standards or guidelines.
- They include systems for rigorous record-keeping.
- They include measurement of outcomes and promote continuous quality improvement.

## Part 1 | Background

### 1.3 What do we mean by transition?

#### 1.3.1 Definition of Transition

There are many types of transition, but this care pathway is focussed on the important transition from child to adult services.

The Department of Health (England) has published useful generic guidelines for the transfer of young people's care from children's to adult services and suggest the handover should be planned and managed as a process, for which the term 'transition' is more appropriate. The guidelines suggest how this can best be accomplished in the context of the evidence base and suggest a definition of transition as follows:

'...a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems.'  
(Blum RW et al, 1993)

There is increasing recognition of the particular challenges faced by young people and their families in the process of transition. There is a need for seamless and co-ordinated healthcare to prevent medical deterioration or psychological distress, alongside help in managing social, education and employment opportunities and challenges as well as independent living skills and self care where appropriate. There is increasing evidence of the link between 'good transition' and better outcomes for young people, as stated in the DH (England) Guidelines:

"Good transition programmes improve outcomes. Changes in morbidity and mortality following improved transition processes can only be measured with large numbers and over a long time period, but there is emerging evidence that well organised transition protocols and programmes do have measurable benefits for young people and their parents".  
(Department of Health (England), 2006)

The guidelines refer to the benefits in relation to young people and their parents (Steinkamp G et al, 2001; Zack J et al, 2003; Salmi J et al, 1986) improved follow up (Rettig P et

al, 1991), better disease control and improved documentation of transitional issues (Robertson LP et al, 2006).

For young people with palliative care needs transition is particularly complex. Their independence and need to aim for personal goals are very important, but deteriorating physical health and cognitive faculties may make this a challenging prospect.

There are a number of important principles that should be central in the planning and provision of transitional care:

- Involvement of young people in decision-making.
- Flexibility and choice.
- Continuity of support.
- Anticipation of needs.
- Individually tailored plans.

#### 1.3.2 What works?

We know that services which successfully manage the challenge of moving from children's to adult services include:  
(Beresford, 2004)

For young people:

- specific service provision
- development of skills of self-management and self-determination
- supported psychosocial development
- involvement of young people
- peer involvement
- support for changed relationships with parents/carers
- provision of choice
- provision of information
- focus upon young person's strengths for future development

For parents:

- support for adjustment to changed relationships with young people
- parental involvement in service planning
- a family-centred approach
- provision of information

## 1.4 Who would benefit from this pathway?

All young people who may die in early adulthood as a result of a life-limiting or life-threatening condition will benefit from this pathway. There are estimated to be 6,000 to 10,000 young people living with a life-limiting or life-threatening condition (ACT, 2001).

Some of these young people will have lived with a condition since birth or early childhood. Others may have developed the condition in their teens. For some young people their condition will cause progressive intellectual deterioration, whilst others will only just be realising the life-limiting nature of their condition at the time of transition.

Most of the young people will fall into one of the following groups (ACT/RCPCH, 1997/2003):

1. Young people with life-threatening conditions for which curative treatment may be feasible but can fail. Palliative care may be necessary during periods of prognostic uncertainty and when treatment fails. Examples include cancer, or irreversible organ failures such as heart, liver or kidney.
2. Young people with conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities, but where premature death is still possible or inevitable. Examples include cystic fibrosis, Duchenne muscular dystrophy, HIV/AIDS.
3. Young people with progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Examples include Batten disease, mucopolysaccharidosis, CJD.
4. Young people with severe neurological disability, which may cause weakness and susceptibility to health complications leading to premature death. Deterioration may be unpredictable and not usually progressive. Examples include severe multiple disabilities following brain or spinal cord injuries, severe cerebral palsy.

## 1.5 The different needs of young people

The population of young people with life-threatening and life-limiting conditions is growing as many chronic

progressive conditions now reach a crisis during late adolescence and young adulthood. Many young people have conditions which were formerly limited to childhood, and there are therefore limited relevant services that have been developed in the adult sector.

“When I was 7 I couldn’t walk without support but I was OK academically. I had a teaching assistant full time and they re-designed the building. When I was 8 or 9 years old I lost the ability to walk. Well, I had things to help me walk but it was agony! I went to a mainstream secondary school. They had a new block with a lift. They planned to build a ramp but it took 5 years to do it, so it was pointless.”

Providing palliative care for young people requires detailed understanding of developmental issues, such as the young person’s physical, emotional, social and cognitive abilities. These spheres will continue to develop, despite the onset of an acute condition or progressive impairment. Providing care for young people is complex because of the interaction between physical health and emotional well being.

Nothing much happened until I was 11 and in mainstream. I didn’t get on well there, because people were different. I was bullied quite a bit.

NICE (2005) recognised that teenagers with palliative care needs require special provision, which will often entail the development of partnerships between childrens’ and adults’ services. These young people require individual packages of care that:

- Recognise teenagers and young adults as a distinct group with special needs.
- Give full involvement in all aspects of decision-making.
- Are provided by multi-disciplinary or inter-disciplinary services.
- Provide co-ordinated joint working with adult services where appropriate.
- Address specific staff training needs regarding both palliative care and the management of young people.

## Part 1 | Background

### 1.6 Issues for young people

#### 1.6.1 What young people want:

ACT carried out a series of focus groups with young people during the development of this pathway and during some earlier focus groups in 2001. Young people said that they wanted:

- To be viewed as a young person first and as being unwell as a secondary consideration.
- To receive emotional and psychological support.
- To live independently.
- To go to school or college and have a career.
- To be involved in the process of transition and make decisions about their care.
- To have leisure opportunities and develop a social life, e.g. seeing friends.
- To have opportunities to do things that other young people do, including developing personal relationships and having sexual experiences.
- Not to have to wait for services.
- To have an efficient wheelchair service.
- To have an advocate or key worker to co-ordinate services.
- To have access to short breaks that are appropriate for young people.

I could organise to go somewhere alone but for me if something goes wrong then I can't sort it out without a carer, so you have to arrange care. You can't be spontaneous. You have to plan.

#### 1.6.2 Involvement in decision-making

Involvement in decision-making is based on communication and this includes information giving, listening, discussion and negotiation. If the options are understood, a young person's personal preference should be pivotal in the planning of the future care and occupational provision or care package. With good information and support, and if they are well enough, young people can take over the organisation of their own lives – from organising daily activities to deciding to cease a particular treatment. Young people want an adult, future-

focussed approach, with long-term goals, more control and increasing self-management during their adolescent years. However, many young people with a long-term life-threatening condition will have been brought up in a protected environment and will rarely have been involved in decision-making. Even when the young person is cognitively aware, parents may find it difficult to accept that their child is old enough to make decisions for themselves. There may be a conflict if a young person under the age of 16 requests information about their prognosis, which their parents have asked to be kept from them. (Parent(s) or guardians may value and benefit from support, information and guidance in advocacy).

Negotiation and explanation of the issues is essential, even though it might be time-consuming, to help the young person (and family where appropriate) make decisions.

Advocacy services should be available for all young people who are accessing palliative care. This is particularly important for young people with learning disabilities who should be encouraged and enabled to make decisions as far as possible. It should be recognised however that the knowledge of parents or long-term carers is invaluable for those young people who are intellectually impaired or unable to express their views.

#### 1.6.3 Developmental Issues

It is important to consider the reactions and needs of young people with a life-threatening condition in the context of normal adolescence. In the past 50 years, our understanding of the sociology, social, developmental and educational psychology of young people has crystallised and there are good descriptions of the 'developmental tasks' that young people have to meet (Stevens & Dunmore, 1996). Work with this age group demands detailed understanding of the continuing rapid development in physical, emotional, social and cognitive spheres (Coleman & Hendry, 1999).

Several studies have divided this transitional period into three phases, early, middle and late adolescence. Although this is rather arbitrary and with blurred boundaries, it can help in the understanding of behaviour, relationships and the impact of a condition. The following table is derived from the work of Stevens and Dunsmore (1996).

Age	Early adolescence 12-14 years (female) 13-15 years (male)	Middle adolescence 14-16 years	Late adolescence 17-24 years
<b>Key issues &amp; characteristics</b>	Focus on development of body. Most pubertal changes occur. Rapid physical growth. Acceptance by peers. Idealism. Mood swings, contrariness, temper tantrums. Day dreaming.	Sexual awakening. Emancipation from parents and authority figures. Discovery of limitations by testing boundaries. Role of peer group increases.	Defining and understanding functional roles in life in terms of: <ul style="list-style-type: none"> <li>• Careers</li> <li>• Relationships</li> <li>• Lifestyles</li> </ul>
<b>Social/ relationships, behaviour</b>	Improved skills in abstract thought. Foreseeing of consequences, planning for future. Physical mobility prominent. Energy levels high. Appetite increased. Social interaction in groups. Membership of peer group very important.	Relationships very narcissistic. Risk-taking behaviour increases. Intense peer interaction. Most vulnerable to psychological problems.	Increasing financial independence. Planning for the future. Establishment of permanent relationships. Increasing time away from the family.
<b>Impact of life-threatening illness</b>	Concerns about physical appearance and mobility. Privacy all-important. Possible interference with normal cognitive development and learning (school absence, medication, pain, depression, fatigue). Comparison with peers hindered, making self-assessment of normality more difficult. Possible lack of acceptance by peers. Reliance on parents and other authorities in decision-making. Hospitals perceived as very disturbing.	Illness particularly threatening and least well tolerated at this stage. Compromised sense of autonomy. Emancipation from parents and authority figures impeded. Interference with attraction of partner. Fear of rejection by peers. Limited interaction with peers may lead to social withdrawal. Dependence on family for companionship and social support. Hospitalisation, school absences interfere with social relationships and acquisition of social skills. Non-compliance with treatment.	Absences from work, study. Interference with plans for vocation and relationships. Difficulties in securing employment and promotion at work. Unemployment hinders achieving separation from family and financial independence. Discrimination in employment, health cover and life insurance. Loss of financial independence and self-esteem. Concerns about fertility and health of offspring.

## Part 1 | Background

### 1.6.4 Spiritual Care

Professionals should actively work with young people and their families to acknowledge, respect and support people from all faiths, religions and belief systems. Cultural, spiritual and religious beliefs are even more important at key points in people's lives, shared family occasions or in the face of adversity. (Brown, 1994)

Spirituality is a very individual concept that means different things to different people and it is important to draw a distinction between spirituality and religion. Many people with religious beliefs are profoundly spiritual individuals but the two concepts are not interchangeable and spirituality may be equally important to an individual who has no religious beliefs. Research is also beginning to address the relationship between spiritual belief and health outcomes and it has been suggested that spirituality can contribute to both physical well-being and quality of life (NICE 2005).

Adolescence can be a time of many questions and challenges as young people begin to explore the world they live in. Professionals and others supporting young people with life-limiting or life-threatening conditions should have the necessary skills, knowledge and support to offer sensitive and appropriate spiritual care and support throughout the young person's life and following their death.

Families from different faith backgrounds will have a variety of religious, spiritual and cultural needs that will need to be respected and catered for at all points along the pathway of care (Brown, 2006).

### 1.7 Issues for parents and carers

**Emotional Issues** Adjusting to a child getting older can be exciting but more often, because it necessitates change, it can be anxiety provoking, emotionally difficult and physically exhausting. The transition from adolescence to young adulthood, with the change from familiar child services to adult services raises many practical and emotional issues for parents.

Many parents cope by doing as much as they can for their child so that their life is as rich and full as possible. Many will inadvertently have become very protective and this can often cause conflict when the young person wants to take

risks for themselves and become more independent.

This can be very hard for parents at a time when their child's condition may be deteriorating, their physical dependence increasing and their peer group shrinking.

*I may be young, but in terms of my condition I am old.* 13 Year old girl

Whilst seeking out new experiences young people and parents will also have to come to terms with many things that they may never be able to do, such as driving a car or being a parent.

Transition to adult services will mean new systems to learn about and new battles to fight. The move away from familiar paediatric services can be a very real loss to come to terms with.

Grief is not a static emotion but an ongoing process that manifests in varying ways at different stages and at different times. For example, the acute time around diagnosis can be very painful as the implications of what lies ahead become apparent. As the condition progresses it can be equally painful to realise that a young person is starting to lose skills that they once had.

Parents will be dealing with their own losses and ongoing grief, as well as concerns over their ongoing caring role as they become older and their child becomes more aware of their own deterioration.

On-going grief takes its toll on the whole family.

### 1.8 Issues for siblings/young carers

Many siblings assume the role of carer and find that as their brother or sister approaches adulthood the demands on them became greater. The Office for National Statistics (2001) estimates the number of young carers at 175,000, whilst the Children's Society considers this to be the tip of the iceberg (Frank, 2002).

One in ten young carers care for more than one person (Becker et al, 1998), which is particularly likely when there is an inherited condition in the family.

It should however be noted that there are positive as well as negative consequences of being a young carer (McClure, 2001). 'However much hard work it is. It's always worthwhile for the smiles and looks he gives me.' (Bibly & Becker, 2000)

Siblings will be under huge emotional strain and may struggle to understand what is happening to their brother or sister and the impact that this is having on their parents. They may try to minimize their own needs or may assert them loudly to get themselves heard.

Transition planning must take account of the needs of siblings and the contribution that they make to the family. Their vital contribution is often overlooked until they leave home themselves and the family find they can no longer cope.

For siblings who have assumed a caring role there may be pressure from themselves or their family to put their own life on hold (e.g. not going away to University or college), but they need to prepare for life without their sibling and should be encouraged to move on in their own life.

Proactive work with siblings to support and prepare them for the transition period and inevitable changing dynamics in the family should be integral to planning and service delivery. This may include one to one work with siblings as well as opportunities to share experiences and test out feelings with peers at sibling groups and social events. Schools and colleges can offer invaluable support, advice and a place for young people to express their views safely, if involved as part of the multi-disciplinary team.

Useful organisations:  
[www.carersuk.org](http://www.carersuk.org)  
[www.sibs.org.uk](http://www.sibs.org.uk)

## 1.9 Issues for service providers

**Letting Go** When services and individuals have known and worked with a young person and their family for a number of years, they can find the notion of 'letting go' and transferring their duty of care very difficult. This is often exacerbated when it is not clear exactly who will be taking on the caring role and doubts over whether the care will be as effective.

The young person and family may also be unwilling to open up to the possibilities offered by new and unfamiliar people or services.

If the young person is experiencing a period of degeneration or thought to be entering the end of life stage, professionals will have their own feelings of loss and may be finding it difficult to plan for the young person's effective transition to adult services whilst also planning for the young person's death. This process of planning for both eventualities is called parallel planning.

These factors, although understandable, can hamper the process of transition and prevent real exploration of suitable alternatives and the formation of partnerships with adult services that would be in the best interests of the young person and family.

Both paediatric and adult care professionals need to be supported and trained so that they are able to develop an understanding of working practices and establish effective working relationships. Services need to be flexible, supportive of each other and willing to adapt to new ways of working with different clinical skills.

She advocates to different services to try to pull them together. There is lots of disparity in what they know about me and what they think they need to do. They often clash and oppose each other, and a lot of them are completely naïve – they think their service is the only important one when in fact they are all important, and if one makes a decision it can make all the others go wrong. There is lots of wrangling and upset and my parents have got very stressed.

There should be someone central who can advocate... It's much better to have someone trying their best to get what you need – not pass the buck or say, 'You're a child so we can't do that', or 'you're an adult so we can't do that'.

## Part 2 | The Transition Pathway

### 2.1 Entry Stage: Recognising the need to move on

(See Diagram 1)

#### 'A Stage not an Age'

There is no one 'right' time or age for transition from children's services to adult services. Rigid age limits to define the boundaries of paediatric and adult services are unhelpful, other than to demarcate funding issues. The timing of transition should depend on the health and developmental stage of each individual young person as well as the capacity of the adult providers. It is important that transition planning begins in good time and the process should have started by the time the young person is 14 years old. Young People with disabilities may already be thinking about transition as this starts automatically for all young people with a statement (Council for Disabled Children, 2007).

It is important to provide information on the proposed transition process to young people that is appropriate to their age and developmental level and takes into account their communication needs. They should be enabled to manage their condition themselves with a full understanding of the implications of their condition, how it can be treated and how this will impact on other areas of their life.

Parents should feel reassured that the transition process will enable the young person to retain close relationships with family members, whilst promoting their own resilience and independence.

'The challenge to health care providers is advocating for the young person while remaining inclusive of the parents. In the context of life-threatening illnesses it is particularly important for health professionals to be aware of the executive role of the parents and avoid any marginalisation of young people in the development of therapeutic alliances.'

#### 2.1.1 STANDARD 1: Sharing significant news

**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.**

#### Key goals

1. News should be shared in a face-to-face discussion in privacy.
2. Families should be together to receive the news.
3. Helpful written material should be provided and information conveyed in readily understandable language.

#### Goal 1: News should be shared in a face-to-face discussion in privacy

Plenty of time should be made available for a face-to-face discussion, including opportunities to ask questions at the time and afterwards. Young people and their families should be treated with openness and honesty.

#### Goal 2: Families should be together to receive the news

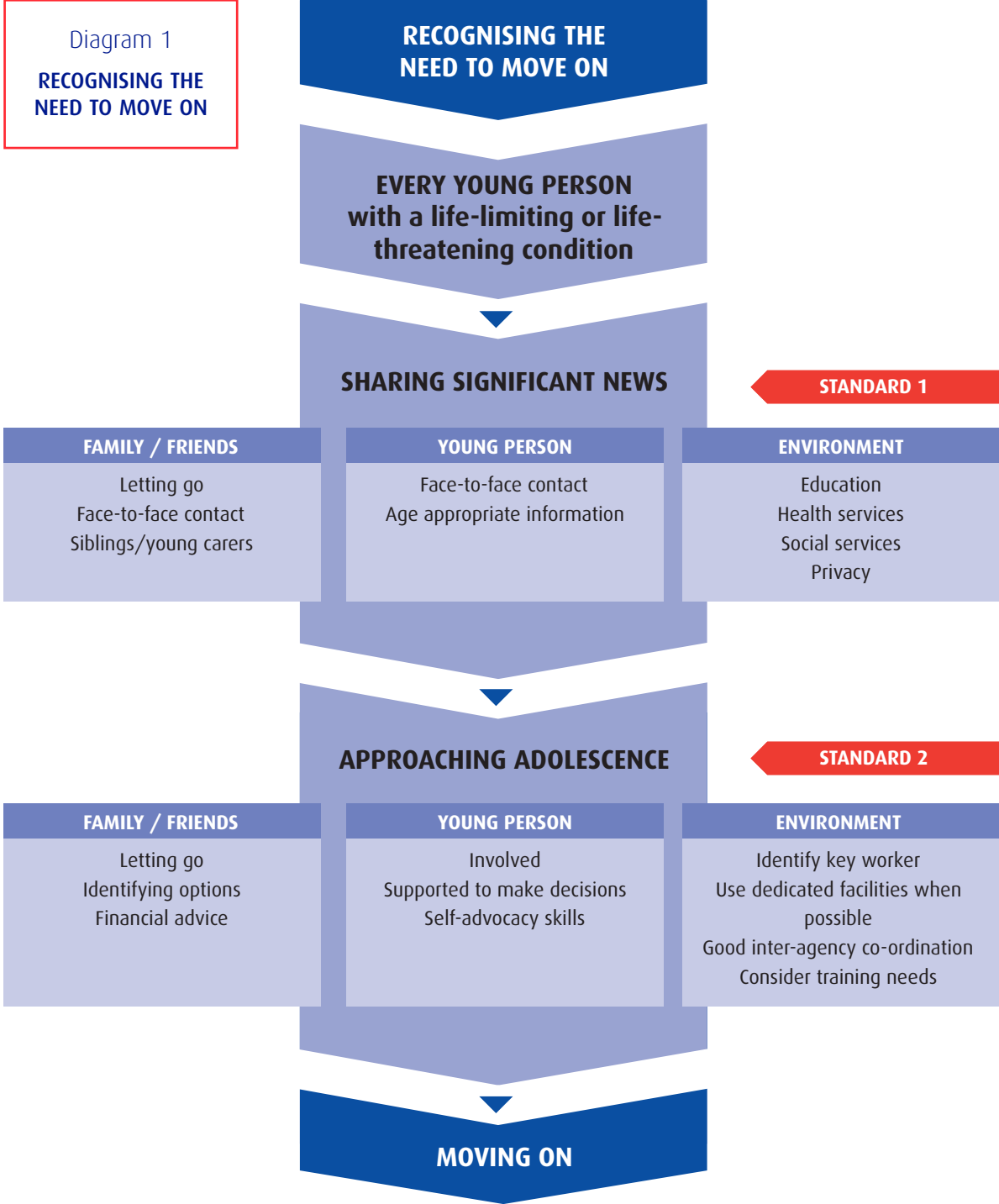
News should be shared in a place that ensures complete privacy. Young people and their families should be together to receive the news. If not possible, every effort should be made to ensure that another relative/friend is present to support the person hearing the news first. Parents should be acknowledged as experts in the care of their child. Young people should be supported in decision-making, which may necessitate additional support to ensure the involvement of young people with communication difficulties.

#### Goal 3: Helpful written material should be provided and information conveyed in readily understandable language

Written material should be provided as a supplement to, but not a substitute for, direct communication. Information should be conveyed in readily understandable language, using a skilled interpreter where necessary who had been trained to give sensitive information. Information appropriate to a young person's age and understanding should be provided.

I was diagnosed when I was three. My mum was pregnant with my sister... it was a bit worrying for my parents, they were very upset. They didn't know how I got the condition, and they thought it might be genetic, and there were tests, but they were inconclusive.

Diagram 1  
**RECOGNISING THE  
 NEED TO MOVE ON**



## Part 2 | The Transition Pathway

### 2.1.2 STANDARD 2: Approaching adolescence

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 is 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 on to adult services from their 14th birthday.

#### Key goals

1. Transition should be an actively managed process.
2. Young people should be listened to, involved and encouraged to ask questions, express opinions and make decisions.
3. A key worker should be identified for each young person to take them forward to the next stage.
4. Dedicated facilities should be used for young people when possible.
5. There should be good inter-agency and inter-disciplinary co-ordination across statutory and voluntary sector and adult/paediatric services.
6. Training needs of both adult and paediatric providers should be considered.

#### Goal 1: Transition should be an actively managed process

There should be timely planning and preparation for the young person to leave children’s services and enter adult services. Systems should be in place to ensure that young people are identified as they approach adolescence and that a key worker is appointed to lead transition.

#### Goal 2: Young people should be listened to, involved and encouraged to ask questions, express opinions and make decisions

There should be a move towards young person-centred care with an awareness that attitudes, thinking and behaviour will vary between individual young people.

#### Goal 3: A key worker should be identified for each young person to take them forward to the next stage

A key worker should be identified in a timely manner for each young person to facilitate their progress to the next stage. Agencies should ensure that a trusted adult is available who can act as advocate for the young person and help them to develop self-advocacy skills.

#### Goal 4: Dedicated facilities should be used for young people when possible

Dedicated services for young people are scarce, but where available should be accessible to young people.

#### Goal 5: There should be good inter-agency and inter-disciplinary co-ordination across statutory and voluntary sector and adult/paediatric services

Good co-ordination and joint working between agencies and disciplines is critical. This should be across the statutory and voluntary sector as well as adult and paediatric services to minimise the disruption to continuity of care. A shared philosophy should be established between adult and paediatric care providers. This will involve sharing information about services, communication about individual cases and developing lines of accountability, ideally within a supportive strategic network.

#### Goal 6: Training needs of both adult and paediatric providers should be considered

Both adult and paediatric professionals will need training in relation to providing care for young people with complex and palliative health needs.

On my 19th birthday I will change from being with social services for children to social services for adults. When I change, I am going to be needing 24-hour care. Me and my parents have decided that it will be best if they stop being my carers so somebody else more trained will step in. I want to leave home. I want to live in an independent situation. At 19, technically I will be homeless, applying for a university place.

## 2.2 Stage 2: Moving on

(See Diagram 2)

Once the transition phase has been identified and initial discussions have taken place a three to four year process commences which we have termed 'Moving on'.

There are two underpinning themes:

1. Proactive planning for the future.
2. A change of focus from family-centred care to a young person-centred approach (Valuing People, 2001).

When considering transition in palliative care it is important to consider the breadth of conditions that may necessitate palliative care (see the four ACT groupings of conditions on page 11). Within these groups transition needs will vary from well-defined conditions with clear reciprocal adult services (e.g. cancer), to those with no diagnosis and a complex set of physical and learning needs with no clear reciprocal adult service. With this level of complexity any pathway will need sub pathways to support such diverse needs. The three standards used in this stage of the pathway are key generic standards that should be applied across this range of need.

### 2.2.1 STANDARD 3: Proactive Planning

**Every young person with a life-limiting or life-threatening condition has a right to plan proactively for their future.**

#### Key goals

1. Transition planning should continue even during times of uncertainty.
2. Young people and their parents will be helped with the transition from family-centred to young person-centred care.
3. Every young person will 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.
4. Every young person will be supported to consider future plans, which are supported by a full multi-agency assessment.
5. Every young person will have an appropriate reciprocal service identified in adult services.

### Goal 1: Transition Planning continues even during times of uncertainty

**Parallel Planning.** By late adolescence many young people may have higher care needs due to the increasing instability and degeneration of their condition and the possibility that they are entering end-stage care. This adds another dimension to transition planning for this group of children and young people.

Effective transition planning should commence at the academic year nine (age 14) and plans should be in place by the time the young person reaches late adolescence. This may or may not coincide with the end stage of their lives. End-stage care as recognised by this pathway is not always easy to identify and the temptation can be for the focus to turn to end-of-life needs of the young person and to lose the focus on the young person's future.

Transition planning can feel inappropriate as significant and frequent episodes of instability will often appear to be the approach of end-of-life and that there will therefore be no need to plan for the young person's life in adulthood. Such periods of instability can come and go many times before the final end-of-life phase occurs. Service providers may discontinue or put on hold arrangements for transition, which, although appropriate for some young people, will for others mean that placements and other opportunities are lost. Such young people can lose a sense of purpose for the future. Young people who come through periods of instability often 'plateau' for a significant time in their condition.

Parallel planning is a concept, which aims to support the ongoing transition arrangements for young people. In parallel planning, arrangements made for transition continue to be advanced alongside care planning for the possibility that the end stage will be reached. Placement opportunities are held and adult teams are utilised to support children's teams during a gradual handover process. If end stage care is reached then both children and adult services can work together. If the young person stages a recovery, opportunities remain open and relationships with the adult team will have strengthened as will their confidence in supporting the young person when end stage care is next required.

## Part 2 | The Transition Pathway



### Case Example – Parallel planning

'Billy was never expected to survive into adult life. Billy lived with his mum and younger brother. Billy's mother now had significant medical needs herself having devoted herself to Billy's care expecting every day to be the last. The end of schooling represented an increase in the burden of care that was beyond Billy's mother's abilities.

Transition planning had started late but was now well advanced with adult district nurses fully involved and a private agency trained up to deliver care in and out of the house.

Billy's condition suddenly deteriorated and end stage care was commenced. Adult and children's services worked together enabling a significant level of care to be delivered. Billy confounded expectations and returned to his normal self. Billy and his mum had a real confidence in their new care team and transition completed shortly afterwards.'

Advanced care planning for the degeneration in the young person's condition and the end of life should continue in parallel to transition arrangements. The young person needs to be supported to access opportunities and achieve personal goals. Similarly family members need support to plan for their needs and wishes. The young person and their family will benefit from opportunities to articulate and discuss their preferences and choices about place and type of future care, with the appropriate information available to enable them to make these decisions and choices.

**Goal 2: Young People and their Parents will be helped with the transition from family-centred to young person-centred care.**

**Moving to Young Person-Centred Care.** Many of the young people who will need palliative care have had a long-term condition that causes progressive disabilities over time. Often young people have clear ideas about how they want to live their lives and, like any young adult, they are keen to make their own choices. As the young person approaches transition it is good practice to identify an appropriate advocate to work with them. The advocate's role is to enable them to express their wishes without fear of causing distress to their loved ones and to prevent them being coerced into making

decisions they are not comfortable with. Advocates may have an informal role or may be officially appointed to comply with legislation.

Professionals who support young people should aim to support and promote their independence and active involvement in decisions that affect the care they receive. Both professionals and parents/carers should acknowledge and respect their need for open and honest information.

Where the wishes of the young person are in conflict with those who have parental responsibility the situation should be handled with sensitivity, with support provided for all parties to enable them to feel valued and respected. Professionals and families are often unaware of the current legal position, which at time of going to print will be changing due to the introduction of the Mental Capacity Act, which comes into force in April 2007.

Now I make more decisions for myself. The college has helped me make them. They used to make choices for me.

This Act states that anyone over 16 years of age must be assumed to be competent to make their own decisions, and that they must be given any support they need from professionals in order to do so. The individual may nominate someone to make decisions on their behalf in the event that they lose their capacity to do so. This person will have "Lasting Power of Attorney". If an individual is not competent to make their own decisions, professionals will make decisions on their behalf, on the basis of 'best interests'. Whilst family members will be consulted on their views, these are not legally binding. This process can be very challenging for families.

**Goal 3: Every young person will 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.**

The role of a key worker is an identified standard in ACT's Integrated Multi-agency Care Pathway for Children with Life threatening and Life-limiting Conditions (2004) and has been a recommendation in all of ACT's previous publications. The role has been widely recommended in a variety of

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government and voluntary sector guidance (Every Child Matters, 2003; National Service Framework for Children, 2004. Care Co-ordination Network UK has developed a definition of key working and a set of key worker standards (CCNUK, 2007), which have been endorsed by the Department of Health (England).

### The role of the key worker should include:

- Regular proactive contact with the young person and their families
- Offering support
- Giving information and advice
- Coordinating effective and timely service delivery
- Acting as an advocate  
(Barton & Clark, 2005)

### Useful Organisation:

Care Co-ordination Network UK  
Website: [www.ccnu.org.uk](http://www.ccnu.org.uk)

### Effective key working can be achieved by:

- A supportive, open relationship based on respect for the views of parents, children and young people.
- A family-centred (not only a young person-centred) approach.
- Working across agencies – including agencies such as housing, leisure and the benefits agency. Key workers need to know what different agencies offer and how to go about accessing them. It is important that managers see this as an integral part of the key worker's role.
- Working with the families' strengths, acting as an advocate or enabling parents, children and young people to access advocacy support as required.
- Provision of induction training and on going training and development for key workers.
- Regular supervision of key workers, including both professional/clinical and management supervision, from a manager who understands and is committed to the role of key worker. Peer support systems should also be available.
- Giving non-designated key workers protected time for their role. This needs to be formally arranged, authorised and monitored to ensure ongoing commitment from line managers and organisations.

- Disabled children, young people and their families should be given a clear explanation of the role of the key worker/care co-ordination service and the responsibilities of this role.
- An inter-agency care plan (see below) giving key workers the agreed power to access resources and credibility with the agencies involved in provision for the family.
- An information resource covering local services and their roles, information about different conditions and impairments, and national organisations. Key workers or an information facilitator should guide families and ensure that they have information tailored for them that is accurate and accessible.

In transition the key worker will form the link with adult services and ensure continuation of care until the young person is established in adult care.

The key worker designate is a link person working in an adult service who works closely with the children's services key worker and through whom adult services can be effectively accessed. The identification of a key worker designate can be difficult as there may be concerns about expectation and volume of work created by this role. The care of people with long-term conditions is now a key priority in adult services (Our Health, Our Care Our Say, 2001). Learning disability services and adult social care may act in this role, as may further education or university staff. Health agencies are developing roles such as those of Community Matrons and Continuing Healthcare Leads have particular responsibilities in this area. Adult hospices may have link nurses who can adopt this role as end stage care approaches.

The role of the key worker in transition is to maintain the key elements listed above and to gradually hand the baton to the key worker designate in adult services. The key worker designate will organise the multi-agency assessment and ultimately the package of care once transition is complete, eventually taking on all the key elements of the key worker role.

Apprehension about transition can be greatly reduced when there is a clearly identified key worker designate for young people to identify with and to take forward the co-ordinated planning of care within adult services.

I was building a relationship with a connexions person and looking at colleges but none had wheelchair access and time was getting on. The transition social worker is looking after my transition.

**Goal 4: Every young person will be empowered to consider future plans, which are supported by a full multi-agency assessment.**

A young person's ability to shape his or her own health and social care plan will vary greatly. Professionals have a duty to ensure all possible means have been utilised to ensure young people have a meaningful input into their plan of care. The key worker will initially lead this process until the key worker designate from adult services is identified.

**Person-centred planning.** Person-centred planning is a process for continual listening and learning, focused on what is important to someone now and for the future, and acting upon this in alliance with family and friends.

The ongoing process of listening and learning is used to understand a person's capacities and choices. Person-centred planning is a basis for problem solving and negotiation to mobilise the resources necessary to pursue a person's aspirations. These resources may be obtained from a person's own network of friends and family and from statutory and voluntary sector service providers. To find out more about person-centred transition planning see the Council for Disabled Children's Transition Guide.

**Using person-centred planning can:**

- Help young people to work out what they want in their lives and make them feel stronger and more confident.
- Clarify the support needed for young people to pursue their aspirations.
- Bring together people who have a part to play in supporting young people for joint problem solving.
- Stimulate and motivate people based upon better understanding of and commitment to a young person.
- Help to shape the contributions made from service providers to ensure these are based on what is important to a person from their perspective and hence more effective in helping young people meet their goals.

#### Case Example – Person-centred planning

The purpose of this person-centred review meeting is to:

1. Review the information that everyone has about what they like and admire about Colin; what is important to Colin (now and for the future); and what help and support the person needs.
2. Identify what else we need to learn to develop this information into a person-centred transition plan and agree actions for this.
3. Identify what is working and not working from different perspectives (e.g. Colin, the school, the family).
4. Agree actions that will ensure continuation of those that are working and change what is not working.

We put lots of flip chart paper on the walls of the schoolroom. On the flip chart we put the following headings for Colin's meeting:

- What we like and admire about Colin
- What is important to Colin now
- What is important to Colin for the future
- What support and help Colin needs
- Questions to answer/issues we are struggling with
- What is working and not working (we used four sheets for this, what is working and not working from Colin's perspective, from the school/s perspective, from the family's perspective and from others perspective)
- Actions

We then used the headings and adapted a process from a person centred planning guide called Essential Lifestyle Planning (Smull and Sanderson, 2001).

**Exploring the options and opportunities.** Where the young person wants to live, work, study and socialise will be the most important facts to establish. Services can then be identified around this location. For young people moving into a different district, services can be located by accessing the following resources:

- A comparison guide to hospital services and statistics via [www.drfooster.co.uk](http://www.drfooster.co.uk)
- Information on all kinds of health problems and links to local NHS services via [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)
- A guide to local and national NHS services and links to

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other information areas, including a section for young people and support groups can be found via [www.nhs.uk](http://www.nhs.uk)

- Social Service information can be accessed locally through a main contact number, which will be found in the phone book.

I want to go home to be a web designer. I am in the process of discussing this with Social Services. I want to live in an adapted bungalow and not go back to my parents' home when I leave here.

For young people staying within the district, care planning will need to establish:

- Medical lead
- Nursing lead
- Social services lead
- Further education link

You've got to decide what you want to do. Do you want to go into a home? It would be easier if they put you in a home but they know that's not right and you'd probably be better in an independent situation.

There will be a variety of opportunities and options available to young people and their families and carers. It is important that professionals from all sectors work together with them to provide information about the full range available so that they can make informed choices. It can be easy to make assumptions about what someone with a particular condition might want. Ideally key workers in an area will be able to collaborate and share knowledge and ideas about possible options available about places of care, sources of support, social opportunities, educational options, work or other activities. It is important that information about all aspects of the young person's future life, not just their healthcare needs, is considered equally.

When considering options available the notion of safe risk-taking needs to be taken into account. Risk assessment is key to determining the feasibility of the options available to a young person with specific needs. It is important that young people are involved in all discussions and decisions

about what they can or cannot be 'allowed' to do safely. Risk-taking is a normal part of adolescent development and this is no different for this group of young people, although harder for them to achieve.

There can be difficulties if parents and / or professionals have a particularly cautious approach to activities and prevent the young person accessing places or activities under the guise of 'risk assessment'. Additionally if the young person requires a 'carer' with them for the majority of the time, it is hard for them to have private time with peers or doing things that are really 'not allowed'.

If you are talking about a concert, you plan it in advance. You can't go to Basingstoke and buy things you need today, you can't do it.

Those working alongside the young person, or involved in planning their care need to be very sensitive to these issues and services need to adopt flexible and innovative approaches to risk assessment and service delivery that enable risks to be minimised without preventing the young person from achieving desired goals and enjoying the best quality of life possible.

### Case Example

Kate has a congenital heart condition and has now developed life-threatening pulmonary hypertension. She is dependent on oxygen day and night and has poor mobility. At her mainstream secondary school she was determined to participate in her class field trip to an outward-bound centre, including the abseiling and quad biking events. Her community children's nurse undertook risk assessments with centre staff and teachers and made plans for her to be able to access both these activities with their help and support and some ingenious ways of securing her liquid oxygen cylinder.

**Multi-Agency Assessment.** Palliative care in children covers a wide range of conditions and consequently most young people will have care provided by a wide variety of agencies and service providers. Given the complexity in care planning a transitional meeting is often an important step in assessing care.

An agreement between providers about who will contribute what to an initial assessment can prevent much repetition. Children's services need to discuss with young people and their families what information they feel is appropriate to pass on. All young people have a right to a fresh start in adult services and long forgotten disagreements are likely to have little relevance to future care. Well thought-out summaries can capture key relevant points without passing on confidential information that no longer has relevance to adult care.

In principle, adult teams should undertake assessment, not children's services. Many adult services have a more individual approach to care, which may feel alien to children's services staff and difficult for parents to deal with. It is important that this approach is fully supported by the children's team and explained to the young person and their family.

**Assessment should consider:**

- Wants, wishes and aspirations of the young person
- Symptom management
- Daily care
- Procedures and therapies
- Independent living
- Further education
- Employment
- Social opportunities
- Mobility
- Aids and equipment adaptations (required in new care environment)
- Financial support
- Short break care – age appropriate
- Spiritual needs
- Diversity and cultural needs
- Sexuality
- Health promotion (including alcohol, drugs, safe sex)

**Goal 5: Every young person should have an appropriate reciprocal service identified in adult services.**

**Care Staff.** For a number of young people any move towards independence will necessitate the support of a care team.

The principle providers of care services are:

- Staff at residential colleges
- Social services - often via an agency contract
- Health - through continuing health care packages
- Commercial care agencies
- Charities/voluntary sector agencies
- Directly employed staff via direct payments

**For any care team there are key questions to ask.**

- Is there consistency in staffing?
- Does the organisation employ staff for specific packages of care?
- Will the organisation carry out more complex nursing tasks such as gastrostomy feeding?
- Where will training for nursing tasks come from?
- Will the organisation allow staff to support care in all settings?
- Can the young person be involved in recruiting his or her own care team?

Some young people will choose to employ their own care staff due to difficulties in gaining satisfactory flexibility in the above areas or to gain more control of their own care. Direct payments have their own complexities and the above questions are equally important when employing staff directly.

There's not enough staffing. We rely on people to do physical things. Therefore, technically, it means that it depends on how free the person that is looking after us is to facilitate our freedom. We can't choose our freedom – they might be able to do it, and they might not.

For young people who do not require a care package approach the focus should be on identifying appropriate, named individuals who can gradually get to know the young person, enable them to develop trust and learn their care preferences prior to gradual transition. This will need to include arrangements from a healthcare perspective for clinic, home care and follow-up wherever they are living that takes account of their intended lifestyle choices. For some young people moving away to university or college, with shared care arrangements between centres may be

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### Case Example: Getta Life – A Not For Profit Agency

Getta Life is a small not-for-profit organisation, which supports people with learning difficulties to live in their own homes. The organisation aims to support people with multiple and profound learning difficulties to live ordinary lives in the community with person-centred support. Small teams of three to four staff are recruited to work with an individual.

Getta Life worked to support a young man who was leaving school to access daytime activities. S was not able to access existing day services as his physical needs meant he was too at risk. S had a tracheostomy tube in place and severe physical disabilities as well as profound learning difficulties. S only used his eyes and body movements to communicate. Getta Life in partnership with mum, recruited three support workers, one to support him three nights per week at home and two to work with him during the daytime. S's Mum helped Getta Life to interview staff and the interviews were in her home with S present.

S had a small room as a base in a drop-in centre just down the road from his home and from there he was helped to develop his interests and take part in normal activities such as swimming or shopping. S's Mum started to acknowledge him as a young man rather than a boy. During this time staff got to know his family well.

Sadly S's Mum went into hospital unexpectedly. During this time we saw him each day and continued his daytime support. S's Mum died in hospital after five days and within a few days he was taken ill and admitted to hospital. From there he was transferred to a hospice where we supported him with the help of the hospice staff. The chaplain at the hospice helped us to have a service for his Mum in his room at the hospice on the day of her funeral. S died within two weeks of his mother.

Good staff training and flexible support for S and his family was what enabled us to help S to access community activities when most people felt he was too fragile to live an ordinary life.

appropriate to ensure continuity and communication as they move between a parental home and their 'new life'.

**Adult District Nursing Services.** Moving from children's nursing services into an adult district nursing service will bring about some key changes. Adult palliative care is co-ordinated by the district nursing service in conjunction with the GP, Macmillan teams and other allied services. District nursing teams are often small and based within GP surgeries. Although this could be seen as limiting it has the advantage of facilitating easy communication between GPs and district nurses, which means that some issues, such as new medications, can be more quickly resolved.

Some adult services may have extensive experience of palliative care in the older person, although most district nursing services will have less experience in palliative care for young adults. Assessments are carried out by the district nursing sister allowing needs to be identified and patients to be referred directly to other services and therapists.

District nursing services tend to have limited experience of complex technological care. Where there is experience for example in ventilation it tends to be held within one small geographical area. Continuing care teams have emerged in some localities to support complex care. The District Nursing team will be a key adult service to be involved in the young person's care particularly around end stage care but also for ongoing care.

There are two major initiatives in adult palliative care which aim to ensure good standards of care:

**Gold Standards Framework.** Practices using the Gold Standards Framework include children and young people with life-limiting conditions in their palliative care provision. Patients nearing the final year of life are placed on a supportive care register and their care discussed within the team. Advanced Care Planning is an essential part of GSF with both proactive management by the clinical team and discussion of advance statements of wishes with the family. Overall this improves care in the final months/year of life, particularly care at home provided by the primary care team.

**Liverpool Care Pathway.** The Liverpool Care Pathway is implemented across the continuum of care settings once the dying phase is recognised to support end-of-life care in the final days (See Appendix 2).

Advanced directives that attempt to plan ahead for a variety of eventualities will help to inform new doctors and nursing staff and reassure them that such discussions have taken place. Adult services will often have different policies and protocols for advanced care planning. Particular attention should be paid during the transition period to keeping plans valid and up-to-date.

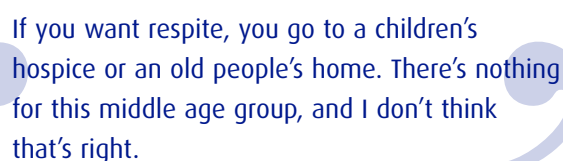
**The Role of GPs.** There are a variety of roles that GPs may play in the process of facilitating transition of young people with life-limiting conditions to adult services. They represent roles that an 'average' GP could be expected to undertake, rather than those that might be carried out by a GP with a 'special interest' or one with additional training.

A key function of general practice is that of providing a failsafe mechanism – to try to fill gaps when other services have either failed or are not available. Some of the roles listed are therefore 'potential' roles that may not be required at all if the process of transition is managed well in secondary care. The roles might include:

- Early recognition and referral of young people with signs of serious or life-threatening conditions.
- Providing medical input into the care of terminally ill young people preparing to die at home, in association with specialised teams.
- Providing 'normal' general practice-based care for common minor conditions and co-morbid chronic conditions where these do not require specialised input. Part of the process of transition may need to involve the transfer of responsibility for primary health care needs back to general practice.
- Providing long-term adult follow-up for the life-threatening or terminal condition. In some cases there may be no necessity for continued specialist services into adulthood.
- 'Normalising' adolescence, as far as possible, for the young person by providing advice on developmental changes and health promotion as for any other patient of the same age.
- Negotiating and promoting concordance with medication and other treatments.
- Facilitating the process of transfer of responsibility for health care from parents to the young person.
- Informing young people about their rights to receive confidential health care, independently of their parents (subject to competence).

- Supporting the young person's parents and family during transition.
- Reviewing correspondence and monitoring the process of transition, intervening if necessary.
- Acting as an advocate for the young person and their family, if required, in negotiations and transfer of care to adult medical or social services.
- 'Signposting' and referring to secondary care services where transition has not automatically occurred within the secondary care sector.
- Providing information on relevant self-help services and support groups.

### Children's and Adult Hospices



If you want respite, you go to a children's hospice or an old people's home. There's nothing for this middle age group, and I don't think that's right.

There are many parallels between child and adult hospice care, but it should also be recognised that there are some significant differences.

Broadly speaking, it is recognised that children's hospices are set up to provide care over a longer period of time, which will often entail regular planned short breaks, with support for the whole family, including siblings. This type of planned short break care is not so prevalent within adult hospices, where the focus (often from necessity due to the larger numbers of patients) tends to be on end-of-life care and symptom control.

In addition the adult hospice movement, which has traditionally focused on the care of those dying from cancer, has been established since the 1960s. Palliative care in paediatrics with its broader approach is new and has only been in existence since the early 1980s (Goldman et al, 2006). Many adult services are now looking to expand their approach to include people with a wider variety of conditions.

Young people should have the choice to be cared for in the hospice environment that best suits them.

## Part 2 | The Transition Pathway

### Case Example: Whitby Lodge Young People's Unit

Martin House in Yorkshire opened in 1987. In 2000, of the 240 'children' receiving support from Martin House 129 [54%] were over the age of thirteen, 69 [29%] were over the age of sixteen and the numbers were increasing. The teenagers and young people were asking for more appropriate facilities and activities:

- They wanted to stay up late at night, either socialising or being on their own in their own room.
- They wanted to get up late in the morning and did not want to be disturbed by the noise of younger children.
- They wanted to have one or two separate social areas just for people of their age group.
- They wanted to have a bedroom where they can retreat for privacy or even entertain their own guests or partners.
- They wanted to retain a family atmosphere.
- They wanted to have the freedom to come and go as much as possible.

Martin House has a catchment area covering several PCT's and investigations showed limited availability of services for this age group. Discussions were held with trustees and with the young people and their families. Feedback from the young people included:

"The teenage unit will be good because I will have privacy

from the rest of the children and parents. It will be nice to be with people of my own age."

"It will give me more space to be me."

"Other people's parents are OK, but don't let mine in!"

"If this unit were to go ahead, it would mean we would be able to do what every other teenager wants to do".

The teenagers and young adult house opened in 2002. The young people were included in discussions along the way; meeting with the architects, their ideas on how they wanted to use the facility and their views on staffing were all taken into account. They also wanted as much independence and privacy as possible. Individual swipe cards [attached to wheel chairs if required] enable them to freely access their own rooms and access all areas.

The young teenagers, who are using Martin House, sometimes go between the two houses, gradually getting used to the different atmosphere and getting to meet the other young people and team. There is some accommodation available for parents if required.

"The team have witnessed the blossoming of quiet individuals who have discovered their own voice in an atmosphere of supportive 'peership', talking of their hopes and fears and finding friendship and inspiration from each other." Staff Member at Whitby Lodge.

### 2.2.2 STANDARD 4: On Going Planning

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.

#### Key goals

1. An appropriate holistic care team will take over the young person's therapy and care needs.
2. A person-centred co-ordinated care plan is developed
3. Appropriate funding will be identified to enable transition
4. Transition is a planned and staged process

### Goal 1: An appropriate holistic care team will take over the young person's therapy and care needs

I need a speaking valve. I saw an ENT consultant last summer and he is really slow. I'm still waiting to hear from him. It gets a bit complicated. He said I could speak. He had to speak to some people before he could come back to me and say that.

The agreed employer of the care team will need to delegate or employ staff to the transitional team. There needs to be a clear time frame, for example:

- Recruitment time 3-4 months
- Induction time 1-2 weeks

- Training/familiarisation time 1 week-3months (depends on complexity, e.g. 3 months for long-term ventilation)

#### Wider Inter-disciplinary or Inter-agency Team

Depending on the complexity of care this list can be modest or vast, and could include:

Hospices	Voluntary sector
College / occupational health nurses	
Special needs link from education	Dietician
Podiatrist	Specialist dental services
District nurse	General Practitioner
Learning disability nurse	Specialist nurse
Housing	Hospital Consultants
Physiotherapist	Social worker
Transport services	
Speech and language therapist	
Wheelchair clinic	Social work support team
Employer	Occupational therapist
Head of the education provider	

**Place of residence.** The place of residence is paramount and must be finalized first. Once identified, site visits by the young person, family, key worker and key worker designate will help identify:

- Adaptations required
- Equipment required
- Risk assessment
- Supplies
- Training requirements
- Ongoing training
- Clinical supervision

Some young people will stay living in the parental home, some will be able to live independently, either in their own home or sharing with friends Some will live away from the parental home at university or college.

**Short Break Care Options.** Short break care is often a determining factor in the sustainability of home placements and the key factor in the quality of a young persons life experiences.

Provision of residential short break care for adults is limited and varies widely around the country, although there are a number of children’s hospices that are developing their ability to support young people to the age of 25.

Adult hospices have a very different role to children’s hospices and tend not to provide planned short breaks. For young adults residential educational placements remain the most significant out of home placements, reducing short break needs in this group. Private nursing homes offer residential respite however the majority of their clients will be elderly and this will rarely be suitable. Voluntary organisations such as Leonard Cheshire Homes may offer a more suitable environment but often have middle-aged clientele.

For young adults with learning disabilities and palliative care needs short break and day care facilities provided for adults with learning disabilities could be considered. Adult versions of short break fostering, where a young person stays in a carer’s own home, are another possibility.

Access to all these facilities will be problematic for those with nursing care needs. Sometimes services can be accessed if appropriate training and on call support is provided or if a dedicated care team accompanies the young person, either from statutory services or employed by the young person themselves via direct payments.

A number of voluntary organisations provide holidays for young people with complex/palliative care needs. See the ACT website for details [www.act.org.uk](http://www.act.org.uk).

**Goal 2: A person-centred co-ordinated care plan is developed.**

The care plan needs to be comprehensive and developed through multi-agency planning to allow for safe care. Plans for adolescents need to include the wider issues that affect all young people.

## Part 2 | The Transition Pathway

**Growing up.** Adolescence and the transition to adulthood are complex stages of development in which young people test out and practice a range of roles and relationships. Some adolescents find these processes turbulent and challenging (Coleman and Hendry, 1999). The secure world of childhood is left behind as a search for adult identity begins. This often includes a wish to explore sexual experiences.

All young people should learn that sex is much more than the physical act and that sexual interaction encompasses the micro-personal world of daily contact with others. People with disabilities tend to be excluded from the environment where initial sexual interaction takes place and may also, as a direct consequence of this exclusion, suffer low self-esteem. Recognising sexuality as a need is essential in the holistic approach to caring for young people, but it is a difficult subject to approach both in terms of legal issues and the sensitivities involved. Given this it is vital that agencies have robust policies relating to sexuality, and that they ensure that staff are trained and have the skills to empower and support young people so that their needs are taken seriously.

When I was 11 or 12, I had social problems. I found it hard to relate to others. I thought they were scared of me, and I think I was scared of them. From the ages of 12 to 14 years old I was a bit of a loner.

**Safe Risk-taking and Decision-making.** Young people with complex health issues need support and protection so that they are not exposed to unacceptable risks. At the same time, their rights to develop and learn and be included in all aspects of community life must be recognised. An important part of growing up involves taking risks and young people with complex health conditions, like other young people, have the right to have the opportunity to do so (Lenehan et al, 2004). Where possible a shared risk assessment can avoid barriers and unnecessary duplication of care. The risk assessment will be a fundamental part of the care plan.

**Contingency Plans.** Contingency plans will follow on from the risk assessment and care plan. End-of-life care planning is discussed in the next section, but this should be considered early in the transition process to prevent delays later on.

**Contact List.** A contact list should be developed that identifies who is responsible for what and when. Complex

packages of care require 24-hour contact numbers. Young people in new environments can feel anxious and isolated. Clear, contact lists can reduce anxiety in times of need or crisis. Contact lists should include general numbers for routine care, (e.g. GP, NHS Direct) and specific numbers for more specialist aspects of care.

**Transitional Plan.** The transitional plan lists key transfers of responsibility and needs to be updated for any slippages that occur. It is vital that all members of the transitional team have a copy of this document and are involved and committed to its delivery. Every transitional plan requires a definitive end point for the transfer of care.

**Goal 3: Appropriate funding will be identified to enable transition**

Some of the things are about blind need. It's not 'want' and there's a cheap alternative. Give it to me or my life won't be worth living. If they don't give me a lift, well, do they want me to lie in bed all day?

Universal services such as GPs or District Nursing are fully funded and available to all. However most other aspects of the multi-agency plan will require separate funding.

Commissioners in Primary Care Organisations may need to be approached for funding-enhanced hospital-based services or for the funding of new community services. They will also be involved in continuing care processes when a young person is moving out of county. Guidance on who should have responsibility is available from the Department of Health 'responsible commissioner' website. Most areas have multi-agency out of area funding panels to address these issues.

Having a condition like this should be an automatic ticket to all different kinds of healthcare, but it isn't always like that, and it depends on where you live.

**Benefits.** There are a number of benefits available to disabled young people. Disability Living Allowance (DLA) is automatically reviewed when a young person reaches 16. A young person may also be eligible for Incapacity Benefit at this age, depending on circumstances.

Young people may also be eligible for financial support from the Independent Living Fund. These funds were set up as a national resource dedicated to the financial support of disabled people enabling them to choose to live in the community rather than residential care.

Disabled young people can also receive and manage direct payments from the age of 16, which previously were managed by parents. Direct payments are local council payments for people who have been assessed as needing help from social services, and who would like to arrange and pay for their own care and support services instead of receiving them directly from the local council. This self-directed method of providing support is being extended and broadened out to be available to more people. This wider self-directed support, still in pilot stage at time of going to press, will involve giving people an 'Individual Budget' which will enable them to have more choice and control over the type of support they have. For more information about benefits and further and higher education funding see the Council for Disabled Children Transition Guide.

I had direct payments until I got into adult services. Because my needs are only medical I don't need a social worker. My mum used to pay for a carer to take my brother out. My brother has special needs as well. They won't fund the cover to take my brother out, and he drives us crazy.

#### Useful websites:

<http://www.dialuk.info>

<http://www.direct.gov.uk/DisabledPeople/fs/en>

<http://www.cafamily.org.uk/benefits.pdf>

<http://www.ilf.org.uk>

<http://individualbudgets.csip.org.uk>

Transition always involves some level of overlap funding this could be:

- Transitional clinic
- Training for carers
- Time to get to know a young person

In complex care this may involve months of training and working together.

It is important that all packages are fully costed and funded prior to finalising any package of care. Young people and carers can be put through unnecessary trauma by well meaning plans that have not been financially thought out.

**Further Education Funding.** Further education is funded via the Learning and Skills Council (LSC). Funding for young people with learning disabilities and/or disabilities beyond school age is the responsibility of the LSC. In the case of young people remaining in schools post-16 this funding passes to the Local Education Authority and the student's statement of Special Educational Needs continues.

When I came here I had to have 24 hour care. It took 18 months to sort that out. Well that's life.

When a young person moves to a sixth-form or further education college, the LSC directly funds the placement, including any assessed needs arising from their disability, such as assistive technology, personal support in class, or with personal care and therapy. Local mainstream colleges can bid for this funding under the 'additional support mechanism'.

If the young person cannot access further education at a local college – often because their educational needs require independence training or life skills – they can apply, with the support of their Connexions personal adviser, for a place at a specialist independent college. After an assessment of their needs for specialised equipment, therapy, personal and nursing care and learning support, they may be offered a place for three years.

Young people with complex needs and life-limiting conditions are, in general, well-served by this process once funding is agreed. It comes from a single source, can take account of all their needs and is transparent.

It took a long time to get a place at the college, waiting for funding to become available. It took about a year. The social worker kept in touch and helped me. I have a good relationship with my social worker. I wasn't getting my hopes up, but I still wanted to come.

## Part 2 | The Transition Pathway

### Case study: Further Education Provision

Julie is a young woman with a form of Hereditary Sensory Motor Neuropathy Type II. She uses a powered wheelchair, with a ventilator and has a nurse or health care support worker with her 24 hours a day in case the ventilator malfunctions.

The PCT purchase the entire package from a specialist agency. While at school, Julie's mother also had a major responsibility for her care. Julie very much wanted to have the quality of life and independence of other young people of her age and a place was secured at a residential specialist college an hour's drive from her home. She lives in college during term-time, in a training flat, which includes room for her waking night carer. A team of nursing and residential support staff have been trained to provide emergency support to her primary nurse/health

care support worker and special adaptations have been made to college vehicles to transport her oxygen supply. College staff are able to meet all her personal care needs.

She has chosen a vocational qualification in photography as her main course, and enters fully into the vibrant social life of the college. Over the eighteen months of her placement so far it is very noticeable that her carer positions herself within sight, but further and further in the background so that she does not 'cramp Julie's style'.

The placement appears to be succeeding because of Julie's determination and the detailed preparation, planning and agreement of each contributor. Clarity of roles and responsibilities have allayed anxieties among staff and ensured everyone's commitment.

**Higher Education Funding.** For young people with complex needs wishing to enter higher education, the funding regime is complex and fragmented and the whole process requires lengthy preparation and planning to ensure services materialise in time for Fresher's Week.

The local authority is responsible for the statutory element of the fees, and the young person has access to the student loan. The Disabled Students' Allowance is also the responsibility of the local authority, and this is awarded after a comprehensive assessment of the purely educational needs - assistive technology, computer access, a scribe or assistant for practical activities. The assessment is carried out at one of a number of regional centres.

The young person's personal care needs will be funded by their home social services department, after a needs assessment, though the funding mechanism may vary depending upon, for example, whether a Direct Payments Scheme is in operation. Delivery of the personal support may be the direct responsibility of the young person, if they are recruiting and employing their own carers, or may be provided by the local authority in the university area under a service agreement with the home local authority.

Once the young person has registered with a general practice in the university area, their health care needs become the responsibility of that Primary Care Organisation.

**Continuing Care.** The 1994 ombudsman report showed the failure to provide long-term NHS care for a brain-damaged patient referred to as the 'Leeds Case'; this resulted in the creation of Continuing Health Care Funding. This policy currently only applies to adults who are over 18 years of age. The Department of Health is currently working on a Children's Continuing Care Criteria as outlined in 'Our Health, Our Care, Our Say' (2001).

For those over 18 years this policy has significant effects on care planning. Continuing Care funding is awarded where the person's primary need is identified as a health need. A young person assessed as reaching this criteria for continuing care has all their care provided free at the point of delivery by the NHS. This is non-means tested care.

Social services transfer all responsibility for care to the NHS as the primary need is for health care. Where necessary this includes accommodation costs. Any arrangements where social care or the Independent Living Fund provide resources for the young person to employ their own staff cease and these responsibilities transfer to the NHS. The NHS cannot legally make direct payments ('Our Health, Our Care, Our Say', 2001). When planning post-18 care packages it is important to involve adult continuing care assessors at an early stage to ensure any possible issues are considered.

#### Goal 4: Transition is a planned and staged process

Transition ideally should be a three to four year process, which can cause major challenges:

- Remaining sensitive to young peoples' changing wishes
- Remaining aware of changing clinical needs
- Maintaining interest in multi-agency/multi-disciplinary working
- Changing structures/organisations

A clear transitional plan with a clear timetable can help to ensure that transition is a process with timely delivery. It is essential to develop a realistic schedule of planning meetings at the outset so that the transition process can be receptive to changing needs. These meetings should be clearly minuted with actions for each member of the team that are followed up by the key worker or key worker designate prior to each meeting. Continual review of the transition team by the key worker and the key worker designate can help ensure appropriate representation is maintained.

I got handed over to adult services when I was 14. It's better. I am already seeing a transitions officer.

Funding can be one of the most complex areas to get agreed. Decisions in principal can help decision-making without reducing choice for the young person later on.

#### 2.2.3 STANDARD 5: Settling into Adult Care

**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.**

##### Key goals

1. There is an overlap of care team and resources until a sustainable adult service is established.
2. Young people are kept out of hospital (where possible).
3. Transportation is facilitated.
4. There is evaluation of the process.

#### Goal 1: There is an overlap of care team and resources until a sustainable adult service is established.

Dual funding needs to be maintained until there is a fully staffed and functioning team or the young person is settled in adult care. There may be a mechanism within the transition plan for staged withdrawal of children's services as staff complete their training and begin to deliver the care package.

I have met my new consultant, and then I had my final appointment with my paediatric consultant.

Many forms of technological support used in children's care are infrequently used in adult services. Adult services often require support in expanding into these new areas. Children's services can support this move with nursing training. An investment in supporting adult services in this way can often open new opportunities for young people at transition. Sustainability of adult care is difficult if services cannot support on-going training of the new care team.

"Attrition rates at transition are very high and the cost of losing ongoing medical care can be considerable". (Watson, 2000)

I liked the nice friendly children's unit. The adult unit is not warm and inviting.

#### Goal 2: Young people are kept out of hospital

There is an increasing emphasis on moving care into the community with a particular focus on long-term conditions, with the emergence of community teams delivering access to 24 hour health and social care in the community (DH, 2005). Models of care currently vary across the UK but local delivery imperatives will support this developing agenda and adult services are beginning to focus on long-term case management models. It is important that young people and their carers are integrated into these developing services and their particular needs taken account of.

When I was 15 I had my first severe chest infection which landed me in hospital. It was quite a scary experience, but I have got used to it now.

## Part 2 | The Transition Pathway

### Goal 3: Transportation is facilitated

An accessible transport system is one that recognises the need for every stage in the journey to be accessible to disabled people. By considering people's diversity, accessible transport systems try to break down unnecessary barriers and exclusion.

**Blue Badge Parking Scheme.** The Blue Badge scheme provides a range of parking benefits for disabled people who travel either as drivers or as passengers. The scheme operates throughout the UK. The concessions only apply to on-street parking and include free use of parking meters and pay-and-display bays. The badges – sometimes known as disabled parking permits – can be used throughout the UK and while travelling abroad within the European Union (EU) and in some other European countries. Social services departments at the local council will advise individuals how to apply for a Blue Badge.

**Motability Scheme.** The Motability Scheme can help with leasing or buying a car if a person is getting the higher rate of the mobility component of Disability Living Allowance (DLA). The disabled person can apply for a car as a passenger and propose two other people as nominated drivers. Applications can be made on behalf of a child aged three or over, who is entitled to the mobility component of Disability Living Allowance.

**Rail Travel.** National Rail need advanced warning if passengers need any assistance from staff – ideally more than 24 hours' notice. When booking travel, give as much detail as possible about the disabled person's needs. For services that offer seat reservations, the local contact person can reserve a seat or wheelchair space without charge.

**Coach Services.** Coaches may not always be accessible to all disabled people, especially wheelchair users, however by 2020, all buses and coaches must be fully accessible for disabled people.

**Community Transport Services.** These might include door-to-door transport and services offering trips to shopping centres. There is wide local variation, often with fewer services in rural areas. More information is available from the public transport officer at the local authority, social services or the Community Transport Association.

**Oxygen.** Some public transport services have bans on the transport of oxygen.

### Goal 4: There is evaluation of the process

Care pathways for transition need regular review, investigation into areas of deviance and re-evaluation and onward reporting. In complex transition no two experiences will be the same but each transition will add insights to a "toolkit of approaches" that will inform future work.

Transitions pathways and individual complex transitions in each area need to be reviewed yearly by a delegated senior practitioner to identify transitions or pathways that are losing direction. This may be particularly valuable in cases where there is a high level of clinical instability. Organisational difficulties should be identified to leads within the health and social care bodies.

## 2.3 Stage 3: End of Life

(See Diagram 3)

The ultimate goal for this stage of the pathway is that all young people die with dignity and where possible in their chosen place of care if possible, so that the family are left with what can be only described as a 'good enough memory' of their child's life, dying and death.

There are three distinct phases in this part of the pathway:

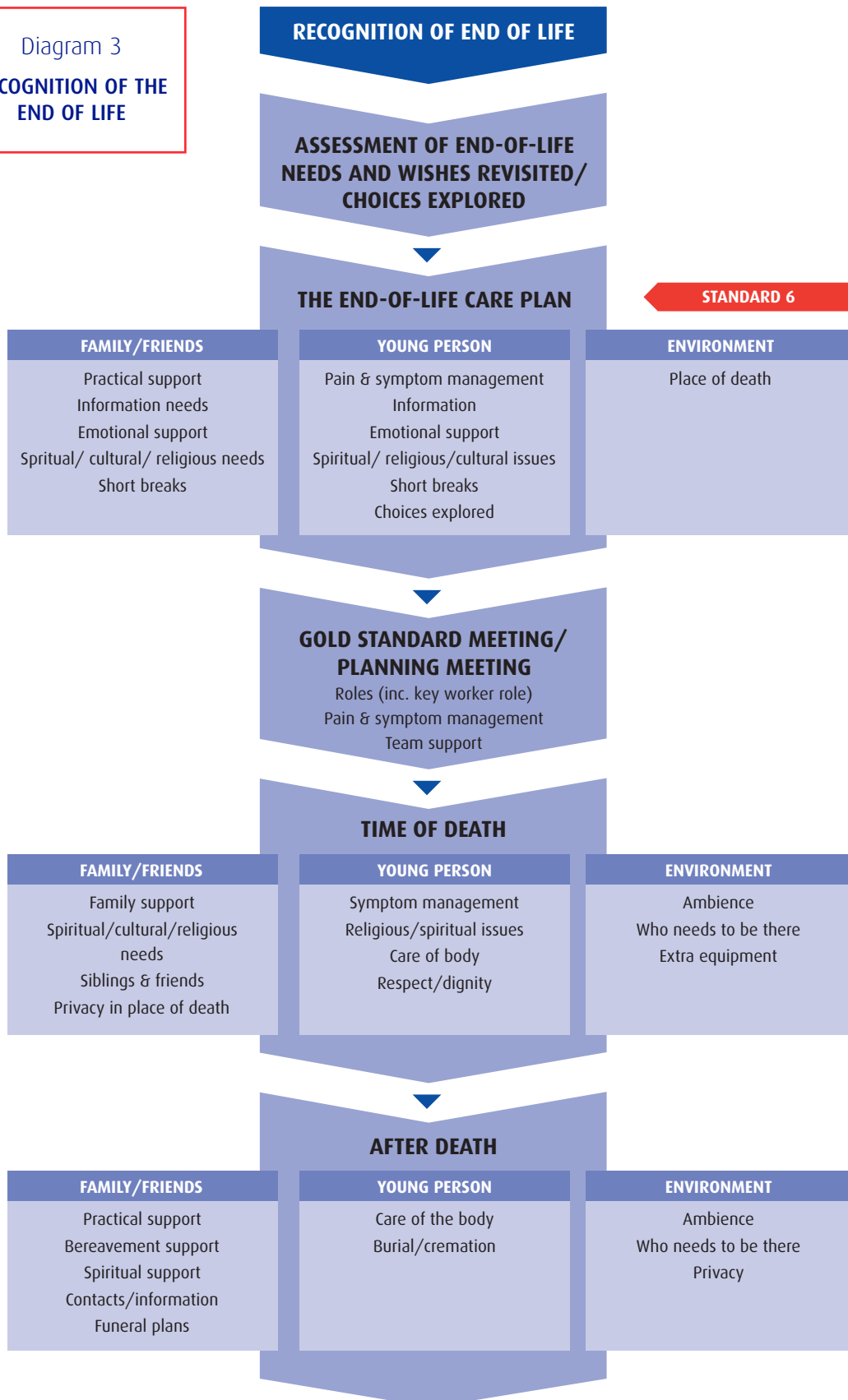
- Planning for death
- Time of death
- After death

We have focussed on one standard throughout that should be achievable in all settings; that all young people should have an end of life plan.

It is also important that all staff involved in the care of young people at this stage receive the support and clinical supervision that they need.

Young people from all four of the 'ACT groups' (see page 11) will at some stage enter this part of the pathway. Some young people will enter this stage of the pathway without having been through the first two stages. This is important to

Diagram 3  
**RECOGNITION OF THE  
 END OF LIFE**



## Part 2 | The Transition Pathway

remember, as the language we use and the team involved may be new to them and their family and friends. Some of the core elements of good palliative care during this phase of the pathway are given in Table 1. Many of these core elements are equally applicable throughout the care pathway.

Table 1

### Core elements of end-of-life care for young people

- Care in the place of their choice.
- Professionals should be open and honest with young people and families when the approach to end-of-life care is recognised, with timely and open communication and information.
- Joint planning with young people and their families and relevant professionals should take place, with choices / options in all aspects of care, including complementary therapies.
- Young people and families should be supported in their choices and goals for quality of life issues should be respected.
- A written plan of care should be agreed including decisions about 'allowing a natural death', which takes into account acute or slow deterioration. It is important that all professionals who may be involved are informed, including emergency services.
- Co-ordination of services at home, where this is the chosen place of care, including provision of specialist equipment, should be in place.
- Expert symptom management, including access to 24-hour specialist symptom management advice and expertise by those suitably qualified and experienced with teenagers and young people, including access to out-of-hours medication.
- Access to further disease treatments, e.g. radiotherapy and chemotherapy.
- Emotional, spiritual and practical support for all family members should be available.
- Short break (respite) care, with medical and nursing input, when required.
- Care plans and end-of-life plans should be reviewed and altered to take into account ongoing changes.

**What services are available?.** The death of a young person can be a rare experience for many healthcare professionals, particularly in primary care. Access to specialist paediatric and adult palliative care expertise is therefore essential for good end-of-life care.

There are very few dedicated nursing services for teenagers and young people. Community children's nursing services provide much of the care for those dying at home, but provision is variable across the country and out-of-hours cover is patchy. District nursing services and adult Macmillan nursing services have useful expertise in palliative care for older adults but do not generally have experience in caring for younger adults.

**Hospice provision for end-of-life care.** There is at present only limited hospice provision that is specific for young people. If an adult hospice needs to care for a young person under the age of 18 they need to apply for an individual licence from the Healthcare Commission. However, where hospices exist, they provide an important resource and an alternative choice in the preferred place of care for a young person.

**Key worker roles during end-of-life care.** 'Where palliative care includes primary and secondary care teams, it is essential to communicate care plans and end-of-life decisions in a timely fashion so as to provide clear direction and optimise clinical care. The role of a key worker is crucial in ensuring the co-ordination of care between all settings'. (NICE 2005)

The family will need a key worker throughout this part of the pathway. However, the family and the rest of the care team may need to be prepared to change the key worker at this stage and to have their roles redefined.

Some of the tasks of the key worker during this time will be to:

- Assess, implement and review the care plan with the young person and multi-disciplinary/inter-disciplinary team.
- Maintain ongoing contact with the young person and family, providing information and support.
- Monitor changing needs.
- Act as liaison when required between the family and the service providers.

**Role of GPs.** If the young person's place of care is outside the acute setting or hospice, then the role of GPs is key and they need to be kept fully informed during the terminal phase of a young person's life, as they are often well placed to play an active role, particularly in home-based care and in providing holistic care to the whole family. A good way to achieve this is through the Gold Standard Framework (GSF) meetings within the practice.

**Strategic planning.** Strategic planning is key to delivering timely services as the young person's condition may change very quickly at this stage of the pathway and if there is a local strategy or network already in place this can reduce some of the trauma that families and professionals can experience. Some GPs now have a palliative care co-ordinator in post who can be very helpful in sign-posting. This role could also be undertaken by a clinical nurse specialist or nurse consultant. If there is a local palliative care network in place, they may be well positioned to take on the development of a local strategy that is co-ordinated and equitable. Any network would need to make sure that representatives from all the local agencies and commissioners are present around the table.

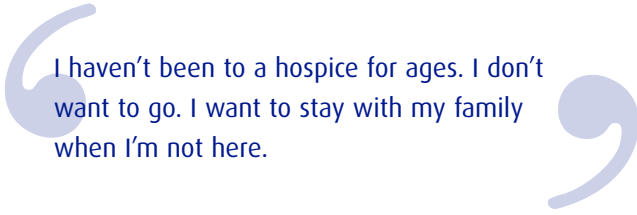
### Needs of the Young Person and Family

**Symptom management.** Anxieties around the issue of pain and symptom control are very common for families and professionals. Some of these symptoms can be distressing which can detract from the 'good enough memory' for families. However in most cases plans can be put in place so that symptoms can be alleviated quickly and effectively. It is good practice to discuss possible symptoms with young people, their families and carers, so that they won't be surprised by them if they occur.

A secure box containing emergency medication and syringe driver along with symptom guidelines can be a very helpful way of achieving this, as long as the person administering the drugs and treatment is trained and qualified to do so. This can be discussed at the multi-disciplinary meeting at the GP practice.

**Education.** The role of education may still play a very important part in the young person's life and it should therefore not be forgotten. The college or university community will need information and ongoing support.

**Short Breaks (Respite) Care.** Access to age appropriate short breaks is difficult for all young people with complex conditions, but is even less accessible for those in the end stage of their life. Paediatric and adult teams will often need to work together to provide appropriate short breaks.



I haven't been to a hospice for ages. I don't want to go. I want to stay with my family when I'm not here.

### 2.3.1 Phase 1: Planning for death

#### STANDARD 6

**When end of life is recognised there should be a review of the young person's and family's needs and goals and an end-of-life plan drawn up. This should be an inter-disciplinary 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.**

As soon as it is recognised that end-of-life care is needed the young person and their family will need to review their needs with the care team. A planning meeting will need to take place as soon as possible to plan care goals with the young person and their family to discuss the individual plans and management. This meeting will also need to review any previously made plans and set out clear guidelines around roles and responsibilities.

Many young people choose to die at home. For some, the terminal phase of their condition can be protracted and they may require complex packages of care and symptom management during this time. Therefore every young person and their family should be helped to develop an end-of-life plan and should be provided with the care and support they need to achieve this as closely as possible. There may well be conflicts between young people and their families, which will need to be addressed at an early stage.

The Liverpool Care Pathway and the Gold Standards Framework can be useful tools in this planning process as they can facilitate a conversation around end-of-life care (see appendix 2).

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Being at home for these last two weeks, was the one good thing that happened to us since she was diagnosed. It was the only privacy we had since she went into hospital for treatment. It was the only time she could do what she wanted to do. Choose to spend time with us, time with her friends, to be alone in her room or listen to her music, just like any other teenager. Thanks for allowing us this precious time.

The decision to move towards a goal of symptom control rather than curative treatment is a particularly sensitive time for families. The young person, wherever possible, and parents should feel their decision to stop any non-essential drugs or other invasive interventions is understood and respected. As mentioned previously it is helpful to discuss issues with the young person and family to develop an end-of-life care plan. Within this plan issues such as 'allowing a natural death' need to be addressed.

This may be in addition to an Advanced Directive (Living Will). It enables the discussion of more specific planning about issues such as whether they would prefer to remain at home and if so what needs to be in place to achieve this? Issues such as 'allowing natural death' (sometimes called DNR) are also included as are issues regarding proxy and Enduring or Lasting Power of Attorney.

The Advanced Care Plan is a statement that reflects the family's and young person's wishes at that particular point in time. It should be signed and dated, but can be updated at any time. A copy should be left with the patient and carer to inform future care. Local policies for Advanced Care Planning may be in place and procedures should be discussed with ambulance and emergency staff to avoid inappropriate resuscitation attempts or hospital admissions.

In developing an Advanced Directive and end-of-life plan there will be need to be close attention to the Mental Capacity Act. This Act affects everyone aged 16 and over and provides a statutory framework in England and Wales to empower and protect people who may not be able to make some decisions for themselves, for example, people with

dementia, learning disabilities, mental health problems, stroke or brain injuries. It sets out who can take decisions, in which situations, and how they should go about this. It also enables people to make provision for a time in the future when they may lack capacity to make some decisions. Professionals working with young people need to consider the relevance of the Act in relation to the care decisions being made; further guidance is available from <http://www.dca.gov.uk/legal-policy/mental-capacity/guidance.htm>

Good communication skills are needed in this sensitive area of care and professionals should have the opportunity to develop their communication skills via advanced communication skills courses. Some families will prefer to see the Advanced Care Plan sheet before discussing it. Although difficult, this type of advanced planning makes it more likely that wishes are fulfilled and that there are fewer emergency decisions.

### Key goals

1. The young person's emotional, cultural and spiritual needs should be met.
2. The young person and family should feel reassured that pain and other symptoms will be dealt with effectively.
3. The young person and family should feel reassured that every effort will be made to ensure that their death will take place according to their wishes in their place of choice wherever possible.
4. Family members and other carers should be supported, informed and involved.
5. The young person should have the best quality of life and care to the end.

### Goal 1: The young person's emotional, cultural and spiritual needs should be met

The young person should feel safe, loved, cared for and comforted during this time.

### Goal 2: The young person and family should feel reassured that pain and other symptoms will be dealt with effectively

A 'good' death must mean the young person receiving effective pain management and good control of other distressing symptoms, which may include: seizures, breathlessness, nausea, vomiting, and constipation. The young person and family dread suffering pain and distressing symptoms, therefore they need reassurance that these can be managed effectively and that the care team will be assessing and managing the young person's symptom management issues.

The young person should receive appropriate pain relief at regular intervals together with therapies to treat adverse side effects and other symptoms. Complementary or non-pharmacological therapies can play an important role in symptom management, but they need to be both age appropriate and in line with the young person's ability to communicate. This will be different for all young people and a base line assessment needs to be made. For example, school or college work is a good distraction for some young people and offers some respite from the trauma of what is going on. For others, aromatherapy, massage, reflexology and reiki can be helpful complementary treatments. For some, relaxation techniques and even hypnosis may have a role to play and may be a particular wish of the young person or their parents.

Fear can often play a significant role in young people's pain, therefore the need for honest and skilled communication is paramount. A desire to 'protect' the young person and not tell them too much for fear of worrying them may actually lead to increased anxiety as the young person doesn't understand what is happening.

Pain management of young people is complex and carers need access to expertise and training to ensure effective symptom management. Pain and other symptoms that are badly managed may result in unnecessary and distressing hospital admissions.

**Goal 3: 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**

Care should take place where possible wherever the young person and/or parents choose. This may be home, hospital or a hospice. If hospice is their place of choice, it is important

that it is age appropriate. The young person and parents may prefer a package of shared care options between home / hospital / hospice and this should be accommodated through collaborative inter-disciplinary working. It is also possible that young people and families may change their minds at short notice about where they want to die. This becomes an issue if the family become tired or symptoms are not being managed well. Therefore, it is important that wherever the place of care, the young person and family have access to 24-hour expert symptom management and palliative care. It is also important to acknowledge that the young person and their families/carers may encounter dilemmas about where they want to be cared for and who they would like to have with them.

Better advanced care planning with better information leads to less fear and fewer crisis admissions to hospital as:

- Young people live and die where they choose with better-controlled symptoms.
- Families are well supported, empowered and satisfied.
- Staff have confidence, communicate better and work better within a team.

**Goal 4: Family members and other carers should be supported, informed and involved**

Parents and other family members, including siblings and grandparents should be listened to, supported, kept fully informed and encouraged to continue their caring relationship with the young person throughout the end-of-life phase.

The young person may still be attending school or college and their place of education should continue to be involved and kept informed. Some young people will choose to continue to access education.

**Goal 5: The young person should have the best quality of life and care to the end**

Young people need to carry on with normal routines for as long as possible and need to see their friends and carry on with activities that they have enjoyed in the past. Many young people crave 'normality' and they should be enabled to live as ordinary a life as possible during the terminal phase of their condition. There may be a clash between the

## Part 2 | The Transition Pathway

young person and parents over who is viewed as the 'most important person' to be with them. The care team will need to be sensitive to possible tensions and offer support to all parties.

Many young people gain comfort from planning their own funeral and will need support in this. They may want to discuss any special wishes they have surrounding their death, such as organ donation, writing letters, putting together a memory box or making a video.

### 2.3.2 Phase 2: Time of death

#### Goals during this phase will include:

1. There should be good care of the young person's body and of the family at the time of death.
2. Parents should retain their parenting role after the death of the young person.
3. Siblings should be supported and included in all decisions.
4. Parents should be asked whether they wish to take their child's body home, if appropriate.
5. All professionals/agencies should be informed of the death with the parents' consent.
6. Families should receive appropriate written information.
7. Plans for after death care should be revisited.

#### **Goal 1: There should be good care of the young person's body and of the family at the time of death**

This is by far the most painful stage for all involved in the care of a young person. The family will have to start to think about what needs to happen at the time of the young person's death and what needs to be put in place for this to happen. (Department of Health, 2005).

Some of the key issues at this time are:

- Effective pain and symptom control.
- Current medication assessed and non-essentials discontinued.
- The need for the young person to be with their parents/siblings/ grandparents/friends and other loved ones.

- Privacy and quiet for the young person and family.
- The time and space for the family's spiritual needs, religious beliefs and cultural practices.

Some of the key questions, which need to be addressed, are:

- Who needs to know?
- Who will sign the death certificate?
- What emergency situations in the home might arise?
- Does the Ambulance service need to be informed?
- Does the family have a letter which sets out their resuscitation status and other plans should an emergency arise?
- What out-of-hours medical cover has been planned and are they well informed about the young person's care needs at this stage? At the very least, has this been organised at the inter-disciplinary planning meeting within the GP practice.

#### **Goal 2: Parents should retain their parenting role after the death of the young person**

The young person's parents do not cease to have a parenting role after the death of their child. It is vital they feel that they retain control and choice in the care of their child's body. Parents need to have time and privacy with their child's body in the hours and days following the death. They should be consulted about whether they wish to be involved in laying out their child's body and choosing their clothes. Parents should feel reassured that any care team members who touch their child's body would do so with dignity and respect. All care team members should respect the family's religious or cultural practices associated with care of the body after death.

Parents should be supported to hold on to some good memories of their child. They may wish to take photographs of their child or take a lock of their hair.

#### **Goal 3: Siblings should be supported and included in all decisions**

Siblings have been referred to as the 'Forgotten Mourners' as their needs can be overlooked by parents overcome with grief and by busy professionals. It is important that they receive support for their loss and grief and have the opportunity to ask questions. They may wish to see their sibling's body and will need support to do this.

Siblings need to be included in family gatherings and decisions that are made about funeral arrangements. They may wish to make a special contribution such as choosing a reading or prayer at the service. They may also wish to place mementoes in their sibling's coffin.

**Goal 4: Parents should be asked whether they wish to take their child's body home after death, if appropriate**

If a young person has died in hospital, it should be possible for parents to take home the body. Unless there is a need to inform the coroner, they will simply need to complete the necessary forms. They may also wish the body to go to a hospice that the young person has used in the past. There is now guidance from the Department of Health (England) on these issues (Department of Health, 2007).

If possible, it is easier if this decision is made before the death and recorded in the young person's notes. The funeral director should be able to provide parents with advice about care of their child's body.

**Goal 5: All professionals/agencies should be informed of the death with the parents' consent**

An up-to-date list should be kept with the young person's records of those who need to be contacted following the young person's death. This should be part of the key worker's role and contacts may include:

- The GP
- Hospital and community consultants
- Community and district nurses
- Spiritual or religious leaders
- Social worker
- School/college/university
- Ambulance /transport/wheelchair services
- Young person's place of respite care
- Therapists (e.g. Physiotherapist, Occupational Therapist, Speech & Language Therapist)
- Dietician and nutritional support suppliers

**Goal 6: Families should receive appropriate written information**

Families should have written information with regard to:

- Registering the death.

- Procedure if they wish their child to be cremated.
- Contact numbers for funeral directors.
- Advice on benefits and entitlements including help with funeral expenses.

**Goal 7: Plans for after death care should be revisited**

Planning for this stage starts at the very beginning of the pathway, but will need to be revisited at the time of the young person's death. Families will need to know what is possible and may need support in planning the funeral.

**2.3.3 Phase 3: After death**

Bereavement support should be offered as part of the 'package' of care by a trained bereavement support worker and be continued for as long as the family need it. Some families may need specialised bereavement support from outside agencies and these will need to be signposted for the family. They may also need to talk to somebody who was not involved in the care of their child or sibling.

'To live through the death of your child is perhaps one of the most painful experiences known to humankind. It is instinctive in parents to nourish and protect their child. Death is to be fought, even to the point of sacrificing your own life, but sometimes the fight is lost. Life is quite literally beyond control. The death of your child leaves you feeling helpless, guilty, powerless and broken'.  
(Sister Frances Dominica, 1997).

'Nothing can take the pain away and poor care can exacerbate and prolong families' distress, whilst care that is sensitive and appropriate can help families in their grief. The effects of this are positive and long lasting.'  
(Child Bereavement Trust, 2003)

**Key goals:**

1. All family members should be supported according to their individual needs.
2. All family members should receive support for as long as they need it and from appropriately trained staff.

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### to their individual needs

There should be an awareness of the individuality of grief and the different patterns it takes in different members of the family, including siblings (Smith, 1999). All family members need to feel empowered to ask for the help they really need. Professionals who have been trained in this area of care and/or who were involved with the family before the young person's death are best placed to give this support. Support provided should always reflect and respect the family's culture and ethnic background.

**Goal 2: All family members should receive support for as long as they need it and from appropriately trained staff**

Support should be adapted to reflect the changing needs of the family as time passes after the young person's death. The family's key worker should have knowledge of their particular needs in bereavement and be able to refer them on to a trained bereavement support worker if required.

It is important to maintain frequent contact with the family and to remember those times that can be particularly difficult, such as religious festivals, birthdays or the anniversary of the young person's death.

'The death of their child is not the end of the pathway for a family. The journey continues albeit in a very different way.'

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### Appendix I: The Transition Care Pathway

#### STAGE 1: Recognising the need to move on

##### STANDARD 1: Sharing significant news

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.

**Goal 1:** News should be shared in a face-to-face discussion in privacy.

**Goal 2:** Families should be together to receive the news.

**Goal 3:** Helpful written material should be provided and information conveyed in readily understandable language.

##### STANDARD 2: Approaching adolescence

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.

**Goal 1:** Transition should be an actively managed process.

**Goal 2:** Young people should be listened to, involved and encouraged to ask questions, express opinions and make decisions.

**Goal 3:** A key worker should be identified for each young person to take them forward to the next stage.

**Goal 4:** Dedicated facilities should be used for young people when possible.

**Goal 5:** There should be good inter-agency and inter-disciplinary co-ordination across statutory and voluntary sector and adult/paediatric services.

**Goal 6:** Training needs of both adult and paediatric providers should be considered.

#### STAGE 2: Moving on

##### STANDARD 3: Proactive planning

Every young person with a life-limiting or life-threatening condition has a right to plan proactively for their future.

**Goal 1:** Transition Planning continues even during times of uncertainty.

**Goal 2:** Young People and their Parents will be helped with the transition from family-centred to young person-centred care.

**Goal 3:** Every young person will 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.

**Goal 4:** Every young person will be empowered to consider future plans, which are supported by a full multi-agency assessment.

**Goal 5:** Every young person should have an appropriate reciprocal service identified in adult services.

##### STANDARD 4

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.

**Goal 1:** An appropriate holistic care team will take over the young person's therapy and care needs.

**Goal 2:** A person-centred co-ordinated care plan is developed.

**Goal 3:** Appropriate funding will be identified to enable transition.

**Goal 4:** Transition is a planned and staged process

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### STANDARD 5

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.

**Goal 1:** There is an overlap of care team and resources until a sustainable adult service is established.

**Goal 2:** Young people are kept out of hospital.

**Goal 3:** Transportation is facilitated.

**Goal 4:** There is evaluation of the process.

### STAGE 3: End of Life

#### PHASE 1: Planning for death

### STANDARD 6

When end of life is recognised there should be a review of the young person's and family's needs and goals and an end-of-life plan drawn up. This should be an inter-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.

**Goal 1:** The young person's emotional, cultural and spiritual needs should be met.

**Goal 2:** The young person and family should feel reassured that pain and other symptoms will be dealt with effectively.

**Goal 3:** 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.

**Goal 4:** Family members and other carers should be supported, informed and involved.

**Goal 5:** The young person should have the best quality of life and care to the end.

#### PHASE 2: Time of death

**Goal 1:** There should be good care of the young person's body and of the family at the time of death.

**Goal 2:** Parents should retain their parenting role after the death of the young person.

**Goal 3:** Siblings should be supported and included in all decisions.

**Goal 4:** Parents should be asked whether they wish to take their child's body home, if appropriate.

**Goal 5:** All professionals/agencies should be informed of the death with the parents' consent.

**Goal 6:** Families should receive appropriate written information.

**Goal 7:** Plans for after death care should be revisited.

#### PHASE 3: After death

**Goal 1:** All family members should be supported according to their individual needs.

**Goal 2:** All family members should receive support for as long as they need it and from appropriately trained staff.

## APPENDIX II: Adult Palliative Care Guidance & Policy

**Preferred Place of Care.** The preferred place of care document is a patient held record, designed to record and monitor patient and carer choices and services received by all terminally ill patients. It aims to give patients and carers choices and aid communication between visiting professionals.

**Liverpool Care Pathway.** The Liverpool Care Pathways (LCP) for dying children and adults, are useful tools for the last days and hours of life. The LCP has been developed to transfer the hospice model of care into other care settings. It is a multi-professional pathway, which provides an evidence-based framework for end-of-life care. It provides guidance on different aspects of care required, including comfort measures, anticipatory prescribing of medicines and discontinuation of inappropriate interventions. The Pathway is recognized by the ambulance service and if in place the paramedics will not take the person into hospital. Following the pathway can help to ensure that the right drugs and syringe drivers are set up in the patient's house by the district nurse or GP to ensure that pain and other symptoms are controlled and that the patient is comfortable

**Gold Standards Framework.** The Gold Standards Framework (GSF) programme is a means to improving home care provided by primary health care teams for all patients in the final 6 to 8 months of life. It offers primary health care teams the tools and resources to help improve the planning of palliative care so that they can fulfil the wishes of patients and carers. It also improves staff satisfaction and morale and has a positive impact on hospital admissions and waiting times. GSF involves the identification of people with palliative care needs estimated to be in the final year or so of life, assessment of their needs and issues and planning – both clinical management plans and advanced care planning discussions. The GSF Supportive Care Register includes all people with any life-limiting condition and enables good planning and provision of care to help people to live well until they die. There is also a GSF in Care Homes Programme that includes care of some children, all those in transition with disabilities or life-limiting conditions. By improving the proactive care and communication, there is evidence of an improvement in quality and patient outcomes (eg, more home deaths) and improvement in cost effectiveness. For more details see [www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)

## Part 3 | Appendices

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# foreword