

Stepping Up

A guide to enabling a good transition to adulthood for young people with life-limiting and life-threatening conditions



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A guide to developing a good transition to adulthood for young people with life-limiting and life-threatening conditions

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Foreword

21 year old Lucy Watts, who has Ehlers-Danlos Syndrome, explains why good transition to adult care is essential.



Fantastic advances in medicine mean that more and more children with life-limiting conditions are living into young adulthood and beyond. I am one of these lucky young adults who have benefitted from these advances and I have been fortunate enough to celebrate my 21st birthday.

The transition from children's to adult services can be a scary and confusing time. Young adults must leave the people, teams and services they have built a trusting relationship with for new specialists, new services and a different system with an unfamiliar approach. It can seem daunting and the number of changes can be overwhelming. My own transition was very mixed. My transition with social services was fantastic, preparing me well in advance, supporting me and taking everything at a pace that I was happy with and able to cope with. However, within health services, there was no transition of care. I was discharged from a paediatric ward on one visit and my next hospital admission was onto an adult ward with five other elderly dementia patients. I was suddenly expected to make decisions alone, when only weeks before my mum had been at my side to support me through any medical decisions I needed to make. I had to start again in adult services with new doctors and a system that is vastly different from children's services.

As young adults we need to be supported to achieve the best quality of life possible, and this guide is here to assist you in making our transitions smooth and manageable. We are not children any more, however we are also not yet mature, experienced adults either. We need to be treated and respected like adults, but still supported in our transition into adulthood with age and ability appropriate assistance. We need to be at the centre of our care but still have the support of our parents or a trusted person who can help us to make decisions and support us in managing our life, our care, finances and other aspects of our lives like relationships, education and employment. Our transition needs to encompass all aspects of adulthood and we

need to be prepared for this. It's not only the transition of care, but the transition into adulthood and all the responsibilities and expectations of being an adult. We need to be supported into higher education if that is what we want, to help us navigate the benefit system to get the financial help we need, or to be supported into paid and/or voluntary work. We also need to be supported fully in managing our healthcare and facing and preparing for the inevitable deterioration in our health. Having an end of life plan is vitally important. We need to have our wishes written down while we are able to make these plans, but know that these can be altered at any stage if things change.

Stepping Up sets out how all services and individuals can work together to give the young person the best transition possible, how the young people need to be prepared for and supported through transition and how adult services can accommodate these young people. I must stress that there is no one-size-fits-all way to do this, services and individuals must be flexible and adapt the pathway to suit the young person in question. Plans need to be in place, and the young person prepared for their transition from as early as age 14.

I am so grateful to all the people who have worked hard to put this transition guide together. If service providers use this holistic guide, it will give each young adult a smooth, successful and enriching transition into adulthood, giving them the best opportunities in adult life.

Lucy Watts

Introduction

We know that the population of young people with life-limiting or life-threatening conditions is growing and it is vital that their 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.

Stepping Up aims to provide a generic framework that can be adapted locally to plan multi-agency services for young people with life-limiting or life-threatening health conditions as they become adults and move into adult service provision. Multi-agency working involves services in the statutory sector, voluntary sector agencies and independent providers, as well as those employed directly by the young person and their family through direct payments.

In 2007, ACT published the first edition of the *Transition Pathway* which set out a generic pathway for planning services around the needs of young people. We now recognise that we need to adopt an even more holistic approach to supporting these young people into adulthood. This includes providing for their health needs and planning for their end of life provision, but must also focus more on involving the range of agencies who can be engaged in providing them with the life chances that they deserve. This document builds on the original version of the ACT *Transition Pathway* and includes learning from the most recent evidence and knowledge about transition for young people with life-limiting or life-threatening conditions.

An important development since the publication of the original ACT Pathway has been the establishment by Together for Short Lives of a UK wide Transition Taskforce. This document captures the vision and approach of the Transition Taskforce and provides a framework within which this can be considered and implemented locally.

The reforms to Special Educational Needs and Disability services for young people aged up to 25 in England and similar approaches in Scotland, Wales and Northern Ireland have the potential to provide a much more joined up experience of transition for disabled young people. But we are not there yet, particularly in relation to health. The findings from the 2014 Care Quality Commission report "From the Pond into the Sea" show that young people with complex health needs do not always receive the care and support they need when they move on to adult care services.

Key changes since the 2007 version of the ACT *Transition Pathway*:

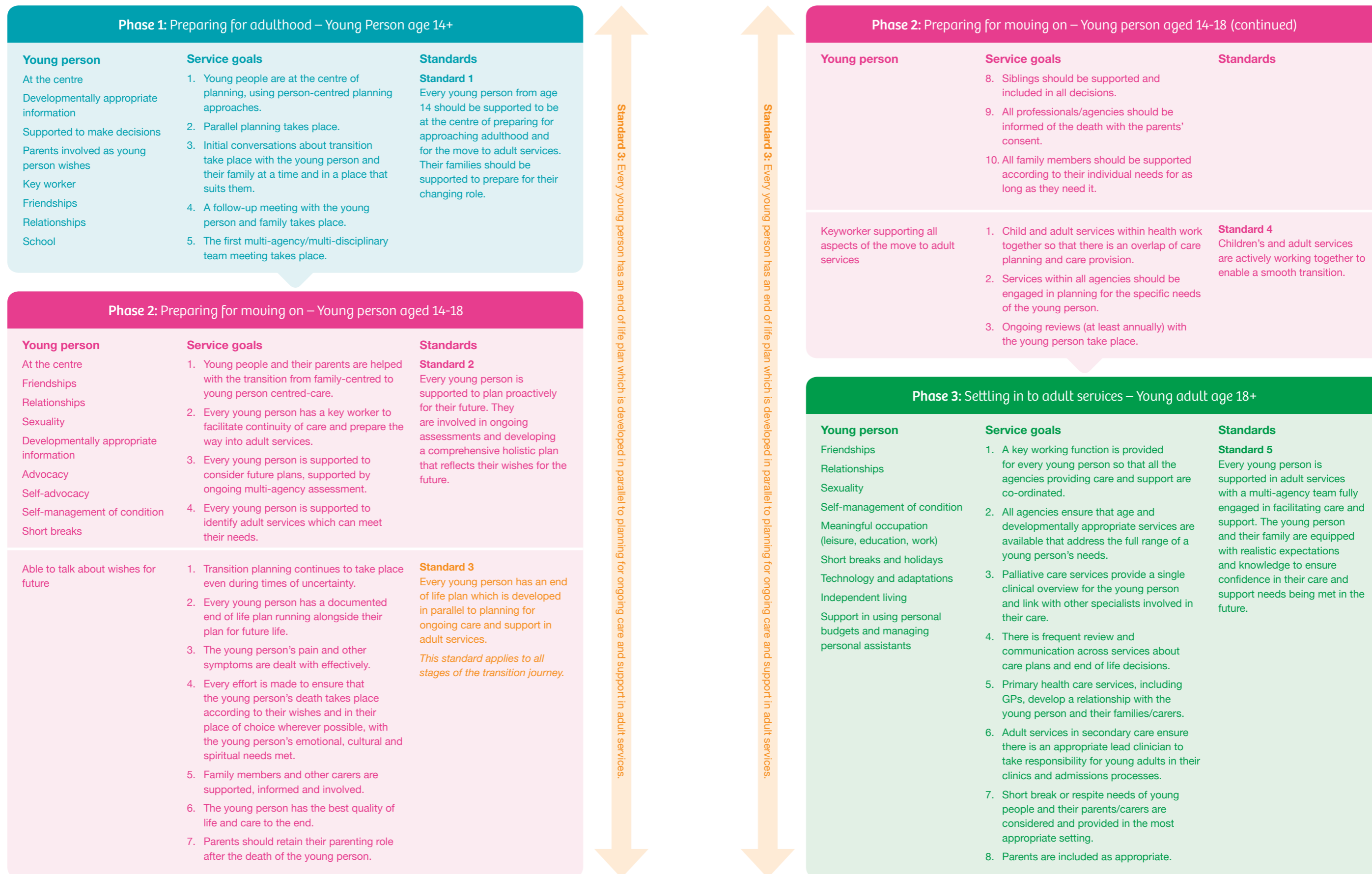
- A stronger focus on enabling young people to maximise their potential, rather than a focus on the process of transition between services.
- A move away from the term 'pathway' as this can be misconstrued in the adult palliative care context.
- A more multi-agency approach, enabling young people to live their lives to the fullest extent possible, including health, social care, education, employment and housing/independent living.
- An approach which is more about supporting young people who have life-limiting or life-threatening conditions in all aspects of their lives, with less focus on the children's palliative care providers' perspective.
- More focus on the adult service providers' perspective and how they can support young people through transition and enable them to feel settled in adult care.
- Greater focus on the need for parallel planning throughout the transition process, so that plans are continually reviewed to meet the young person's ongoing care and support needs as well as their plans for end of life care.

Stepping Up is written to support the transition of young people with life-limiting conditions in all aspects of their life. It provides a multi-agency framework to support local planning. It is written from the perspective of health services being the lead agency in this process as the young people we are concerned with have such significant health issues.

We have included the standard about end of life in the middle of the document, because the focus is about enabling young people to feel settled in adult services. We also want to reflect the fact that death can occur at any point during transition for young people with life-limiting conditions – which is why parallel planning is so important from the beginning of planning for transition.

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

Diagram of the transition journey



Background

What do we mean by transition?

Young people will experience many types of transition. This guide is focussed on the important transition from children's to adult services.

One well known definition of transition is that it is:

"...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)

In this guide we explore the process of transition and how it can be improved in all these spheres and beyond to ensure that there are good outcomes for young people with complex and life-limiting health conditions.

Although we are not just concerned with the palliative care service input for these young people, their complex, unpredictable and deteriorating health needs are often the element of a care package that makes it so difficult for them to achieve their goals as young adults. Health care must underpin the provision of all other services so that young people and their families feel confident that their medical and nursing needs will be met, whatever setting they are in.

What is palliative care?

The following two definitions show the similarities and some of the differences between children's and adult palliative care.

Children's palliative care

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.

Together for Short Lives, 2012

Adult palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

World Health Organisation, 2002

One of the historical reasons for transition being so difficult for young people with life-limiting conditions is because of the differences between the services provided by adult hospice and palliative care services and those in the children's hospice and palliative care sector. Put very simplistically, the adult palliative care sector has previously, by necessity of numbers, been more focused on those expected to die within the coming months or year, especially the elderly and those with cancer. This is changing, with many adult palliative care services now providing care over a longer period for those with long term conditions such as Motor Neurone Disease or Chronic Obstructive Pulmonary Disorder – conditions which have parallels to conditions familiar in children's palliative care such as Duchene muscular dystrophy or respiratory difficulties. There is now growing recognition among adult providers of the need to adapt services to better meet the needs of young adults; to work alongside children's services to help them to prepare for transition to their care; to feel more confident about talking with young people; to better understand their health conditions and to create environments that better cater for their needs.

Who will benefit from this guide?

We know from research by Fraser et al (Fraser, 2013) that the numbers of young adults with life-limiting and life-threatening conditions are much higher than previously thought and that the numbers are increasing. Over the 10 years of data collection (2000-2010) the prevalence had increased from 26 to 34.6 per 10,000 population, an increase of 33%. This increase has come about because many young people are now living longer due to improvements in medical technology, such as night-time ventilation.

There were 55,721 young adults aged 18-40 living with a life-limiting or life-threatening condition in England in 2009/10 and 12,827 of these were in the 18-25 year age group. This is a small, but significant and growing proportion of the total population of adults living with a life-limiting or life-threatening illness.

Some 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 (Together for Short Lives, 2013):

- 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 and 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 and 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 and mucopolysaccharidosis.**
- 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 and severe cerebral palsy.**

Young adulthood as a distinct phase

It is important to consider the needs and attitudes of young people with a life-limiting condition in the context of normal adolescence. Over the past 60 years our understanding of the sociology, social, developmental and educational psychology of young people has crystallised (Coleman & Hendry, 1999) and there are good descriptions of the 'developmental tasks' that young people meet during key phases of adolescence, for example in the following table, which is derived from the work of Stevens and Dunsmore (1996).

	Early adolescence 12-14 years (female) 13-15 years (male)	Middle adolescence 14-16 years	Late adolescence 17-24 years
Key issues & characteristics	Focus on development of body Most pubertal changes occur Rapid physical growth Acceptance by peers Idealism Mood swings, contrariness & temper tantrums Daydreaming	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"> • careers • relationships • lifestyles
Social, relationships, behaviour	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
Impact of life-threatening illness	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 authority figures 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

As well as the physical development during adolescence, young adulthood is recognised as a distinct phase of cognitive development which impacts many young people's ability and capacity to manage their own health care, make decisions and their attitude to taking risks.

Issues for young people

Over the years we have heard from young people about their experiences of transition. More recently we spoke with young people involved in the Transition Taskforce about what is important to them as they grow up and become young adults.

All young people want to be seen first and foremost as individual young people with their own views and aspirations, not to be defined by their health condition. Although every young person will of course have individual plans and wishes, there are many priorities in common:

- Independence.
- Friendships.
- Relationships and intimacy with partners.
- Information they can easily access and understand.
- Education and/or vocational training.
- Access to meaningful work opportunities.
- Suitable housing.
- Involvement in decision making, with parental support if requested.
- Short breaks, holidays, fun and leisure time.
- Reliable and comfortable transport and wheelchairs.
- To have an advocate and/or key worker who can co-ordinate their transition.
- Emotional support and a trusted professional to talk to about issues such as end of life planning, when the time is right for them.

It is also important to remember that there are many young people with severe cognitive impairments who will need considerable support to reach their goals in life and for whom 'independence' in its true sense is not realistic. All young people should be supported in communicating their future aspirations and in planning ahead within a person-centred framework which enables them to develop socially, emotionally and psychologically and to lead fulfilling lives in which they are supported to achieve their goals.

Issues for parents/carers

We spoke with parents who are members of the Transition Taskforce parent carer group and they outlined some key priority areas which they would like to see addressed:

- Person-centred working across all agencies.
- Better education of adult healthcare services so they understand the complex nature of the conditions affecting their children.
- Greater understanding of the transition process in healthcare, especially in hospital settings, with more dedicated adolescent and young adult units.
- Acknowledgement of the needs and wishes of young adults as they approach independent living and university.
- Improvements in how professionals speak and listen to the young person and their families/carers.
- More suitable short breaks for young people.
- Dedicated multi-agency transition teams in all areas for young people aged 14-25.
- Simpler funding arrangements with joined up education, health and social care budgets.
- Provision of better information for young people so they know where support will come from as they progress into adulthood.

Issues for siblings

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. Many siblings assume the role of carer and find that as their brother or sister approaches adulthood the demands on them became greater. For siblings who have assumed a caring role there may be pressure from themselves or their family to put their own life on hold (eg not going away to university or college), but they need to prepare for life without their sibling and should be encouraged to move on with their own life.

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. 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.

The following areas have been identified as key issues for siblings:

- Being able to be 'just a sibling' to their brother or sister and not just be seen as a resource for care and support, whilst also having their experiences and expertise acknowledged and being included proactively in the transition process for their brother or sister.
- Being supported with the big transitions in their own lives which are often happening around the same time for many siblings.
- Access to information about their own rights to assessment and support as young carers and young adult carers including opportunities that promote their wellbeing and resilience such as one to one work or siblings' groups.
- Access to facilitation by professionals of difficult discussions between family members.
- Being identified as siblings and young adult carers within educational settings so that barriers to their learning and wellbeing are addressed.

Information about sibling support is available from the charity Sibs www.sibs.org.uk

Issues for service providers

- Professionals in the children's sector need to 'let go' and really support young people to embrace transition to adulthood as a positive step. Similarly, professionals working in adult services need to reach out to young people to get to know them and to help them to feel comfortable and settled in new and unfamiliar adult services.
- Those in children's and adult services will need to develop their skills and knowledge of communicating with young people. It is difficult both for staff trained to support younger children as well as for those used to working with older people.
- Professionals working in adult services in particular may need to develop skills and knowledge about the range of complex health conditions affecting this population of young people and the implications of these health conditions for their daily living.
- It is important that staff are familiar with the Mental Capacity Act and Deprivation of Liberties Safeguards and the implications of these when supporting young people as they move towards person-centred rather than child and family-centred care. It is important to also recognise that many young adults still need and want support from their families in some decision-making processes.

- Partnership working between agencies is crucial and must involve all the agencies that need to be in place around a young person: health, social care, education, employment and housing.

Issues for commissioners

Some of the key points for commissioners to consider are:

- What do young people with life-limiting conditions need?
- How does this differ from children or older adults?
- How many young people with life-limiting conditions should services be commissioned for?
- Who provides services to young people with life-limiting conditions?
- Who else should be involved in commissioning for this population?
- What outcomes can be improved through good commissioning?

Further information about commissioning for transition is available in the Together for Short Lives *Transition Guidance for Clinical Commissioning Groups* (2015).

The transition journey

1

Phase 1: Preparing for adulthood

“We would like to see a holistic, joined up person-centred approach – with all systems being tailored around the needs of our young people.”

Parent

Introduction

It is now widely recognised that the transition process should begin at or around the age of 14 years to tie in with the Year 9 school review. This section of the document describes the processes and conditions that are required in order to begin the process of moving from children’s to adult services. For the process of transition to be successful it is essential that everyone involved acknowledges the need to move on and engages with the process. This includes professionals, the young person and the family.

“In the end, culture will trump rules, standards and control strategies every single time.” (Berwick Report, August 2013)

For transition to be managed successfully, the professional team needs a culture of raising and progressing the process of moving on. This includes both children’s and adult teams. Whilst policies and procedures have their place it is the attitudes of those involved and the culture of the organisations in which they work that will ultimately lay the foundations for a successful transition.

A positive culture will celebrate the achievement that the young person and their family have made in reaching the age of transition. This is becoming more common as supportive treatments enable many young people to survive much longer. Professionals and teams can demonstrate this by having a positive approach, acknowledging the limitations of children’s services and recognising the benefits of adult services in supporting young people as they reach adulthood. It is everybody’s responsibility to understand the need for dynamic plans, appreciating that every young person is different, and every transition plan will be unique.

A positive approach can be supported by exposure to adult services and commissioning, links to transition groups, community groups, the development of relationships, partnerships and networks, and learning from examples of good practice, enhanced through robust training and development.

Many young people who live in England will already have an Education, Health and Care (EHC) Plan (Children and Families Act, 2014) which takes a person-centred, outcomes-focussed approach to planning care. Of particular interest will be

the young person and family's own contribution around future aspirations and wishes. Wherever possible this should be used as a framework for developing an integrated transition plan to take the young person forward into adult services.

Together for Short Lives has supported a number of useful resources that are designed to support professionals working with young people who are approaching transition. These include:

The STEPP Project: Supporting health transitions for young people with life-limiting conditions: researching evidence of positive practice (2013). This research involved interviews with young people, families and professionals to identify small changes in practice that can make a big difference to the experiences of young people and their families within adult health care settings. Key findings from the research related to:

- who a young person is and how young people with life-limiting conditions differ from their peers
- young people and their parents' involvement
- early days in the adult clinic
- staying on an adult ward
- helping young people deal with uncertainty
- conversations around end of life
- developing partnerships with palliative care services
- when a young person dies – bereavement support for parents.

The Bridging the Gap Project (2014). The primary purpose of this work was to identify the specific palliative care elements and needs of young people in transition. The project developed a practice guide which outlines six planning tools that captures health and social care issues that are commonly missed in transition plans.

Other useful tools that support transition are the Ready Steady Go materials, a transition toolkit produced by Helen and Douglas House and the many transition resources available on the websites of the Preparing for Adulthood programme and the Transition Information Network.



Transition in practice

East Midlands Young Adult Renal Service

The East Midlands Young Adult Renal Service exists to support young adults aged 18-25 with kidney disease in Nottingham and Derby to support and empower them to take greater control of their health condition and achieve their future aspirations. The service also supports young adults in paediatric care who are preparing to transfer to the adult renal units. The service provides specialist support to young adults accessing renal care at the hospitals through a young adult worker who can provide one-to-one support on a range of health and social care topics as well as group activities. At the request of young adults, these activities are generally social events which allow them to meet each other in an informal environment to form friendships which can grow into ongoing peer support. The qualified youth worker offers a new skill set and perspective to both the young adults themselves and the team caring for this group of patients.

Standard 1

“Planning for independent living – or for any kind of support – takes time and you have to start as early as possible. It took me nearly two years and for young people like me, two years is a long time.”
Young person

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

Key goals:

1. Young people are at the centre of planning, using person-centred planning approaches.
2. Parallel planning takes place.
3. Initial conversations about transition take place with the young person and their family at a time and in a place that suits them.
4. A follow-up meeting with the young person and family takes place.
5. The first multi-agency/multi-disciplinary team meeting takes place.

Transition in practice

Whitby Lodge, Martin House

Whitby Lodge opened in 2002 and was the first specialist hospice facility for teenagers and young adults in the UK. The young people were included in discussions along the way; meeting with the architects and taking into account their ideas on how they wanted to use the facility. This involvement has continued over the years, with the young people helping to design the new, high-tech social centre in Whitby Lodge, the 'Den', which opened in 2014. The Lodge offers the teenagers and young adults as much independence as possible when they come to stay and allows them the chance to do things other young people do, in the company of their peers.

Teenagers can use the Lodge from the age of 13 and children 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 in Whitby Lodge. The Lodge has six bedrooms, plus a recording studio and the 'Den'. There is also accommodation available for parents if required.

“The team has 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



Goal 1: Young people are at the centre of planning, using person-centred planning approaches

There are three key principles of person-centred planning (Sanderson, 2000) which are:

- The person is at the centre.
- The person is consulted throughout the planning process.
- The person chooses the setting and timing of meetings.

Family members and/or friends should also be partners in the meeting and it is essential that planning focuses on the life of the young person and not just services, so that it reflects what is possible and not just what is available.

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.

Using person-centred planning can:

- help young people to work out what they want in their lives, increase their self esteem and make them feel emotionally stronger
- 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

"I want to have my own home and 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."

Young person

As part of a person-centred approach it is important to ensure that a young person's ethnic background and any specific cultural needs are considered. To enable a young person to communicate and be fully engaged in planning for their future it may be necessary to use interpreters who have received special training. Consideration may need to be given to specific care issues, for example providing care workers who are the same sex as the young person.

Opportunities should also be given for a young person to talk about relationships, intimacy and sexuality. This can be a really important area of life for young people as they mature as adults and want to know about starting relationships, possibly getting married and having children of their own. Together for Short Lives is currently working with the Open University to develop guidance on sexuality issues for young people with life-limiting conditions.

"My parents didn't like the way professionals talked to me at assessments. They were focussed on my needs rather than goals. Once they identified what I needed they then had an open debate about who was responsible for sorting it out. It was really impersonal."

Young person

Goal 2: Parallel planning takes place

It is important to recognise that children and young people with a life-limiting or life-threatening condition may have significant periods of clinical instability that suggest they are moving into an end of life phase, but from which they later recover. Parallel planning means that the process of transition and moving on will always stay focussed on the wishes and aspirations of the young person and their family, whilst ensuring that they remain well supported should the young person's condition deteriorate and require end of life care.

It is very difficult to start conversations about end of life with young people who are very much focussed on living their lives to the full, but it is important that the issue is discussed and documented. A short guide on having difficult conversations about end of life care with young adults has been produced by National Council for Palliative Care in partnership with Together for Short Lives (NCPC & Together for Short Lives, 2015).

Goal 3: Initial conversations about transition take place with the young person and their family at a time and in a place that suits them

With the family

The initial conversation should take an outcome-focussed approach and should take account of future wishes and aspirations. It is important that this conversation is well planned and that good preparation has taken place, including consideration of who should be involved and who should lead the discussions. The ideal person would be respected, trusted and well known to the family, and have the authority to bring about change.

Consideration should be given to the timing of the meeting to ensure that all key family members are able to be present and have enough time to make a full contribution. An appropriate environment is also important as this will enable everyone to feel relaxed, for example, ensuring that the meeting takes place in familiar surroundings, with minimal interruptions and that privacy is maintained throughout.

There should be a positive focus to setting the scene around the concept of transition and moving on. This is vital to the family's perceptions of the process and its ultimate success. There should be a clear commitment to understanding any concerns and answering the family's questions. Relevant information and resources should be made available and it is important to clarify the support that will be accessible throughout the period of moving on. A written summary of the discussion should be made available as soon as possible and a timely follow up date agreed.

With the young person

Wherever possible the young person should be integral and at the centre of any initial discussion along with their family, however if appropriate, they should also be offered an opportunity to meet with the lead professional on their own or with a chosen supporter. Again it is important to consider the best time of the day for the young person and to be mindful of the environment, as well as any communication needs. There should be an opportunity to explore the concept of moving on and outline a commitment to person centred planning, wishes and aspirations.

Discussions with the young person should maintain a positive approach; recognise cognitive awareness and understanding, and ongoing physical and psychological development. They should be given information about ongoing support, including the role of an advocate and should be given the opportunity to raise concerns and ask questions. Again a summary of the discussion and agreements should be made available in an appropriate format as soon as possible and a timely follow-up date agreed.

Goal 4: A follow-up meeting with the young person and family takes place

A follow-up meeting with the young person and family should take place as soon as possible. The purpose of this meeting is to review the initial discussions, identify differences of opinion/barriers (between family members) and explore any questions or concerns. It will also be an opportunity to build on the positive aspects of moving on, and introduce new names and people who will become involved with the young person and family in due course. The meeting should also reinforce commitment to parallel planning, and prepare the young person and family for their first transition planning meeting. Following discussions, consent should be sought to share information with all professionals involved and a multi-agency/multi-disciplinary team meeting should be convened as soon as possible.

Goal 5: The first multi-agency/multi-disciplinary team meeting takes place

The meeting chair should be agreed beforehand, during the discussions with the young person and their family. As discussed previously, the ideal person would be respected, trusted and well known to the family, and have the authority to bring about change.

It is the chair's role to ensure that the following principles are adhered to:

- The agenda should be set by previous discussions with the young person and their family and be centred on their hopes and aspirations.
- Tools such as pictures, videos or written information should be used to keep the young person at the centre.
- The key worker should be identified at this meeting.
- This phase of the process is likely to be exploratory and initial outcomes may be for individual professionals to gain understanding of the young person and family's aspirations in order to focus on these when searching for resources and services.
- Everyone involved should be made aware of their individual role and responsibilities in moving the process forward.

The meeting should be formally documented and a time and date agreed for a follow-up meeting. The minutes should confirm clear lines of responsibility and timescales, and a copy be made accessible to the young person and their family.

Transition in practice

Route 66

Route 66 is the name given to a group of projects which are all designed to improve the lives and experience of young adults (16 to 30) with life-limiting conditions living in Wales. Route 66 was set up in January 2013 and some of the projects run so far have included organising private accessible gigs with bands and jamming sessions and linking up with 'Jumbulance' (special coaches designed for disabled access) to facilitate an '18-30' type holiday. Route 66 has also run a series of training days for adult palliative care professionals, all of which have been very well received and evaluated.



2

Phase 2: Preparing to move on

"Health professionals need to realise it's people's lives they're working with. Transition is not only a massive time of change for the young person involved but for those around them that have played such a crucial care role until then."
Young person

Introduction

This phase will often continue over a period of three to four years and will provide ongoing preparation for the actual move to adult services, with regular multi-agency assessment meetings to work out exactly how different agencies and organisations will work together to meet the young person's needs. By the end of this phase there should be a written multi-agency transition plan in place and organisations from children's and adult services should be working together to achieve a smooth transition.

Parallel planning should continue to take place during this phase so that alongside planning for transition and future life as an adult there is planning in place for the young person's end of life care with their wishes recorded in a plan and shared with relevant agencies.

Throughout this phase of transition there will be a growing emphasis on ensuring that there is a change of focus from family-centred care to a young person-centred approach. It is important to work with families to support them to let go and to support the young person to build their confidence and abilities to make decisions.

Standard 2

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

Key goals:

1. Young people and their parents are helped with the transition from family-centred to young person centred-care.
2. Every young person has a key worker to facilitate continuity of care and prepare the way into adult services.
3. Every young person is supported to consider future plans, supported by ongoing multi-agency assessment.
4. Every young person is supported to identify adult services which can meet their needs.

Goal 1: Young people and their parents are helped with the transition from family-centred to young person-centred care

Moving to young person-centred care

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 and help them to articulate their wishes. In England there are Independent Support Advocates within every local authority that can provide this. 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.

Mental Capacity Act

Professionals and families should be aware of the legal implications of the Mental Capacity Act. They should have been prepared for the changes that it brings to the decision-making process during the earliest phase of transition planning and this process of change will continue during this phase of the transition journey.

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 for health and welfare". 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 and

treatments/interventions not felt to be medically appropriate cannot be demanded. This process can be very challenging for families.

Deprivation of Liberties Safeguards

The Deprivation of Liberty Safeguards (DoLS) are part of the Mental Capacity Act. They aim to make sure that people being cared for in settings such as care homes, hospitals, hospices and supported living are looked after in a way that does not inappropriately restrict their freedom. These safeguards can be difficult for parents/carers as they can challenge the way that they have cared for their child over the years. For example, it may no longer be considered appropriate to use cot sides or video surveillance as the young person becomes an adult. It is important that robust needs assessment and risk assessments are carried out to ensure that appropriate levels of safety are maintained.

Goal 2: Every young person has a key worker to facilitate continuity of care and prepare the way into adult services

All young people should have a named person who provides a key working function. There are different interpretations of the role and indeed a variety of models for achieving this. There may be a key worker allocated within children's services to facilitate continuity of care and who works towards 'handing over' to a key worker designate in adult services. Another model is to have a specific transition key worker or dedicated transition key worker team who bridges the transition to adult services, and helps to co-ordinate all the care and support that is needed, working in partnership with, but independently of, health, social or educational services and able to fulfil a practical co-ordination role.

Useful background about the role of a key worker in transition is provided in the report from the Bridging the Gap Study (Noyes, 2014).

Goal 3: Every young person is supported to consider future plans, supported by ongoing full multi-agency assessment

A young person's ability to shape his or her own multi-agency 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 young person's key worker will usually initiate this process in children's services.

A young person's needs from all agencies should be assessed and joined up where possible so that health elements are part of a wider transition plan. In England, healthcare assessments should form one part of the young person's EHC Plan (Children and Families Act, 2014). The young person should be encouraged to think about their future hopes and plans regarding education, employment, accommodation and supported living, leisure and other things in their life that are important to them.

Goal 4: Every young person is supported to identify adult services which can meet their needs

It is often the case that services which young people have been able to access in children's services are not available when a young person moves into adult services. Children's services will need to explore what adult services are available in their locality and work with them to provide support that is as flexible and responsive as possible to allow for fluctuating levels of need and a degree of continuity during transition.

A person centred-planning approach means that the needs of young people should remain the focus for planning any adult provision rather than trying to match a children's service with a matching service in adult care. It is often possible to identify services that will meet the needs of young people from an entirely different type of organisation or agency, with appropriate support and training.

For a number of young people any move towards independence will necessitate the support of a care team that can meet their health care needs in a variety of different settings. This team may include:

- staff at residential colleges
- social services – often via an agency contract
- health – through continuing health care packages
- commercial care agencies
- hospices and other charities
- directly employed staff via direct payments or personal health budgets

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?

Transition in practice

St Joseph's and Richard House

Initial discussions around transitional care were started in 2007 between St Joseph's and Richard House Children's Hospice. The Transition Lead at Richard House was instrumental in forging relationships with the Nurse Consultant appointed at St Joseph's and informing the transition project between the two hospices.

Richard House Children's Hospice begins the transition process normally by the time the young person is 14 in order to prepare them and their family for transition. St Joseph's holds young adult parties at the hospice in order for them to become

familiar with the services offered and the adult environment. Staff from the children's hospice come over and work alongside the adult hospice staff which really helps with joint working and planning.

Referrals are made via the 'first contact team' – all by telephone, no forms are required. St Joseph's is only licensed for people over 18 years of age so cannot take the young adults at a younger age. If the patient is not thought to be in the last year of life they are not covered by the contract and so are charged, but at a significantly reduced rate, to stay in the hospice. If they are considered to be at the end of life then they can come in under the terms of the contract for respite care, symptom control, and end of life care.

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. The above questions are equally important for young people to consider when employing staff directly.

There is now much more emphasis on young people (and/or their families) being in control of their care, whether directly or through an agency/broker, and having personal budgets to enable them to choose the kind of care and support that they want. Personal health budgets are increasingly popular among young adults and should be made available to all who wish to have one. Together for Short Lives has produced information about personal budgets, available from www.togetherforshortlives.org.uk/sendresources.

"I did consider managing my personal budget myself but my parents thought I should be enjoying life and focusing on my studies rather than worrying about managing my care. They didn't want me to be stressed by all the bureaucracy – directly employing five people was going to be a massive responsibility. There's a real tension being an employer to people who are providing at times very intimate care. The benefit of having a company managing my budget on my behalf is it takes all the HR pressure off whilst enabling me to retain full control. If there's ever any disagreement, the company acts as brokers and take all the strain off me."

Young person

Standard 3

Every young person has an end of life plan which is developed in parallel to planning for ongoing care and support in adult services.

We have included this standard about end of life in the middle of the document, because we want to reflect the fact that death can occur at any point during transition for young people with life-limiting conditions.

Key goals:

End of life planning

1. Transition planning continues to take place even during times of uncertainty.
2. Every young person has a documented end of life plan running alongside their plan for future life.

Time of death

3. The young person's pain and other symptoms are dealt with effectively.
4. Every effort is made to ensure that the young person's death takes place according to their wishes and in their place of choice wherever possible, with the young person's emotional, cultural and spiritual needs met.
5. Family members and other carers are supported, informed and involved.
6. The young person has the best quality of life and care to the end.

After death

7. Parents should retain their parenting role after the death of the young person.
8. Siblings should be supported and included in all decisions.
9. All professionals/agencies should be informed of the death with the parents' consent.
10. All family members should be supported according to their individual needs for as long as they need it.

End of life planning

Goal 1: Transition planning continues to take place even during times of uncertainty

By late adolescence many young people may have more 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 young people.

Transition planning can feel inappropriate as significant and frequent episodes of instability will often appear to signal the approach of end-of-life, but such periods of instability can come and go many times before the final end-of-life phase occurs. Young people who come through periods of instability often 'plateau' for a significant time in their condition. 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. It is important to retain hope for the young person and their family and there may need to be some training on this issue for those unfamiliar with transition planning for young people.

Parallel planning is a concept which aims to support the ongoing transition arrangements for young people so that they can hope and plan for the best whilst preparing for a scenario where things don't go as well as planned. In parallel planning, arrangements made for transition continue to be advanced so that placement opportunities are held and adult teams work with children's teams during a gradual handover process. If end stage care is reached then both children's 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.

Goal 2: Every young person has a documented end of life plan running alongside their plan for future life

A young person may reach the end of their life at any point along their transition journey. They should have developed an Advance Care Plan (ACP) with children's services which will contain both an active plan for life, including wishes for the management of reversible episodes of illness or acute events as well as decisions about end of life care and decisions about resuscitation. Advance Care Planning is a process of planning that will often have been developed in children's services in discussion with the wider clinical team and the resulting document or 'Plan' provides a written summary of previous discussions. Consideration will need to be given as to how the information that has been agreed and communicated as part of this Advance Care Plan can now be translated into the management and documented processes of adult services. The Advance Care Plan can be a useful stepping stone for discussions in adult services, so that the young person's needs can be reviewed and clear guidelines developed around roles and responsibilities. The Advance Care Plan is a statement that reflects the family's and young person's wishes at that particular point in time such as location of care and how they would like to be cared for. It is not legally binding.

End of Life Planning forms one part of the Advance Care Plan alongside planning for ongoing care. End of life planning may include discussions about care at the time of their natural end of life, discussions about place of death, decisions about stopping any non-essential drugs or other invasive interventions and DNACPR (do not attempt cardiopulmonary resuscitation). Decisions about the refusal of a specific treatment in specific circumstances are called Advance Directives or Advance Decisions and they are legally binding. They should be signed and dated, but can be updated at any time.

Young people wherever possible, and their parents, should feel that their decisions are understood, respected and in their best interest. There may well be conflicts between young people and their families, which will need to be addressed at an early stage.

It is likely to be a particularly difficult time for families when a decision is made to move towards care which is focused on symptom management and maintenance of comfort rather than actively curative treatment. It is important, however, to

encourage young people to speak openly about their wishes (NCPC & Together for Short Lives, 2015). The Gold Standards Framework provides useful tools in this planning process to facilitate a conversation around end-of-life care.

For some young people, the terminal phase of their condition can be protracted and they may require complex packages of care and symptom management during this time particularly if they have chosen to die at home. It is therefore really important that their wishes for end-of-life are discussed and documented so that they can be provided with the care and support they need to achieve this as closely as possible.

A copy of both the Advance Care Plan and any advance decisions should be left with the young person and their parent/carers to inform future care. Local policies 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 Advance Care Plan and advance decision to refuse treatment there will need to be close attention paid 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 www.gov.uk/government/collections/mental-capacity-act-making-decisions.

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.

Time of death

It is important that children's and adult teams work together to ensure that young people can have as 'good' a death as possible, with the appropriate support in place both for them and their families.

Goal 3: The young person's pain and other symptoms are dealt with effectively

A 'good' death must mean the young person receiving skilled medical and nursing assessment, explanation, agreement about management and review of symptoms, including effective pain management and good control of other distressing symptoms. Pain and symptom management of young people is complex and members of the care team will need access to expertise and training to ensure their skills are maintained and developed.

Goal 4: Every effort is made to ensure the young person's death takes place of choice wherever possible, with the young person's emotional, cultural and spiritual needs met

Care should take place where possible wherever the young person and/or their parents choose. This may be home, hospital, hospice or other residential setting. The young person may still be attending school or college and their place of education should continue to be involved and kept informed. The young person and their family may prefer a package of shared care options 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. The care team will need to be sensitive to possible tensions and offer support to all parties. The young person should feel safe, loved, cared for and comforted during this time.

Goal 5: Family members and other carers are supported, informed and involved

Parents and other family members, including siblings and grandparents should be supported, heard, kept fully informed and encouraged to continue their caring relationship with the young person throughout the end of life phase. Plans for after death care should be revisited and families provided with written information regarding the following:

- 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 6: The young person has the best quality of life and care to the end

Young people need to carry on with normal routines for as long as possible, 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.

Many young people gain comfort from planning their 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. They may also need support to write a will.

After death

When the young person dies it is important to ensure good support for their family and loved ones. There are some immediate practical issues which will need to be considered such as who needs to be informed about the death and who will sign the death certificate.

Goal 7: 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. Parents should be able to spend time in a quiet and private space with their child in the hours and days after their death. There should be good care of the young person's body and it is vital that families feel that they retain control and choice over this. Where it is appropriate, parents should have the opportunity to be involved in laying out their child's body and choosing their clothes. Parents should feel reassured that any of the care team who touch their child's body will do so with dignity and respect. All care staff should respect the family's religious or cultural practices associated with care of the body after death.

If a young person has died in hospital, it should be possible for parents to take the body home. Unless there is a need to inform the coroner, they will simply need to complete the necessary forms. If possible, it is easier if this decision is made before the death and recorded in the young person's notes or in their Advance Care Plan. The funeral director should be able to provide parents with advice about care of their child's body.

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

Goal 8: 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.

Wherever possible siblings should 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 make a memory box or place mementoes in their sibling's coffin.

Goal 9: 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
- Hospice Care Manager
- 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 and language therapist)
- dietician and nutritional support suppliers

Local protocols will need to be followed for reporting the deaths of young people aged under 18 to the Rapid Response Team and the local Child Death Overview Panel.

Goal 10: All family members should be supported according to their individual needs and for as long as they need it

Bereavement support should be offered as part of the 'package' of care and be continued for as long as the family need it, although the nature of the support may need to change with time. 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.

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.

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.



Transition in practice

The J's Hospice

The J's Hospice provides specialist palliative and respite care services for young adults aged 16-40 with life-limiting and life-threatening conditions across Essex. These services are delivered by a specialist team in the adult's own home, in the community and through the social group Inspire.

We recognise that young adults going through transition from children's to adult hospices and palliative care services face some very tough decisions in what can be a confusing and distressing time for their whole family. Transition is just one of the key areas in which the J's can offer specialist help – guiding them through the pathways, reducing their isolation and supporting their medical needs, whilst getting them the support they need.

The J's team has the experience and skills to support a young adult's medical needs balanced with all the other issues and difficulties the whole family may experience. The well-being and clinical teams reduce social isolation by improving relationships, enabling them to access their community and achieve their life goals, bringing a purpose back to their lives.

Throughout our aim is to give support and respite to family carers-recognising also when a young adult is nearing end of life and preparing them and their family for the difficult time ahead, ensuring that their final wishes and choices are respected.

"I would not be alive today without The J's, nor would I have had the quality of life we managed to achieve or the opportunities to make a difference. In my care plan are all of my favourite things, what I want out of life and what my needs are, they work with me to help me get the best out of life. My end of life plan enabled me to get on with life knowing my final wishes have been thought about, discussed and put down in writing. Doing my EOL plan was difficult but gave me a feeling of relief when it was completed."

Young person

Standard 4

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

Key goals:

1. **Children's and adult services within health work together so that there is an overlap of care planning and care provision.**
2. **Services within all agencies should be engaged in planning for the specific needs of the young person.**
3. **Ongoing reviews (at least annually) with the young person take place.**

Goal 1: Children's and adult services within health work together so that there is an overlap of care planning and care provision

At this stage of transition there should be more focus on establishing joint working with the services in adult health care which will be required. This partnership approach may include the following:

- Joint meetings to discuss transition strategy across organisations and establish a multi-disciplinary team to be established for young people approaching transition (particularly those who do not require continuing care) so that their needs can be identified, discussed and they can be signposted to the most appropriate services for joint planning.
- Joint child and adult clinics.
- Involvement of transition teams to consider funding packages such as continuing health care and how complex health care needs will be met.
- Joint working with adult hospices so that they can get to know the young person and receive any necessary training and support on the young person's conditions.
- Referral to the GP as lead practitioner.
- Health and social care funding assessments to take place.
- Identification of adult community health provision, for example learning disability teams/district nursing/nursing agencies.

Goal 2: Services within all agencies should be engaged in planning for the specific needs of the young person

As part of the development of a holistic transition plan, a range of agencies should come together to address the needs of each individual young person and to explore the following, for example:

- Whether there are appropriate courses and provision within Further and Higher Education.
- What support can be provided by local supported employment agencies if the young person wishes to enter paid employment.
- Opportunities for life skills development or vocational training that the young person may need.
- How the young person's wishes for independent living arrangements could be met.

"It's essential that health work closely with all the other statutory services to create a package that is right for that person. One weak link can make all the hard work from another agency fall apart."

Young person

Goal 3: Ongoing reviews (at least annually) with the young person take place

Once the initial transition plan has been developed it is important that it is reviewed regularly. This may be on an annual basis in line with the educational annual reviews or more frequently if needed.

Young people who do not have continuing care packages are at risk of falling through the net and there needs to be a mechanism for ensuring that they are not missed out.

As the young person approaches the move to adult services it is important to ensure that they remain informed about potential outcomes of decisions that they make and how these may impact on their life. Planning should remain positive and open for the young person, whilst also being sensitive to allowing the young person to talk openly about their emotions, deal with loss of independence or come to terms with their mortality.

It is important to remember that transition is not just about transferring to adult services but is also about supporting young people through adolescence and into adulthood. Whilst transition planning should not solely focus on managing their health condition, it should include supporting them to cope with the complications thrown at them because of their illness, such as being dependent on technology. The plans should also revisit any end of life wishes, to ensure that parallel planning is a thread that runs through the entire transition journey.

Transition in practice

The Bridge

Murray Hall Community Trust was provided with an old unused health centre building in Tipton. The charity worked in partnership with St Giles Hospice and Acorns Children's Hospice to transform it into a new transition centre. The new centre, called The Bridge is the first of its kind in the Midlands to be a dedicated space for young people with life-limiting and life-threatening illnesses in transition from children's services to adulthood. The centre will be available for people across Sandwell and surrounding areas to provide age appropriate care and support. Activities will include: bathing, sensory room, support groups, counselling, complementary therapy, information centre, training and skills development and much more.

3

Phase 3: Settling into adult services

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

Young person

Introduction

Transition is a fluid process but it should begin whether or not there are ongoing uncertainties about the state of the young person's health. Joint working between children's and adult services will be enhanced by standardising this approach but being flexible to the individual needs of each young person and their state of health as they approach adulthood. Any specific health care needs that are identified during transition should be discussed with the appropriate adult service in advance.

As described earlier in the document it is commonplace for there to be multiple healthcare/ social care/education professionals involved in supporting a young person with a life-limiting condition. Within adult healthcare, it is likely that the team will be more diverse and multi-pronged due to the differences in care provision and the proliferation of healthcare specialities, with no direct equivalent to the holistic care provided by a paediatrician.

There should ideally be a key worker model in place so that there is overarching co-ordination of all these different professionals.

The engagement of primary care services (GP, district nurses, community matrons etc) is vital to the success of young adults transitioning from children's services. The GP holds overall responsibility for the young person and has the unique position of usually being the key health care professional for the entire family. GPs may have had little involvement with the young person during childhood, so they will need to be brought back into the team. They will also need updating on recent and current issues to retain the family and young person's confidence.

Standard 5

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

Key goals:

1. A key working function is provided for every young person so that all the agencies providing care and support are co-ordinated.
2. All agencies ensure that age and developmentally appropriate services are available that address the full range of a young person's needs.
3. Palliative care services provide a single clinical overview for the young person and link with other specialists involved in their care.
4. There is frequent review and communication across services about care plans and end of life decisions.
5. Primary health care services, including GPs, develop a relationship with the young person and their families/carers.
6. Adult services in secondary care ensure there is an appropriate lead clinician to take responsibility for young adults in their clinics and admissions processes.
7. Short break or respite needs of young people and their parents/carers are considered and provided in the most appropriate setting.
8. Parents are included as appropriate.

Goal 1: A key working function is provided for every young person so that all the agencies providing care and support are co-ordinated

Once the young person has moved into adult services they will need a named key worker or a dedicated 'young person's' team in place to provide a single point of access and to co-ordinate the multiple services/agencies which will be involved in supporting the young person.

From a commissioning perspective, there may be crossover with young adults who acquire an illness or disability in early adulthood.

Goal 2: All agencies ensure that age and developmentally appropriate services are available that address the full range of a young person's needs

While health is a crucial element of support, it is often not the most important element of support in the eyes of young people themselves. Young people want to lead ordinary lives, have friends, relationships, go to college or university, get meaningful employment and live as independently as they can. They want to be able to forget that they have a life-limiting condition and not let it get in the way of their plans! The following section of this guide sets out the roles and responsibilities of some of the key agencies and disciplines involved and how they interlink. It is important that all agencies work with young people to co-design services and environments that are appropriate.

"Set goals! With a goal to aim for, it's easier to know what to ask for and what your care pathway needs to look like. I knew I wanted to go to University so I needed to get the right housing and educational support in place before I could start."

Young person

Transition in practice

Victoria College

Victoria College is a brand new, purpose-built facility for young adults with profound learning difficulties and complex needs aged 19+. The College was set up at the request of Birmingham City Council who approached special schools in the area to create a specialist provision for young adults who were not currently adequately served in Further Education.

The College initially opened with just five students who are already thriving through being with similar young adults and staff who are highly skilled in delivering a curriculum tailor made for them. These students love being with others their own age and a similar outlook. The College's aim is to enable these young adults to fulfil their aspirations and become valuable citizens in their communities. This September, another ten students joined the College and the upper limit will be set at around 40.

The current cohort of students have settled into the College extremely well and are enjoying participating in a whole range of activities including horticulture, art, sensory drama, communication and holistic therapies. The students also have opportunities to get out and about into the community to go shopping or bowling. The delivery of two mini buses will enable the students to increase their access into the community. There are medical services on site including physiotherapy and nursing as well as access to speech and language therapy.

Goal 3: Palliative care services provide a single clinical overview for the young person and link with other specialists involved in their care

Every young adult should have 24/7 access to hospice and/or palliative care services which are appropriate to their care needs. This will require change and adaptation within adult hospice and community based services to ensure person-centred care is provided in age and developmentally appropriate environments.

The holistic approach of hospice and palliative care means that they can play a key role in providing a single clinical overview for the young person and linking with the many organ/system specialist services that may be involved as well as the local GP. This is particularly important if it is identified that a young person is approaching end of life.

Adult palliative care teams should consider providing specific team members who focus on the care of young adults. These team members could also link in with young adults who develop conditions in adulthood as there will be crossover into this patient population.

Goal 4: There is frequent review and communication across services about care plans and end of life decisions

Plans for end of life care, advance statements and advance decisions need to be regularly reviewed and sent to all care settings, including out of hours and emergency services.

There should be close liaison with children's services to support and develop end of life care planning, particularly if the young person is in the process of moving to adult services or has only just made the transition. Any emergency care plans that have been put in place during childhood need to be reviewed and adapted for appropriate adult services during the transition process, particularly if these have been signed by parents.

Adult services should look carefully at care plans and identify where any further information, training or support is needed for particular interventions that may be needed such as breathing support. It is important to identify how contact details can be stored, such as through electronic alerts and patient held records. Local services such as rapid response teams may be able to hold such information.

Goal 5: Primary health care services, including GPs, develop a relationship with the young person and their families/carers

Even if the young person's health is stable at the point of transition, the GP should be included in regular full needs assessments so that they retain an overarching view of the young person's circumstances. These assessments should be reviewed every six months as a minimum and should include not only the young person's health needs but also their communication, social, educational and employment needs. This enables the GP to play a key role in linking with secondary care/social care to ensure a co-ordinated approach and clear delegation of decision making.

Another benefit of greater GP involvement is that they can provide the young adult with the confidential care to which they are entitled as an adult, independently of their parents/carers.

Where appropriate, young people should have their details added to the locality's electronic End of Life Care Register/special notes held within primary care, which enables key information to be provided to a range of out-of-hours services. Depending on local arrangements, and with the young person's consent, this can mean that key information (such as key contacts, advance care plans, preferences for place of care etc) is shared with services such as the ambulance service and the local A&E Department. This can ensure that appropriate active care is given as well as make sure that inappropriate and unwanted intervention is avoided.

Goal 6: Adult services in secondary care ensure there is an appropriate lead clinician to take responsibility for young adults and consider young adults' needs in their clinics and admissions processes

Within adult clinics and wards in hospital it is important to ensure that there is a lead clinician appointed within appropriate specialties such as respiratory, diabetes, renal, cardiology to take responsibility for young adults.

It is important that staff on the adult ward or in adult outpatient clinics work with children's services and are open to liaison and joint working. This can help to avoid rigid age specific cut-offs in service provision, which can be very distressing for young people when they are admitted to hospital in an emergency.

Staff on adult wards can work to support colleagues in children's services to feel confident they are handing the young person over to a considered and developed service. Remember they may have looked after the young adult and their families for their whole life and developed a strong professional relationship. Children's staff should work alongside adult colleagues to share their knowledge and expertise of the young person. Resources such as the 'You're Welcome' standards (DH, 2011) and the 'Ready, Steady, Go' transition programme (Nagra, 2012) have been developed to help provide a consistent approach to managing transition.

Specific consideration should be given to the needs of young adults in terms of clinic arrangements – thinking about appropriate times of the day, the location and duration of appointments, communicating about appointments electronically, for example by email or text.

Consideration should also be given to the needs of young adults when they are admitted to hospital, for example thinking about having named link nurses on the ward, providing additional access to equipment such as TVs, computer games, internet. Good practice in supporting young adults in adult health care settings was explored in the STEPP project (Beresford, 2013) and resources were produced from this research providing useful tips and prompts.

Support for staff in working with young adults should include regular access to bespoke training, which wherever possible is available locally.

Goal 7: Short break or respite needs of young people and their parents/carers are considered and provided in the most appropriate setting

Short breaks for young people are often provided by children's hospices and other voluntary and statutory agencies and these needs should be reviewed to ensure that short breaks remain in the most appropriate care setting. This may lead to adult hospices needing to make changes to their units or using alternative care locations such as residential colleges with hospice or palliative care staff going into these locations to provide nursing or medical care. Innovative use of what is available will make a huge difference to young adults and their families.

Goal 8: Parents are included as appropriate

It is important to ensure that parents are included in caring for their young adult child (Beresford, 2013). Many young adults want to include their parents in the decision-making process and often want their parents to be close to them at times when their health deteriorates or when they have to stay in hospital, especially if this is in unfamiliar adult critical care settings. Many parents play an active caring role for their young adult children and have been experts in their care over many years. Whilst taking the lead from the young person, care should be taken to ensure that parents are listened to and their views respected.

"Parents need support too. The changes can be really stressful for them. They need to feel that sufficient support is in place before they can start to let go."
Young person

Transition in practice

Acorns Children's Hospice

Acorns Children's Hospice made a decision to change its criteria so that its services were provided for young people up to the age of 18, with focus given to securing alternative adult services for existing service users. A discharge policy and process was established with every young person having a discharge plan on leaving the service with these monitored at transition panels.

A transition team was recruited, which works with young people from 14 and carries out personalised transition reviews with the young person and their parents/carers. Transition workers are proactive and develop a rapport with young people that helps them gain confidence and manage things they would never have had the opportunity to do before.

The transition team works with statutory services in the area, building up professional relationships with relevant adult services. Since the establishment of the transition team a database has been collated of local services for young people with physical and learning disabilities and what they can offer to younger adults with life-limiting conditions. This has been used by social workers and commissioners to identify adult placements.

Training for adult services has been ongoing and shadowing of in house teams has been arranged for some adult providers to gain experience before the young person transfers to their service.

Key indicators that a young person has made a successful transition to adult services:

1. They feel empowered to take ownership of their lives incorporating health, social, educational, occupational and independent living needs.
2. They feel confident in the team supporting their care, with a single point of contact to address concerns to.
3. They are assured of confidential access to healthcare professionals where they desire it.
4. They understand and take an active role in planning for their future needs including emergency care planning, will writing, advance decisions to refuse treatment, advance care planning and preferred location of care/death where appropriate.
5. They have formalised plans in place for appropriate advocacy/court of protection in line with the Mental Capacity Act when they turn 18.

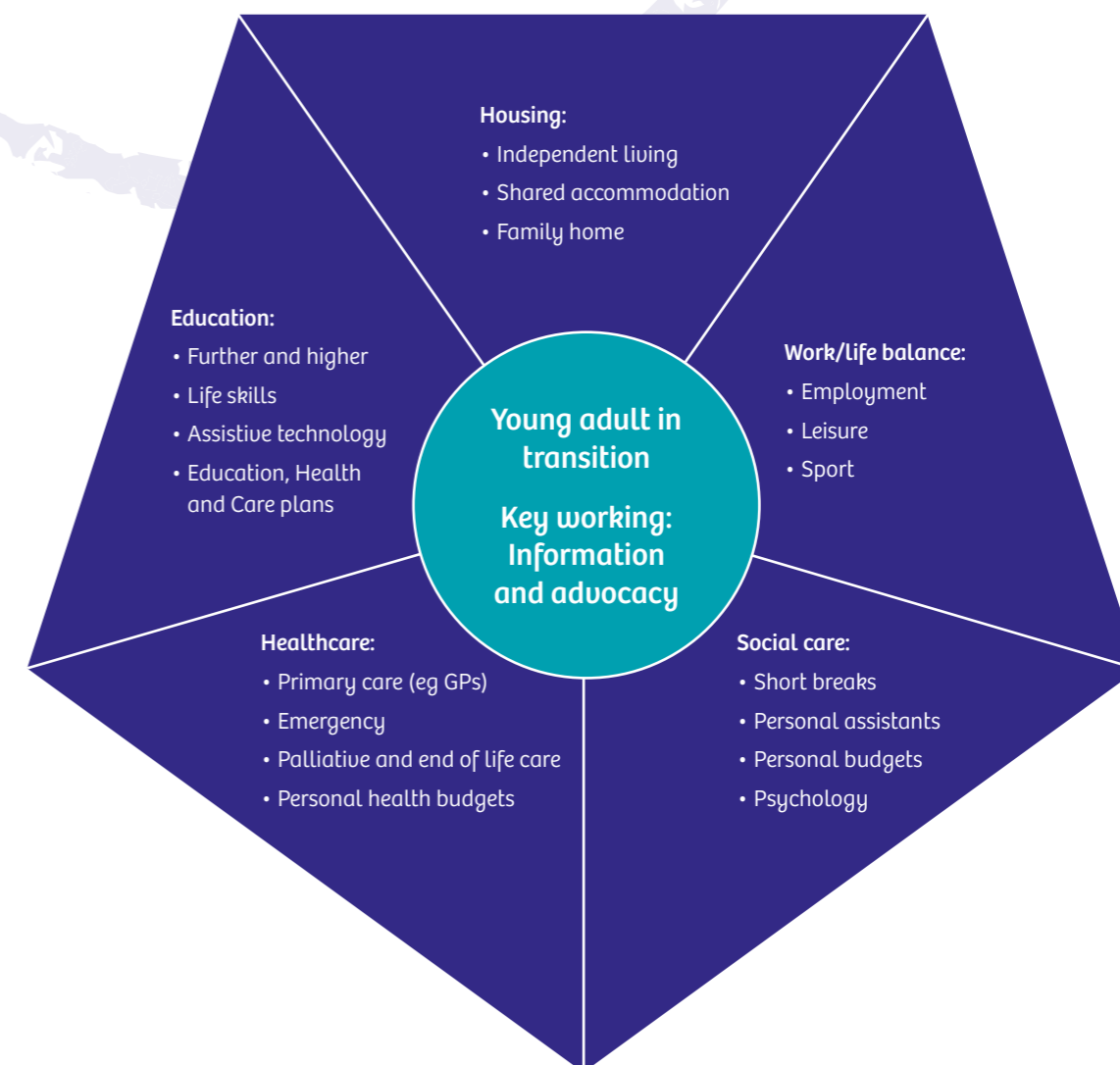
Key indicators that a family feels that their young adult has made a successful transition to adult services are:

1. They feel confident in the team supporting their young person's care.
2. They are assured of ready access to support in dealing with their young person's condition.
3. They understand and are supported in accepting the changes in their role as the young person enters adulthood and feel supported in 'letting go' and enabling their young person to lead as full and fulfilling an adult life as possible.
4. They have confidence that formalised plans are in place if their son/daughter lacks capacity for decision making which involves them or independent advocacy services.



The roles of different agencies in adult services

The Together for Short Lives Transition Taskforce has conceptualised the way that the five key agencies should work together as a 'pentagon of support'. This pentagon is underpinned by health and social care working closely together to provide a foundation for all the other provision, with work/leisure and education being the two 'enabling agencies' on either side and independent living as the 'capstone' at the top.



Some of the key roles of these agencies and of some of the organisations within them are outlined below:

Health

Adult District Nursing Services

Moving from children's nursing services into an adult district nursing service will bring about some key changes. 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. Adult palliative care is provided by a range of services including the district nursing service in conjunction with the GP, Macmillan teams, hospices and other allied services; which means that some issues, such as new medications, can be more quickly resolved. Assessments are usually carried out by the district nursing team allowing needs to be identified and patients to be referred directly to other services and therapists.

Some district nursing services may have extensive experience of palliative care, although they are likely to have less experience in palliative care for young adults and may have limited experience of complex technological care. Education and training may need to be provided during the transition phase to boost the confidence of all parties.

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.

General Practitioners

There are a variety of roles that GPs may play in the process of facilitating the transition of young people with life-limiting conditions to adult services. These are roles that all GPs could be expected to undertake, rather than just those 'with a special interest' or additional training in palliative care.

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.

Here are some of the potential roles:

- 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' GP services such as health promotion and care for common minor conditions and co-morbid chronic conditions where these do not require specialised input.
- 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.
- Facilitating the process of transfer of responsibility for health care from parents to the young person and informing young people about their rights to receive confidential health care, independently of their parents (subject to competence) as well as supporting their concordance with medication and other treatments.
- 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.

Children's and adult hospices

There are many parallels between children's 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 symptom control and end of life care.

In addition the adult hospice movement, which has been established since the 1960s, has traditionally focused on the care of those dying from cancer. Palliative care in paediatrics with its broader approach 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.

Adult hospices and hospice at home services are beginning to look at how they can adapt services and environments for young people and provide specific young adult services, such as day care.

Social care

There are a wide variety of services provided under the umbrella of social care, including:

Short breaks/respite care

Short break care is often a determining factor in the sustainability of home placements and a key factor in the quality of a young person's life experiences. Provision of residential short break care for adults is currently limited and varies widely around the country, although there are a number of hospices both in the children's and adult's sector that are developing their ability to support young adults.

Adult hospices tend to have a very different role to children's hospices and do not usually provide planned short breaks although this may change as initiatives such as the Together for Short Lives Transition Taskforce stimulate new service development for young adults with palliative care needs. Some private nursing homes offer residential respite, however the majority of their service users will be elderly and this may not be a suitable option for young adults.

It is worth seeing if other voluntary organisations or services for adults with learning disabilities provide short break and day care facilities that could be considered. Adult versions of short break fostering, where a young person stays in a carer's own home, are another possibility. A number of voluntary organisations provide fun holiday opportunities for young people with complex disabilities or life-limiting conditions. Training and on call support may need to be provided to enable these services to provide short breaks to young people with appropriate nursing and medical backup.

Transport

Consideration should be given to the young person's needs for accessible transport. This may include applying for a Blue Badge to enable parking concessions, the Motability Scheme which can help with leasing or buying a car and using community transport services provided by the local authority or Community Transport Association.

Education

Education may play a very important part in the young person's life post 16. College or university provides opportunities for young people to socialise with friends as well as to achieve academically and learn about career choices.

The transition into such Further and Higher Education (FHE) settings need to be considered as well as the transition out of education to ensure that young people have the necessary life skills to be able to live independently and vocational training to be able to enter the world of work, where this is a young person's choice.

FHE providers will need to consider the needs of young people with life-limiting conditions, alongside those of other disabled students. They will need to consider the links with local health care providers so that the young person's complex health needs can be met. They will also need to consider the environment and adaptations that are needed. The National Association of Specialist Colleges www.natspec.org.uk provides a wealth of information about supporting young people in educational settings.

World of work

Supported Employment has been successfully used for decades as a model for supporting people with significant disabilities to secure and retain paid employment. The model uses a partnership strategy to enable people with disabilities to achieve sustainable long-term employment and businesses to employ valuable workers. Increasingly, supported employment techniques are being used to support other disadvantaged groups such as young people leaving care, ex-offenders and people recovering from drug and alcohol misuse.

Employment terms and conditions for people with disabilities should be the same as for everyone else including pay at the contracted going rate, equal employee benefits, safe working conditions and opportunities for career advancement.

The British Association for Supported Employment (BASE) www.base-uk.org provides a range of support for employers and young people about being matched for employment, training, in-work support and career development. They provide a list of agencies who can be contacted locally for support www.base-uk.org/about/members.

Housing

Some young people will want greater independence and may wish to live outside the family home. There are a variety of housing options they may wish to consider.

Buying or renting another property

Depending on their financial resources and care needs they may be able to find a property which is suitable for their needs. If they have physical health problems, for example, the local authority could help to find a property which has already been adapted. Alternatively, they may be able to get a housing grant to cover any adaptations which need to be made.

Sheltered housing schemes

Sheltered housing schemes are flats or homes which are designed for independent living but have extra facilities such as a warden who can be called in an emergency or communal facilities such as laundry and lounges. Some of these schemes are specifically for older people but there are some which cater to the needs of younger disabled adults.

Supported housing in the community

There are a wide variety of residential units in the community. They could be managed by the local authority themselves or by housing associations, voluntary organisations and charities which run the units to meet particular needs, such as those of adults with learning disabilities. Whereas residential care homes provide personal care for people with a high level of need, there are many housing units which cater for people who are able to be much more independent. They may go to college, work or day centres during the day and need only a limited amount of support when at home.

Supporting people programme

This government programme aims to keep people in the community with as much independence as possible but with appropriate support. It may be an option for someone, whether they want to continue living where they are or whether they move elsewhere, either to their own property or a hostel or shared accommodation of some type. The programme provides the funding for the support people may need. This support may include help to access training and employment, help with claiming benefits or social skills. It could also include life skills such as healthy eating and budgeting. Personal and health care, such as help with washing and taking medication will not be included.

Shared living schemes (formerly called adult placement)

These schemes match up vulnerable adults with carers in the community who can provide support of various types. In many cases the adult will live with the 'shared living' carer in their own home. This could be a long term placement or a short stay. In other cases the carer will provide support to the adult who continues to live in their own home but the carer will act as a family member, providing a consistent relationship and emotional support.

Appendices

Appendix one: References

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Appendix two: Acknowledgements

Together for Short Lives would like to thank the members of the Working Party for attending meetings and for developing working drafts of the document.

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Stepping Up: A guide to enabling a good transition to adulthood for young people with life-limiting and life-threatening conditions

This guide aims to ensure that all young people and their families have a positive experience of growing up and making a good transition to adult services. With young people at its centre, it provides a framework for all services and agencies to work together to support young people along their whole transition journey – as they prepare for adulthood, prepare to move on to adult services and settle into adult services.

It is based on the first *Transition Care Pathway*, developed by ACT in 2007, but has moved away from this original Pathway approach to focus more on enabling young people to have choice and control over their lives. It is intended to be a generic framework for all young people with life-limiting or life-threatening conditions, which can be adapted for local use according to local protocols, resources and circumstances.

Stepping Up is relevant for children's and adult services working in a variety of agencies that will come into contact with young people who have complex or life-limiting health conditions. Together for Short Lives has also published an accompanying transition resource designed to improve commissioning for these young people called *A Guide for Clinical Commissioning Groups*.

About the Transition Taskforce

Across the UK, the Together for Short Lives Transition Taskforce is working to influence policy, develop sustainable funding models and develop and share research, information and good practice relating to transition for young people with life-limiting conditions.

In the devolved nations, regionally and locally, the Taskforce is establishing and supporting Regional Action Groups to bring together representatives from the widest possible range of services from both the children's and adult sector, including health, social care, education, employment and housing. These Regional Action Groups provide a body of expertise on how to best provide care and support for this growing number of young people and are enabling bridges to be built between children's and adult services.

Transition Taskforce Vision

That all young people with life-limiting or life-threatening conditions will make the transition to adult services and live their lives as independently as possible according to their wishes, while receiving the care and support they and their families/carers need.

Transition Taskforce Mission

The Taskforce seeks to overcome the barriers to good transition for young people with life-limiting and life-threatening conditions, by building bridges between adult and children's services.



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