

Stepping Up

Transition Pathway

to enable 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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Author: Lizzie Chambers

Editor: Marcella Pinto

Together for Short Lives

Suite 1b, Whitefriars, Lewins Mead, Bristol BS1 2NT

T: 0117 989 7820

E: info@togetherforshortlives.org.uk

Helpline: 0808 8088100

www.togetherforshortlives.org.uk

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This publication will be reviewed every three years and amended as needed, at our discretion.

Thank you to Hospice UK for their support in developing this new edition of Stepping Up.





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Foreword

Until the age of 16 I had lived a seemingly 'normal' life. I had a few peculiar things happen with my health – lots of infections, lots of joint injuries and being much shorter than my percentile projections (I am five foot nothing!).

It took six years to discover the cause of my illness, but before we knew the cause my family and I were told the true severity of my situation. During my first appointment with a hospital consultant I was told that my condition is life-limiting, degenerative, and I was in need of 'Supportive Management'. After my mum (an ex-nurse) did some doctor prodding, the fateful words were spoken: *Yes, that does mean palliative care.*

Because I became so seriously ill at the age of 16/17, I wasn't assigned a Transition Co-ordinator. I was, however, warned of some of the problems that might occur in adult services. For example, the fact I wouldn't be shielded from death in the same way that I was in children's services. This came to pass during my first adult hospital admission. I was in a four-woman bay, when the emergency bell was rung, but the curtains were not drawn around like they would be in children's ward. The crash team did many rounds of CPR but completely forgot about the other people in the bay. Families were saying goodbye to their dead with just a curtain wrapped around them. I will never forget the sobbing and how it wracked their bodies. Previously I didn't know the sounds or signs of death. Now I can't forget them. All my fellow patients were over sixty. I was eighteen, and I looked fourteen.

In Paeds I was told that I would need to *step up* and *control my destiny* by reading and signing my own consent forms. I gained the right to understand my surgeries and their ramifications, but it sounded as though I was going to lose my freedom. I understand the need to empower young people, especially those who may have been ill their whole lives. But for me, the way transition was painted was snatching away the very little time I had for myself. I was going to lose the few hours a day I had which were not looking after my medical needs. I was devastated. I don't think there is recognition of the number of secretarial hours behind being a patient with complex conditions, under many specialists and hospitals across the country.

I thought that transition, for me, would mean my mother not being able to come into appointments with me; that she wouldn't be able to ring the pharmacist to chase up my medications for me; that she would only be able to come and see me in hospital for a few hours (if at all), unless I was dying. Obviously this wasn't the case once I landed in adult services.

After hearing these horror stories, I am surprised and relieved to report that I can take my mum into appointments with me; that in fact, you are encouraged to do so, especially if the appointments are high stakes and complex. I was able to tell my GP to harass my mum (consensually!) about everyday things and minor hiccups (like ensuring she is there to take calls about things like equipment deliveries, which is important, because I am deaf and likely to miss the twenty attempted calls practitioners make.) I get the feeling that those working within paediatrics hadn't actually talked to adult teams about what concessions can be made, and so 'worst case' stories stuck with them where they probably had to intervene.

Transition is a time in which we need to empower young people. But it is also a time to let them explore and explain their own destiny and help them achieve that. Not everyone's ambitions look the same, not everyone wants to be fully in, or out, of control. For a long time, transition stood for something which scared me. In hospital, I used to fear there would be a power imbalance when going into a consultant's appointment alone. Thankfully this hasn't been the case.

In terms of hospice respite care, I am going to lose all access to this at the age of 26, due to young people like me living longer, narrow definitions of young adulthood and a lack of funding. Even with my continuing healthcare plan, and my CCG asking all nursing homes if they would take me, the answer was no because their services are only for those age 55+ and adult hospices only take emergency admissions and those who are dying.



You may be shocked to learn that us young people have already seen the darkness of death. Many of us see it coming or are already wrangling with it in our own minds. We attend support groups for people with our conditions and when our friends from these groups die, we attend their funerals. When you live with a life-limiting or terminal illness you should celebrate each and every birthday. Lack of provision makes me scared for my next birthday. As it stands there are many, many young people in my position, many of them with additional communication needs which may mean you don't get to hear this from them.

Transition is a time when we decide my destiny. Be honest about what you know or don't know yourself as a practitioner. Sometimes telling me that my destiny is to have to take full control over my care isn't what I want. It can take away my true destiny; which is to be able to write this for you right now, and work with organisations such as NHS England to help write guidance that will help improve the experience of other young people nearing transition.

I want every young person to get the opportunity to do whatever it is they want with their lives. I hope that all professionals use resources, such as this, to support young people to get there.

Hannah Hodgson

“Transition is a time in which we need to empower young people. But it is also a time to let them explore and explain their own destiny and help them achieve that. Not everyone's ambitions look the same, not everyone wants to be fully in, or out, of control.”

Hannah Hodgson

Introduction

We know that the population of young people with life-limiting or life-threatening conditions is growing and that young people are living longer with increasingly complex health conditions. It is therefore vital that services keep pace and support these young people to live their lives to the full. Whilst palliative care will be a key part of their experience of transition to adult services, what is most important is that they are able to live well with their complex health conditions.

This pathway is written for professionals, predominantly for those working in children's and adult hospice and palliative care services, but also for any professionals who are supporting young adults with life-limiting conditions and their families, whether they work in health, social care, education or other settings. We hope that it will also be a useful tool for commissioners to support the planning and funding of multi-agency transition pathways for local populations of young people with complex health needs.

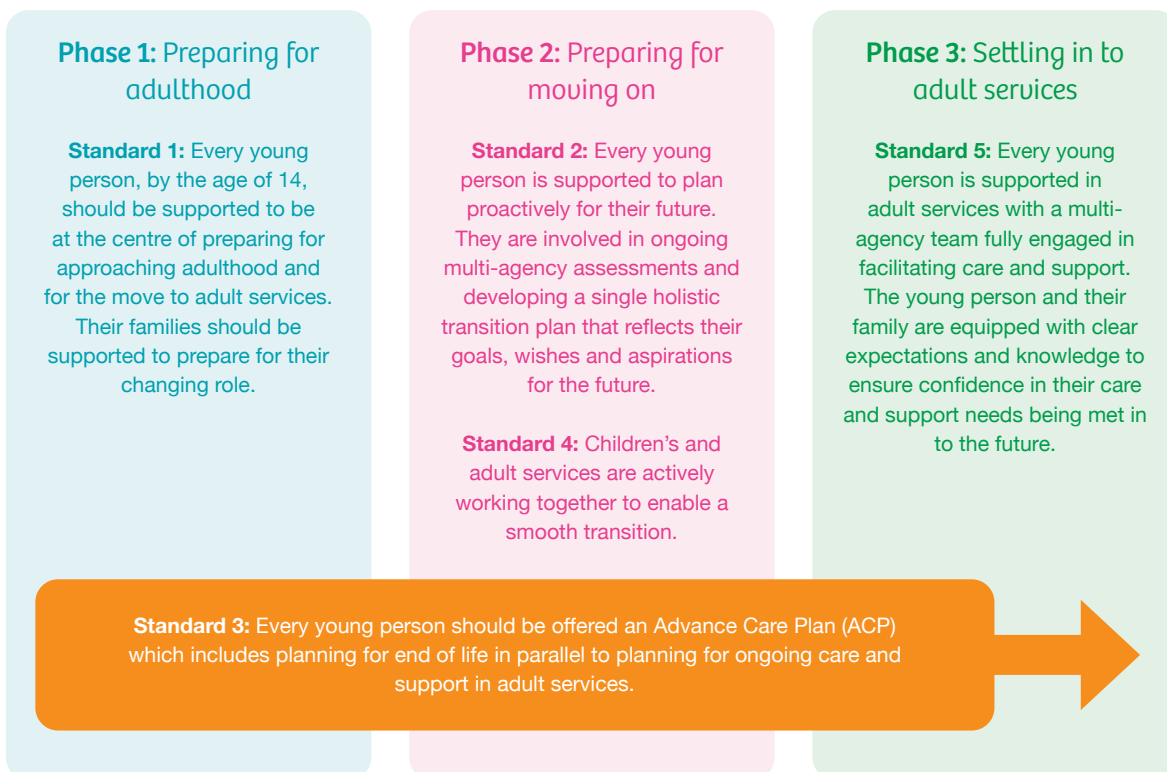
It aims to provide a generic framework that can be adapted locally to plan multi-agency services for young people with life-limiting or life-threatening health conditions as they are growing up and moving into adult service provision. Multi-agency working involves services in the statutory, voluntary and independent sectors, as well as those employed directly by the young person and their family through direct payments. We hope that it can be used as an overarching transition framework across agencies and be used in conjunction with other pathways and guidelines developed for specific conditions or particular settings.

This new edition of the *Stepping Up Transition Pathway* builds on previous editions and has been updated to include new service examples from projects that were funded through an Improving Transition for Young People Programme, which was led by Together for Short Lives from 2017-2022. It is updated with new evidence and to reflect developments in transition for young people with life-limiting or life-threatening conditions.

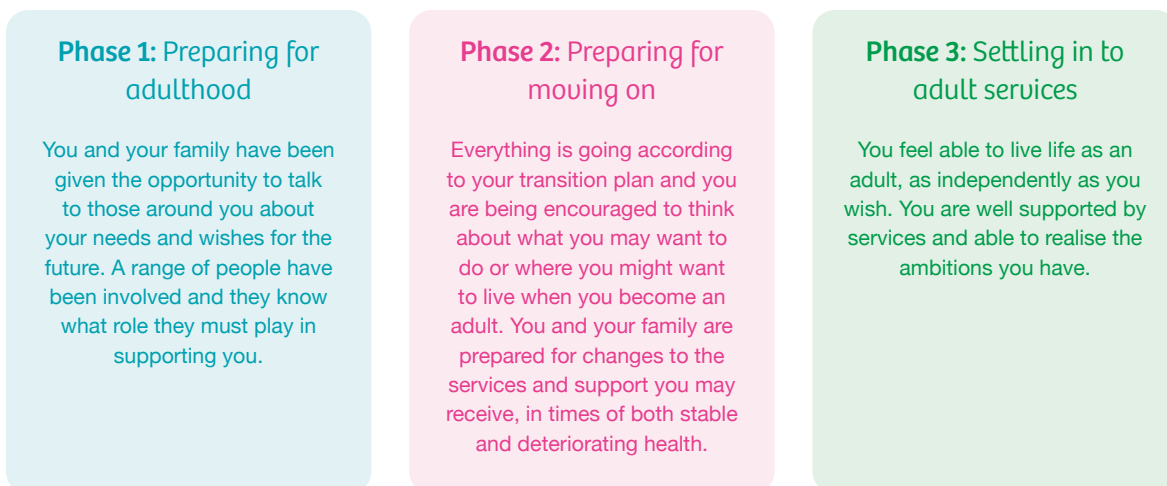
We are grateful to our partner Hospice UK for reviewing this edition of the pathway and providing their expertise on how the adult hospice and palliative care sector can play a more active role in supporting young people through transition. We are also grateful to the Burdett Transition Nurse Advisors for their invaluable input to this new edition of the Pathway.

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

The Three Stages of the Transition Pathway



Outcomes for Young People



There is a version of these standards for young people to use as a checklist to a good transition:
www.togetherforshortlives.org.uk/get-support/supporting-you/family-resources/a-checklist-to-a-good-transition

Transition Pathway Standards and Goals

Standard 1

Every young person by age 14 is 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.

Service goals

1. Young people should be at the centre of planning, using person-centred planning approaches where possible and communication aids where needed to support this. Young people should be offered choices that will help them to manage their own care.
2. Parallel planning should take place for transition to adult services alongside planning for deterioration.
3. Initial conversations about transition should take place with the young person and their family at a time and in a place that suits them.
4. A follow-up meeting regarding transition should take place within three months.
5. A first multi-agency/multi-disciplinary meeting should take place.

Standard 2

Every young person is supported to plan proactively for their future. They are involved in ongoing multi-agency assessments and developing a single holistic transition plan that reflects their goals, wishes and aspirations for the future.

Service goals

1. Young people and their parents should be helped with the change of focus from family-centred to young person-centred care.
2. Every young person should have a named worker to facilitate continuity of care.
3. Every young person is supported to consider plans for all their future care and support needs, as much as they choose and/or are able.
4. Ongoing multi-agency assessment should join up with other assessments and take place at least every three months, or more frequently as needed.
5. Every young person is supported to identify adult services which can meet their needs.

Standard 3

Every young person should be offered an Advance Care Plan (ACP) which includes planning for end of life in parallel to planning for ongoing care and support in adult services.

This standard applies to all stages of the transition journey.

Service goals

1. Transition planning should continue to take place even during times of uncertainty.
2. Every young person should have a documented Advance Care Plan (ACP) which includes planning for end of life alongside their plan for future life. This should be dynamic and regularly reviewed.
3. Every young person's pain and other symptoms are assessed and managed by a clinician with appropriate skills in order to provide high quality care at end of life.
4. Every effort should be made to ensure that the young person's death takes place according to their wishes and in their place of choice wherever possible, with their emotional, cultural and spiritual needs met.
5. Parents, siblings, wider family and others close to them are supported, informed and involved.
6. Parents, siblings, wider family and others close to the young person should be offered the choice of caring for the young person during and after death and supported to do this if it is their choice.
7. All professionals/agencies should be informed of the death with the parents' consent.
8. All family members should be supported according to their individual needs for as long as they need it in bereavement.

Standard 4

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

Service goals

1. Children's and adult services within health should work together so there is an overlap of care planning and care provision, up to the age of 25 if needed.
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 should take place.

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 clear expectations and knowledge to ensure confidence in their care and support needs being met in the future.

Service goals

1. A keyworking function should be provided for every young person so that all the agencies providing care and support are co-ordinated.
2. All agencies should ensure that age and developmentally appropriate services are available that address the full range of a young person's needs.
3. Palliative care services should provide a single clinical overview for the young person and link with other specialists involved in their care.
4. There should be frequent review and communication across services about care plans and end of life decisions.
5. Primary healthcare services, including GPs, should develop a relationship with the young person and their families/carers, and be involved in transition planning.
6. Adult services in secondary care should ensure there is coordination and communication regarding clinic appointments – this may be achieved by having a lead clinician or named worker in adult services.
7. Short break or respite needs of young people and their parents/carers are considered and provided in the most appropriate setting.
8. Parents, wider family and others close to the young person are included and involved as appropriate.
9. Professionals have the skills to provide complex care and have knowledge of relevant legislation.



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 healthcare 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 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. Healthcare 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 there are many similarities 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, and provision of short breaks and care through death and bereavement.

Together for Short Lives, 2018

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 children's and adult hospice and palliative care services. 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. 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.

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. Transition models are emerging and being evaluated (Kerr et al, 2020; Colver et al, 2020), providing evidence to support the development of quality services for young people with complex needs.

Who will benefit from this guide?

Recent research on the prevalence of young people with life-limiting conditions (Fraser et al, 2021; Stiepen et al, 2021) shows that the number of young people who may have palliative care needs is rising, mainly due to improvements in medical treatments and technology. Key findings from Fraser's research show that:

- The overall number of young people aged 14-25 with a life-limiting condition identified in this dataset from England rose from 27,316 in 2009/10 to 38,261 in 2017/18 – an increase of 40%.
- The numbers of young people with a life-limiting conditions who were diagnosed whilst still in childhood rose from 16,107 in 2009/10 to 24,773 in 2017/18 – an increase of 53%.
- The prevalence of young people with a life-limiting conditions who were diagnosed whilst still in childhood rose from 19.7 per 10,000 in 2009/10 to 30.2 per 10,000 in 2017/18.
- Prevalence of life-limiting conditions was highest among young people of South Asian and Pakistani origin and also for those living in areas of higher deprivation.

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, 2018):

- 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. Our understanding of the sociology, social, developmental and educational psychology of young people has crystallised, as has the concept of ‘developmentally appropriate healthcare’ where care is not provided purely on the basis of age, but on the developmental stage of the young person (Colver et al, 2020). As well as 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 healthcare, make decisions, and their attitude to taking risks.

The impact of having a life-limiting condition during adolescence and young adulthood is considerable, as set out below in the table overleaf adapted 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
<p>Concerns about physical appearance and mobility.</p> <p>Privacy all-important.</p> <p>Possible interference with normal cognitive development and learning (school absence, medication, pain, depression, fatigue).</p> <p>Comparison with peers hindered, making self-assessment of normality more difficult.</p> <p>Possible lack of acceptance by peers.</p> <p>Reliance on parents and other authority figures in decision-making.</p> <p>Hospitals perceived as very disturbing.</p>	<p>Illness particularly threatening and least well tolerated at this stage.</p> <p>Compromised sense of autonomy.</p> <p>Emancipation from parents and authority figures impeded.</p> <p>Interference with attraction of partner.</p> <p>Fear of rejection by peers.</p> <p>Limited interaction with peers may lead to social withdrawal.</p> <p>Dependence on family for companionship and social support.</p> <p>Hospitalisation, school absences interfere with social relationships and acquisition of social skills.</p> <p>Non-compliance with treatment.</p>	<p>Absences from work, study.</p> <p>Interference with plans for vocation and relationships.</p> <p>Difficulties in securing employment and promotion at work.</p> <p>Unemployment hinders achieving separation from family and financial independence.</p> <p>Discrimination in employment, health cover and life insurance.</p> <p>Loss of financial independence and self-esteem.</p> <p>Concerns about fertility and health of offspring.</p>

Priorities for young people

Over the years we have heard from young people about their experiences of transition and what is important to them. 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 have individual plans and wishes, they often have many priorities in common:

- Gaining more independence.
- Opportunities for a social life, friendships and relationships.
- Information they can easily access and understand.
- Access to 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 named 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.

Many young people with severe cognitive impairments will need support to articulate and reach their goals in life. Independence may look different for these young people, but the same strengths-based approach should be used to enable them to communicate their future aspirations and plan ahead within a person-centred framework. This approach should enable them to develop socially, emotionally and psychologically so they can lead fulfilling lives in which they are supported to achieve their goals.

Priorities for parents/carers

Parents identified some key areas that they would like to see improved and which would help them to feel more prepared and confident in supporting their young person into adulthood, for example:

- Understanding more about their family's **rights**.
- **Learning how the health and care system** works when moving from children's to adult services.
- Learning tips and techniques to **help increase their confidence** when meeting professionals.
- Being able to **make the best use of time** when meeting with practitioners.



Transition in practice

Council for Disabled Children: Expert Parent Programme

Aim

To deliver a version of the Expert Parent Programme (EPP) tailored to meet the needs of parents of disabled young people with learning disabilities and life-limiting conditions, who are preparing to transition to adulthood.

What they did

The EPP model consists of a sustainable 'train the trainer' programme, delivered by parent/carers with lived experience. The Council for Disabled Children (CDC) developed a bespoke programme of face-to-face workshops for parent/carers of young people with learning disabilities and complex health needs, supplemented by accompanying e-learning modules and website resources. All content for the programme was co-produced with parent/carers and they worked collaboratively across CDC's health and social care teams to use their expert knowledge and lived experience of the health and care systems to develop accurate and engaging content. During the Covid-19 restrictions the delivery team translated the training materials into a format that was suitable to be delivered online.

What they learned

- The importance of creating an environment where families can share personal issues with each other and support each other moving forwards.
- The need for broad content that includes changes in the health system, legislation, legal rights, and support for carers.
- The importance of how language can be an enabler or barrier.
- How evidence will help achieve the best outcomes.
- The importance of a person-centred approach.
- The value of using parents with lived experience as trainers to help build trust.

The benefits/impact of the project

- Helped parents advocate on behalf of their children and navigate the confusing landscape of support that they often face within the health system.
- Helped parent carers realise they are the expert on their young people.
- Improved the outcome of key meetings with professionals including the GP Annual Health Check.
- Improved parents' mental health as they felt less anxious about the future for their young person and had more confidence to challenge and ask questions.

More information about the programme can be found here:

<https://councilfordisabledchildren.org.uk/what-we-do-0/areas-work/health-wellbeing/expert-parent-programme/expert-parent-programme-complex>

Priorities for siblings

Transition planning must take account of the needs of siblings and the contribution they make to the family. Siblings can have a vital contribution which 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 (e.g. not going away to university or college), but they need to prepare for life without their sibling and should be encouraged to move on with their own life.

Siblings can 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 minimise 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 priorities for siblings:

- Being able to be 'just a sibling' to their brother or sister, whilst also having their experiences and expertise as a young carer acknowledged.
- 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.
- Having access to information about their own rights to assessment and support as young carers.
- Having access to facilitation for difficult discussions between family members.
- Being identified as a sibling of a seriously ill brother or sister within educational settings so that barriers to their learning and wellbeing are addressed.

Priorities for service providers

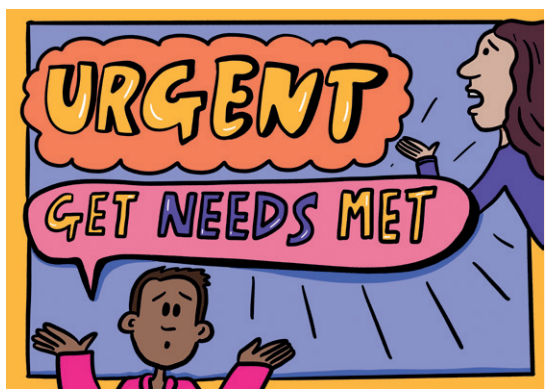
Whilst NICE (2016) recommends that "health and social care service managers in children's and adult services should work together in an integrated way to ensure a smooth and gradual transition for young people," research evidence suggests that many staff feel ill equipped and often lack confidence to provide this care. The Care Quality Commission (2014) emphasised that "everyone seems to want to do the right thing but there seems to be a missing link and no one seems to work together."

- Professionals in the children's sector need support so that they feel comfortable to 'let go' of the young people they have been caring for, and 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. This 'push and pull' approach is critical to achieving a proactive transition.
- Those in children's and adult services will need to develop their skills and confidence in 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 Liberty Protection 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 also important to 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 (Jindal-Snape et al, 2019).

Priorities for those planning and funding health and social care services

In planning services for young adults with life-limiting conditions, NHS bodies and local authorities should:

1. Establish the demand for palliative care among young people in the geographical areas they serve by understanding:
 - How life-limiting conditions affect young people.
 - How this differs between children and older adults.
 - The impact of life-limiting conditions on young people's access to education and other services.
 - How young people who need palliative care can be identified.
 - What young people with life-limiting conditions and their families need – including by engaging directly with young people, families, professionals and services.
 - What outcomes can be achieved for young people who receive palliative care.
 - How many young people need palliative care
 - How demand varies according to ethnicity, age, gender and socio-economic status.
2. Understand the cost savings that can be made in a system if transition support is provided (Jarvis, 2022; Hanlon, 2022)
3. Seek to implement national and/or regional legislation, policies, guidelines and standards. **We have provided details of key national policies and guidance in Appendix 1.**
4. Scope what services are already providing palliative care to young adults and how much activity they are undertaking, for example:
 - Children's & adult hospice care.
 - Community children's nursing and adult district nursing.
 - Specialist children's and adult palliative care services.
5. Plan, educate and train the workforce needed across the statutory and voluntary sectors in the transition process itself, making sure:
 - Staff at all levels have the skills and capabilities to support young people.
 - In England, they use NHS England's Core Capabilities for transition, which set out three levels of competences needed by staff coming into contact with young people.
 - In England, ensure that adult sector professionals have access to training on Education, Health and Care Plans (EHCPs) and essential skills in providing complex care.
6. Organise the workforce as effectively as possible so as to make the most of existing skills and experience; this may necessitate working with other NHS bodies and local authorities within a region to achieve economies of scale in planning and funding low volume, high cost services.





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 early and at the latest by the age of 14 years to tie in with the Year 9 school review. This section of the pathway 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.

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 adulthood. 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 that there are limitations to 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 Plan (EHCP) (Children and Families Act, 2014) which takes a person-centred, outcomes-focused approach to planning care.

The young person and family’s own contribution around future aspirations and wishes are essential

to this planning. Wherever possible this should be used as a framework for developing an integrated transition plan to take the young person forward into adult services.

There are a number of resources available to support good practice in transition, for example:

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.
www.togetherforshortlives.org.uk/resource/making-difference-young-adult-patients

Bridging the Gap Project (2014). This project identified the specific palliative care elements and needs of young people in transition. The project developed a practice guide that captures health and social care issues that are commonly missed in transition plans.
www.togetherforshortlives.org.uk/app/uploads/2018/01/ExRes-Bridging-The-Gap.pdf

Ready Steady Go. ‘Ready Steady Go’ and ‘Hello to adult services’ was developed by the Transition Steering Group led by Dr Arvind Nagra, paediatric nephrologist and clinical lead for transitional care at Southampton Children’s Hospital. It is a generic programme for young people with a long-term condition aged 11+ years. It can be used across all subspecialties as a structured, but where necessary adaptable, transition programme. A key principle throughout Ready Steady Go is ‘empowering’ the YP to take control of their lives and equipping them with the necessary skills and knowledge to manage their own healthcare confidently and successfully in both paediatric and adult services.
www.readysteadygo.net/rsg.html

Transition toolkit. Produced by Helen and Douglas House.
www.helenanddouglas.org.uk/wp-content/uploads/2018/01/hdh-transition-and-beyond-toolkit.pdf

Preparing for Adulthood Programme
www.ndti.org.uk/projects/preparing-for-adulthood

Transition Information Network
<https://councilfordisabledchildren.org.uk/about-us-0/networks/transition-information-network>

Transition in practice

Solent NHS Trust

A 17-year-old young man lives at home with his mum, brother (who also has complex care needs) and 2 teenage sisters. He attends the local special needs school with his brother. Due to his profound learning difficulties and complex care needs which affect his mobility and speech, he is on the caseload of the Community Children’s Nurses (CCNs).

In paediatrics he was having finger prick bloods taken at home to monitor his phenytoin levels, under the guidance of the hospital-based specialist team. There were concerns about how this blood sampling would take place when he was using adult services as his bloods needed to be taken at a specific time, often when the GP surgery and the local phlebotomy clinics were closed, which would mean mum had to drive to him and juggle doing school runs with her other 3 children. This was not a referral the District Nurses would accept, and the neurology team was part time and not available to review results.

At the transition clinic it was agreed that the CCN team would train mum to undertake the finger prick tests, and that disposable equipment would be provided by the GP. Mum could drop the sample at the GP practice to be processed at the labs and the specialist nurses would review the results. A 6-month window was agreed to train and problem solve before the young man was discharged to adult services.

The parent has since commented on how this has “massively improved their morning routine and there is less stress waiting around for the nurse.”

Standard 1

Every young person, by age-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 and communication aids to support this where needed. Young people should be offered choices to help them manage their own care.
2. Parallel planning should take place for transition to adult services, alongside planning for deterioration.
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 to discuss transition plans takes place with the young person and family within three months.
5. The first multi-agency/multi-disciplinary team meeting takes place.

“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

Goal 1: Young people are at the centre of planning, using person-centred planning approaches and communication aids where needed. The young person should be offered choices that will help them manage their own care.

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.

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

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

<http://helensandersonassociates.co.uk>

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.

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.

Transition in practice

Martin House and St Leonard's Hospice: Expanding Worlds

This project was a partnership between Martin House Children's Hospice and St Leonard's Hospice for adults. It worked collaboratively with young people to develop their psychosocial skills and identify their areas of biggest challenge in their move into adulthood. The project ran across two years, with 10 sessions each year, taking place on an approximately monthly basis from 1:30pm – 6:30pm. Sixteen young adults took part in the sessions which were held at the day centre within the adult hospice. They began and ended with a meal together and there was a combination of structured and unstructured time, whole and small group discussions and activities, and a variety of 'mini-projects' that took place over several sessions. Young people could access a one-to-one consultation with Martin House staff and a complementary therapy appointment with a member of St Leonard's staff. The young people also met up for social activities and new experiences in between the monthly sessions.

What they learned

- Children's hospices might usefully consider integrating approaches that support self-determination and active agency of young people into routine practice within their short breaks provision.
- Compared to their peers, young adults with life-limiting conditions may have restricted life experience and opportunities for self-determination. This means that new developments and change can take significant amounts of time. This should be accounted for in the design, objectives and duration of projects/service development activities.
- Providing transport was very important to enable young people to access the sessions.
- Offering complementary therapy appointments – something not provided at the children's hospice – attracted young adults to services provided by adult hospices.
- The aims and objectives of a new service need to be clearly articulated and shared among all involved. This necessarily requires the meaningful involvement of young people.
- Training and supervision of staff should be incorporated into the project specification.

The benefits/impact of the project

This project demonstrated the beneficial impact on the psychosocial development of young adults with life-limiting conditions of new and sustained experiences with their peer group. The project helped to increase understanding within children's and adult hospice staff about the different approaches needed when supporting the development of young adults.

Learning from the project is captured in their evaluation report:

www.togetherforshortlives.org.uk/app/uploads/2021/06/YAP-Evaluation-Report-FINAL.pdf

“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 communicate about relationships, intimacy and sexuality (Earle and Blackburn, 2021). This can be a really important area of life for young people as they mature as adults and want to know about starting relationships and possibly having children of their own.

The early phase of preparing for adulthood should involve supporting the young person to manage their condition, where this is possible. Often young people with life-limiting conditions lack self-agency and it is important to encourage and support them to take more responsibility.

“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

Transition in practice

Open University/Hospice UK Sexuality Alliance – Talking about sex and relationships: young people speak out

Aim

Making friends, having relationships and exploring sexuality are important parts of the transition to adulthood for young people. However, young people with life-threatening conditions may have limited opportunities to learn about relationships and sex. This project aimed to develop short videos by young people and an accompanying professional resource to support conversations about sex and relationships.

What they did

The project supported young people and practitioners with this often neglected but important area of transition into adult life. The project was led by a group of young people called the ‘AdversiTeam’ – a group of approximately 18 young people who came together primarily through a Facebook Group. The project developed a range of Open Educational Resources to help young people to have conversations with their families, carers or professional support staff about sex. The project team also developed a booklet ‘Talking about Sex: A booklet for young people with life-limiting or life-threatening conditions and their carers.’ The project has also equipped health practitioners to provide better support to young people on this topic through knowledge, resources, and a better understanding of the views and experiences of young people themselves.

What they learned

Co-production was a key element of this project and the team learned about:

- The value of building a community for young people.
- The importance of confidentiality and privacy within this platform.
- The knock-on value of this community in terms of providing other opportunities for young people to engage with.

The project identified a demand for ongoing support and training for professionals regarding talking to young people about sex, intimacy and relationships:

www.togetherforshortlives.org.uk/app/uploads/2021/06/4904_Talking_about_Sex_Evaluation_Report_FINAL.pdf

Goal 2: Parallel planning takes place for transition to adult services alongside plans for deterioration

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 focused 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 can be difficult to start communicating about end of life with young people who may be very much focused on living their lives. However it is important that the issue is raised (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 communication should take an outcome-focused 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 by 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 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.

Communications 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 questions. A summary should be made available in an appropriate format as soon as possible and a timely follow-up date agreed.

Transition in practice

Ten Steps Transition to Adult Services

This is an example of a local pathway that has been developed specifically for young people with life-limiting conditions by the palliative care transition team at Alder Hey Children's Hospital. <https://10stepstransition.org.uk>

Transition in practice

Royal Devon & Exeter Hospital Trust: Pathway Clinics

Aims

To improve continuity of care for young people with complex needs by transferring them from a consultant paediatrician to a consultant adult physician and establishing a 'carousel clinic' model.

What they did

Fourteen clinics took place for 30 young people over 39 appointments (30 1-hour new appointments and 9 30-minute follow-up appointments). Clinics at different settings (e.g. in schools) were attended by professionals and carers from more than 14 disciplines and agencies, including medical, nursing, education, social care, allied health professionals and residential care.

What they learned

The main success factors identified for the Pathways Clinic were:

- Allowing a 'robust' handover with information sharing within the multidisciplinary team – including safeguarding.
- Facilitating a patient and family-centred approach to care.
- Providing a clear route for ongoing support into adult services.
- Ensuring the environment is appropriate for the patient, in particular being large enough for the number of people.
- Extending the inclusion criteria for the clinic.
- Promoting greater representation from social care and streamlining the clinic for the professionals (e.g. grouping patients for a specialist).

The benefits/impact of the project

Carers felt the team listened to and understood their concerns, and provided solutions and suggestions. Carers valued having the appointments within the school setting.

Professionals fed back that although their attendance at the clinic appointment took more time than a regular appointment, it was an effective use of their time. They felt that the clinic improved patient care and promoted multidisciplinary working.

The team are delighted to report that following submission of a successful business case to the Health Board, funding has been secured to ensure that the Pathways Clinics are 'mainstreamed' and stay in place as the preferred delivery model to support young adults through transition to adult care.

www.togetherforshortlives.org.uk/app/uploads/2022/03/Royal-Devon-and-Exeter-Pathways-evaluation.pdf

Goal 4: A follow-up meeting regarding transition plans takes place with the young person and family within three months

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 plans, 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 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 multi-agency/multi-disciplinary transition planning meeting. Consent should be sought to share information with all professionals involved and the meeting should be convened as soon as possible.



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

The meeting chair should be agreed beforehand with the young person and their family. 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 based on communications 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.
- A 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

South Tyneside and Sunderland NHS Foundation Trust – Teen matters: transition of each and every need

Aim

To enable all disabled young people and their families to receive appropriate care at every step throughout transition to adult services, and on an ongoing basis throughout their adult lives. The project aimed to ensure access to a team with the right expertise to address every need, every step of the way, through the development of a suite of tools to support the implementation and evaluation of transition care pathways.

What they did

The paediatric, neurorehabilitation and palliative care teams collaborated with the learning disability and mental health teams and Parent Carer Forum to review and improve care pathways for disabled young people as they transition to adulthood and adult services. A suite of resources were produced to underpin the transition journey, including:

- Web accessible version of a traffic light tool to inform clinical consultations and data capture at the point of care: https://hubble-live-assets.s3.amazonaws.com/bacd/redactor2_assets/files/94/HFWSummary.pdf
- Disability complexity calculator.

Key recommendations

1. Identify a learning disability champion in all paediatric teams to lead on the early identification, documentation, and flagging of children and young people with learning disabilities. Consider using the learning disability screening tool within the multimedia resources for families available here <https://learningdisabilitymatters.co.uk>
2. Proactively notify general practice teams about children and young people identified with learning disabilities, so they can include them in their learning disability registers, offer reasonable adjustments when healthcare is needed, and annual learning disability health checks from 14 years onwards.
3. Lead paediatrician to consider, for all young people approaching 14 years of age, which care pathway is most appropriate to their needs on transition to adulthood and adult services, and communicate this with the young person, family and wider team who need to know. Consider using the Needs4Pathways tool <https://needs4pathways.herokuapp.com> to calculate and analyse needs to inform choice of 3 steps of care pathway:
 - i. All young people with a learning disability access step one.
 - ii. Young people identified to need ongoing secondary healthcare as adults also access step two.
 - iii. Young people with the most complex needs who are most medically frail also access step three.
4. Lead paediatrician to identify a clinician in the adult medical team, to 'receive' disabled young people who require ongoing secondary healthcare, and establish joint transition clinics to ensure robust hand over of secondary healthcare.
5. Establish a transition pathway with the adult medical lead, including joint clinics to hand on the baton for leadership of secondary medical healthcare and input from the learning disability nursing team as needed.
6. Lead paediatrician to establish links with the adult palliative care team, including setting up a care pathway for safe transition of the most medically frail young people with the most complex needs. These needs can be assessed using the Disability Complexity Scale (<https://onlinelibrary.wiley.com/doi/full/10.1111/dmnc.13102> supported by the Need4Pathways tool <https://needs4pathways.herokuapp.com>)

7. Establish a multidisciplinary, inter-agency transition pathway for the most medically frail young people, with input from:

- a. Young person and their family.
- b. GP and primary healthcare team.
- c. Learning disability nursing team where appropriate.
- d. Adult secondary healthcare medical lead.
- e. Adult palliative care team.

Transition on this pathway is more likely to be a process over months, or even a year or more, to ensure build-up of confidence in, and relationships with, the new teams in adult services and robust handing on of the baton for care for each and every need.

8. Identify a paediatric data champion in all paediatric teams, to lead on data capture at the point of care to make visible all of the multifaceted needs of children and young people, including those aged 14 years+ approaching transition to adulthood and adult services. This would allow real data to inform service commissioning and design. Reflect on data captured at the point of care to inform the commissioning and design of transition care pathways.

9. Support of all staff involved in the care of young people and their families to be able to have appropriate level communication skills to respond to difficult and sensitive conversations in real-time. This should include school and nursing staff. Offer staff training to enhance and develop communication skills to hold these conversations.

The benefits/impact of the project

This project has developed a suite of resources to improve the processes needed to identify, assess, document and share information about the needs of young people approaching transition. It can support referrals to the most appropriate professional teams, including palliative care for those who are the most medically frail. It can inform care pathway commissioning and design to continue to meet the needs of young people as they approach transition to adulthood and adult services.

You can read their project report www.togetherforshortlives.org.uk/app/uploads/2021/02/Transition-of-Each-and-Every-NeedKH03Feb2021.pdf and watch a video podcast about the project www.youtube.com/watch?v=4Lrb7N0cl14

2

Phase 2: Preparing for transition

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 there is a change of focus from family-centred care to a young person-centred approach. It is important to work with families so they can better support the young person to build their confidence and abilities to make decisions where possible.

Standard 2

Every young person is supported to plan proactively for their future. They are involved in ongoing multi-agency assessments as much as they choose and/or are able, and in developing a single holistic transition plan that reflects their goals, aspirations and wishes for the future.

Key goals:

1. Young people and their parents are helped with the change of focus from family-centred to young person-centred care.
2. Every young person has a named worker to facilitate continuity of care.
3. Every young person is supported to consider plans for all their future care and support needs, as much as they choose and/or are able.
4. Ongoing multi-agency assessment joins up with other assessment processes and takes place at least every three months, or more frequently as needed.
5. Every young person is supported to identify adult services which can meet their needs.

"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

Goal 1: Young people and their parents are helped with the change of focus 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 communicate their wishes. In England there are Independent Support Advocates within every local authority that can provide this. The advocate's role is to enable the young person 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.

Liberty Protection Safeguards

The Liberty Protection Safeguards provide protection for people aged 16 and above who are, or who need to be, deprived of their liberty in order to enable their care or treatment, and who lack the mental capacity to consent to their arrangements. The Liberty Protection Safeguards were introduced in the Mental Capacity (Amendment) Act 2019 and will replace the Deprivation of Liberty Safeguards (DoLS) system. The key changes are:

1. Three assessments will form the basis of the authorisation of Liberty Protection Safeguards:
 - A capacity assessment.
 - A 'medical assessment' to determine whether the person has a mental disorder.
 - A 'necessary and proportionate' assessment to determine if the arrangements are necessary to prevent harm to the person and proportionate to the likelihood and seriousness of that harm.
2. Greater involvement for families.
3. Targeted approach.
4. Extending the scheme to 16 and 17-year-olds.
5. Extending the scheme to domestic settings.
6. Clinical commissioning groups (CCGs), NHS trusts and local health boards as Responsible Bodies.

They apply in England and Wales.

www.gov.uk/government/publications/liberty-protection-safeguards-factsheets/liberty-protection-safeguards-what-they-are

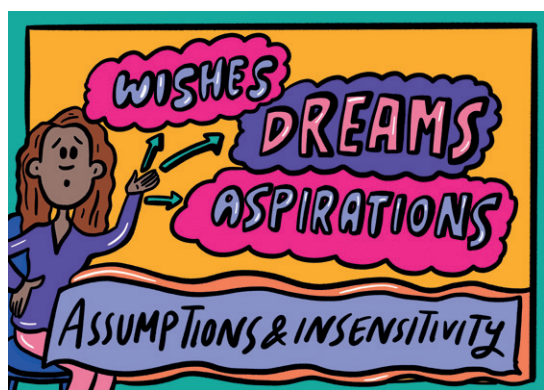
Goal 2: Every young person has a named worker to facilitate continuity of care

All young people should have a named person who provides a key working function. There are different interpretations of the role and a variety of models for achieving this. For example, there may be a named worker who supports the young person (e.g. in a hospital setting) or there may be an appointed worker who is contracted and paid to coordinate all that young person's transition.

There may be a worker allocated within children's services to facilitate continuity of care and who works towards 'handing over' to a designated worker 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.

The role can be filled by different types of professional, for example a Youth Worker or in some settings it could be a nurse.



The following list of duties are taken from a Job Description for a children's hospice-based Transition Nurse:

- To be an experienced paediatric palliative care nurse with an understanding of the needs of young people and families needing transition support to access appropriate adult services.
- Deliver care and role modelling clinical leadership qualities that support high standards of nursing care in the communities and regions across Wales.
- Support the Transition Consultant in developing and delivering a range of support services to meet the needs of young people transitioning into adult services.
- Facilitate the delivery of the multi-disciplinary Transition Hubs alongside direction from the Transition Consultant.
- Support skill sharing and professional development among a range of multi-disciplinary colleagues as appropriate.
- Gather data and employ evaluation tools to evidence impact and guide the design of services, to include the voice of the service user in evaluation and design.
- Provide clinical support for groups and events involving young people.
- Provide appropriate advice and psychosocial support to young people and their families.
- Act as a key contact for a caseload of young people; advocating and attending meetings as required and appropriate.
- Champion the principles of consent and capacity for young people in line with the Mental Capacity Act and to pay due regard to Liberty Protection Safeguards and other relevant legislation and guidance.
- Engage with colleagues in health, social care, education and other relevant disciplines to support a seamless transition from paediatric to adult palliative care services.
- Advocate on behalf of the young person and family where necessary, to ensure transition procedures are in place and progressing with the relevant health boards and Local Authority areas.
- Promote and maintain effective team functioning through the promotion of close working relationships throughout care services and with community partners.

Goal 3: Every young person is supported to consider plans for all their future care and support needs, as much as they choose and/or are able

A young person's ability to shape their 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 named transition 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 (Horridge, 2016).

Goal 4: Ongoing multi-agency assessment should join up with other assessments and take place at least every three months or more frequently as needed

The multi-agency assessment should join up with other assessments. In England for example, it should include information that is held in the Education Health and Care Plan and link to the Preparing for Adulthood Outcomes.

www.ndti.org.uk/resources/preparing-for-adulthood-all-tools-resources

Goal 5: 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 the young person 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 adult service provision, rather than trying to match a children's service with a corresponding 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 healthcare 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 healthcare 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 their own care team?

Transition in practice

Ty Hafan: Transition Hubs

What they did

The Transition Hubs aimed to provide a holistic one-stop point of contact where young adults could receive support with transition and access a 'Hub' hosted at their local adult hospice. The Hubs provided clinical advice alongside more holistic support around independence. They also encouraged social peer group support. The Hubs were facilitated by a transition nurse who also provided emotional support to families. There was a social media group to enable peer support and home visits when possible, to offer reassurance, and help build confidence. Regular study sessions to encourage skill building for adult palliative care colleagues were built into the model.

What they learned

- The appointment of a suitably skilled and experienced co-ordinator was crucial to the success of this project. This post was held by an experienced palliative care nurse, which gave the project the clinical credibility to establish relationships with the adult palliative care teams and inreach to hospital wards. It was also of benefit that the postholder had a pre-existing relationship with the young people and families.
- The social aspect of the Hubs was a key to their success and the team extended these opportunities to enable ongoing peer relationships to flourish. Even prior to the Covid restrictions it was evident that social media and the closed Facebook groups were instrumental in maintaining these relationships. The virtual events levelled out barriers around location, mitigating travel issues and also appealed more to those who found social situations difficult.
- The involvement of the adult palliative care/hospice consultant was very beneficial and if they are engaged early on they strengthen links with the wider adult palliative care team.
- The main resource needed to ensure the Hubs ran smoothly was the role of the transition nurse.

The benefits/impact of the project

Those attending the Hubs felt the benefits of the holistic support and one-stop shop approach. Another important benefit they derived from attending was the opportunity to have a clinic appointment with the adult consultant.

A summary of the project can be found here:

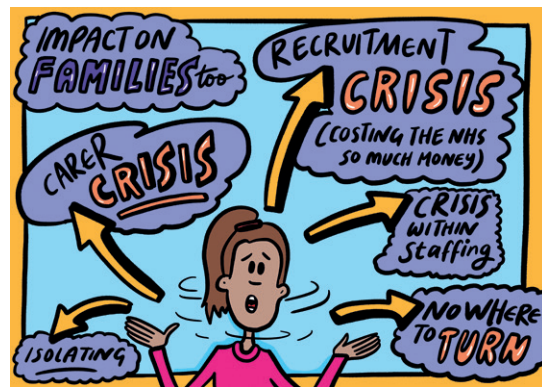
www.togetherforshortlives.org.uk/app/uploads/2022/03/One-slide-Ty-Hafan.pdf

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 they want. Personal health budgets are increasingly popular among young adults and should be available to all who wish to have one.

“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 should be offered an Advance Care Plan (ACP) which includes planning for end of life in parallel to planning for ongoing care and support in adult services.

This standard applies to all stages of the transition journey as a young person with a life-limiting condition may die at any point during their transition journey. It emphasises the need to parallel plan for end of life alongside putting plans in place to support the young person to live as full a life as possible.

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 ACP which includes an end of life plan running alongside their plan for future life. This should be dynamic and regularly reviewed.

Time of death

3. Every young person's pain and other symptoms are assessed and managed by a clinician with appropriate skills in order to provide high quality care at end of life.
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. Parents, siblings, wider family and others close to them are supported, informed and involved.

After death

6. Parents, siblings, wider family and others close to the young person should be offered the choice of caring for the young person during and after death, and supported to do this if it is their choice.
7. All professionals/agencies should be informed of the death with the parents' consent.
8. All family members should be supported according to their individual needs for as long as they need it in bereavement.



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 deterioration 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 the worst. In parallel planning, arrangements made for transition continue to be advanced so that placement opportunities are held, and adult care 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's health improves, opportunities remain open and relationships with the adult care 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 Advance Care Plan (ACP) which includes planning for end of life alongside their plan for future life. This should be dynamic and regularly reviewed

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 (ReSPECT). www.resus.org.uk/respect

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. The resulting document or 'Plan' provides a written summary of previous discussions. Consideration will need to be given as to how the information in this ACP can now be translated into the management and documented processes of adult services. The ACP 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 ACP 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 ACP, alongside planning for ongoing care. End of life planning may include discussions about place of death, decisions about stopping any non-essential drugs or other invasive interventions, and DNACPR (do not attempt cardiopulmonary resuscitation) following the ReSPECT process.

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 palliative 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 communicate openly about their wishes (NCPC & Together for Short Lives, 2015). The Gold Standards Framework provides useful tools to support professionals to communicate around end-of-life care. www.rcgp.org.uk/learning-resources/daffodil-standards

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 ACP 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 ACP 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 and professionals should have access to advanced communication skills courses.

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.

Time of death

Goal 3: Every young person's pain and other symptoms are assessed and managed by a clinician with appropriate skills in order to provide high quality care at end of life

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 in adult services may not have experience of the differing physiology and range of symptoms that young people with life-limiting conditions may have. They will need access to expertise and training to ensure their skills are developed.

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

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.

Care should be provided 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 in education and their school or college 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 interdisciplinary working. They may change their minds at short notice about where they want to die, for example if symptoms are not being managed well.

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 be aware that there may be disagreements between the young person and their family 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 and cared for during this time.

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, their digital legacy, or making a video. They may also need support to write a will.

Goal 5: Parents, siblings, wider family and others close to them are supported, informed and involved

Parents and other family members, including siblings and grandparents and others close to the young person, 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.

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 6: Parents, siblings, wider family and others close to the young person should be offered the choice of caring for the young person during and after death and supported to do this if it is their choice

The young person's parents should be able to care for their child after their death and continue their parenting role if this is their wish. 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. For example, they may wish to take photographs of their child or take a lock of their hair.

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 7: 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 (eg. 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 8: All family members should be supported according to their individual needs and for as long as they need it in bereavement

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.



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 there is an overlap of care planning and care provision up to the age of 25 if needed.
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 there is an overlap of care planning and care provision up to the age of 25 if needed

At this stage of transition there should be more focus on establishing joint working with the services in adult healthcare 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 and discussed, and they can be signposted to the most appropriate services for joint planning.
- Joint paediatric and adult clinics.
- Involvement of transition teams to consider funding packages such as continuing healthcare, and how complex healthcare needs will be met.
- Joint working with adult hospices so 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 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, and allow the young person to talk openly about their emotions, deal with loss of independence, or come to terms with their mortality.

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

St Oswald's: Engaging GPs, improving outcomes

Aim

To develop and pilot a system to enable GPs to confidently provide support in their local communities for young people with life-limiting conditions.

What they did

Piloted a multidisciplinary transition service for young people aged 16-25. The service provided an outpatient assessment with the team, followed by ongoing support tailored to the needs of the patient and their family. The team approach prioritised supporting the GP to lead in the patient's care, and work collaboratively with the other health and social care professionals caring for the patient. To promote the new service, the team were active in networking and training, publicising not only the service, but the wider needs of the patient group.

What they learned

- The need for a retrospective approach – to provide support to young people who had already moved on to adult services after the age of 18.
- The length of time it takes to establish partnerships, but also the huge value of having close collaboration, for e.g. establishing a local MDT with hospital specialists and the hospice, to enable discussion of cases and two-way referrals.
- There were five key issues that young people presented with: sleep problems, pain and symptoms, lack of relationship with GP/Consultant, lack of respite and absence of care planning.
- The most common issue raised by parents was frustration with their GP. They also feared that adult clinicians might not prioritise active regular treatment of their child's symptoms if they were not aware of how such treatment could improve their young person's enjoyment of life.
- The engagement of GPs can enable a preventive approach, for example dealing with more common symptoms before they escalate.
- The project enabled difficult end of life conversations and planning.

The benefits/impact of the project

This project has provided evidence of how effective partnership working can be established between the hospice, hospital specialists and GPs. It has shown how a hospice-led transition service can add value to services that are already in existence, play an effective central coordination role for young people & parents, as well as provide a point of contact, education & training for professionals.

The project's evaluation reports can be read here:

www.togetherforshortlives.org.uk/app/uploads/2021/03/Engaging-GPs_Improving-Outcomes-Learning-and-Recommendations.pdf

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 specialties, with no direct equivalent to the holistic care provided by a paediatrician.

There should ideally be a named 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 healthcare 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.

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

Young person

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 clear expectations and knowledge to ensure confidence in their care and support needs being met into 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, and are included in transition planning.
6. Adult services in secondary care should ensure there is coordination and communication regarding clinic appointments – this may be achieved by having a lead clinician or named worker in adult services.
7. Short break or respite needs of young people and their parents/carers are considered and provided in the most appropriate setting.
8. Parents, wider families and others close to the young person are included and involved as appropriate.
9. Professionals have the skills to provide complex care and have knowledge of relevant legislation.

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

Whilst health is a crucial element of support, it is often not the most important thing 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!

It is important in multi-agency working to ensure that the overall goals and aspirations of the young person are being met. In England, this would mean meeting their Preparing for Adulthood outcomes as set out in their Education, Health and Care Plan. Multi-agency working should include:

- Health (for example Continuing healthcare).
- Social care (children's and adult).
- Education and training.
- Housing.
- Social Prescribing.
- Friendships and relationships.

In the final section of this pathway we have set out some of the important roles and responsibilities of 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

Zest Young Adult Service at St Elizabeth Hospice

Aim

To pilot a new transition nurse coordination role as part of the Zest young adult service – based at the adult hospice – to provide coordination across the Clinical Commissioning Group, Continuing Healthcare Team, children’s and adult hospice, hospital, neuromuscular service and community teams. To upskill the adult hospice, paving the way for a developing young adult service.

What they did

This project provided a transition co-ordinator, (a ‘key worker’) to support young people aged 15-19 and their families to plan, co-ordinate and support seamless transition across multiple services. The transition co-ordinator actively led transition planning from children’s to adult services, providing one point of contact for young people and their families. The project enabled the pilot of a new young adult residential short break service based in an adult hospice, which has subsequently been commissioned.

What they learned

The evaluation of the service was carried out by the University of Suffolk and aimed to develop a greater understanding of the numbers, referral patterns and reasons for referral to the Zest service, as well as evaluate impact of the co-ordinator role. The evaluation evidenced positive impact for service users and explored views of partner organisations and wider stakeholders.

Participants suggested that they key elements which made the service work were good communication and the staff behind the service. In particular, the Zest nurse/Transition Co-ordinator was vital in developing strong relationships through working with the families and young people, and being identified as their key worker. The short breaks were also emphasised as being important for respite, carer/family support, and for the autonomy of the young people.

The benefits/impact of the project

The Zest service provided specialist nurse-led short break care for young adults, which could be in the form of day care, or a short break weekend stay. Over the two-year period, a total of 89 short stays were provided. The Zest nurse/transition co-ordinator provided the relevant knowledge and skills to expand the Zest service, enabling significant growth of a Zest care team. The project has led to commissioned short breaks and Zest days, alongside ongoing transition co-ordination and adult hospice support for an increasing number of families.

Their evaluation report www.togetherforshortlives.org.uk/app/uploads/2022/06/Final-Zest-report-May-24th.pdf

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 link 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.

Adult services should look carefully at care plans and identify where any further information, training or support is required 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 this information.

Goal 5: Primary healthcare services, including GPs, develop a relationship with the young person and their families/carers, and are included in transition planning

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 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 should ensure there is coordination and communication regarding clinic appointments – this may be achieved by having a lead clinician or named worker in adult services

Within adult clinics and wards in hospital it is important to ensure there is a lead clinician appointed within appropriate specialties such as respiratory, diabetes, renal, and 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 the whole of that young person's 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, and 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 communication aids, TVs, computer games, and the internet. Good practice in supporting young adults in adult health care settings was explored in the STEPP project (Beresford, 2013).

It may be helpful to suggest that young people and their families set out their daily care needs so that staff on a ward can see easily how their condition impacts on them and can make adjustments. Together for Short Lives has developed an online resource to help young people and families feel confident that their immediate needs are communicated to staff they may not have met before.

<https://mycaretransfer.togetherforshortlives.org.uk>

There are similar tools that you may be familiar with, for example:

All About Me

<https://includemetoo.org.uk/wp-content/uploads/2020/04/All-About-Me-Communication-Passport-Template.pdf>

My One Page Profile

<http://helensandersonassociates.co.uk>

Health Passport

<https://www.nhsemployers.org/publications/nhs-health-passport>

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. 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, wider family and others close to the young person are included and involved 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

Goal 9: Professionals have the skills to provide complex care and have knowledge of relevant legislation

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

Professionals working in adult services, for example district nurses, continuing care workforce, and adult hospice care team, should have skills and confidence in providing complex care to young people with life-limiting conditions.

The workforce should also have good working knowledge of legislation such as the Mental Capacity Act and Liberty Protection Safeguards.



Transition in practice

Prince and Princess of Wales Hospice (PPWH)

The PPWH has established a Young Adult Service for young adults aged 16–39 years with a life-limiting or life-threatening condition, which currently supports 30 young adults from 4 Healthboards and 12 Local Authorities in Scotland. Our existing young adult pathway offers an initial 90 minute holistic assessment at our dedicated Young Adult Transition Clinic. Following this, where appropriate, internal referrals can be made to other services, e.g. The Living Well, Art, Family Support and Rehabilitation Services. This service gently introduces young adults and their families to the wider MDT teams, helping to reduce their anxieties about an adult hospice, whilst building relationships and trust. Accessing the wider young adult services also laid the foundation for the pilot of a Short Break Stay (SBS), which had been identified as a gap in service provision. Many of the young adults and their families acknowledged that since the pandemic (or longer for some), they received little or no access to respite care, with their families having no option but to provide continuous 24/7 care.

The Short Break Stay Pilot was a 12-week programme, utilising 2 unfunded beds within the specialist palliative care in-patient unit. It ran Monday to Thursday, offering 24 young adults and their families a free short break experience.

What the team learned

- Prior to the SBS starting there was a high level of anxiety from all (young adults, their families, the SBS team and the wider MDT). However, from day 1 we received very positive feedback from all involved.
- The Living Well Services provided a stepping-stone to assist young adults to move forward with accessing the SBS pilot, as staff got to know the young adults, their conditions and how they liked to be cared for before they accessed the SBS.
- To reduce the anxieties of being part of the pilot, families/carers were offered the option to stay overnight in the family bedrooms. A few stayed for 1 night only, with other families staying at home. This is testimony to the SBS team that the young adults and their families entrusted the SBS team to care for them safely.
- Almost all families were having a break for the first time in many years.
- We worried that the young adults might be bored, as for safety reasons the pilot service was only provided in the vicinity of the hospice grounds. However, many of the young people said that just being away from their own home, bedroom and family instigated lots of new conversations and memories. Young adults told us they had 'fun +++'.

The benefits/impact of the project

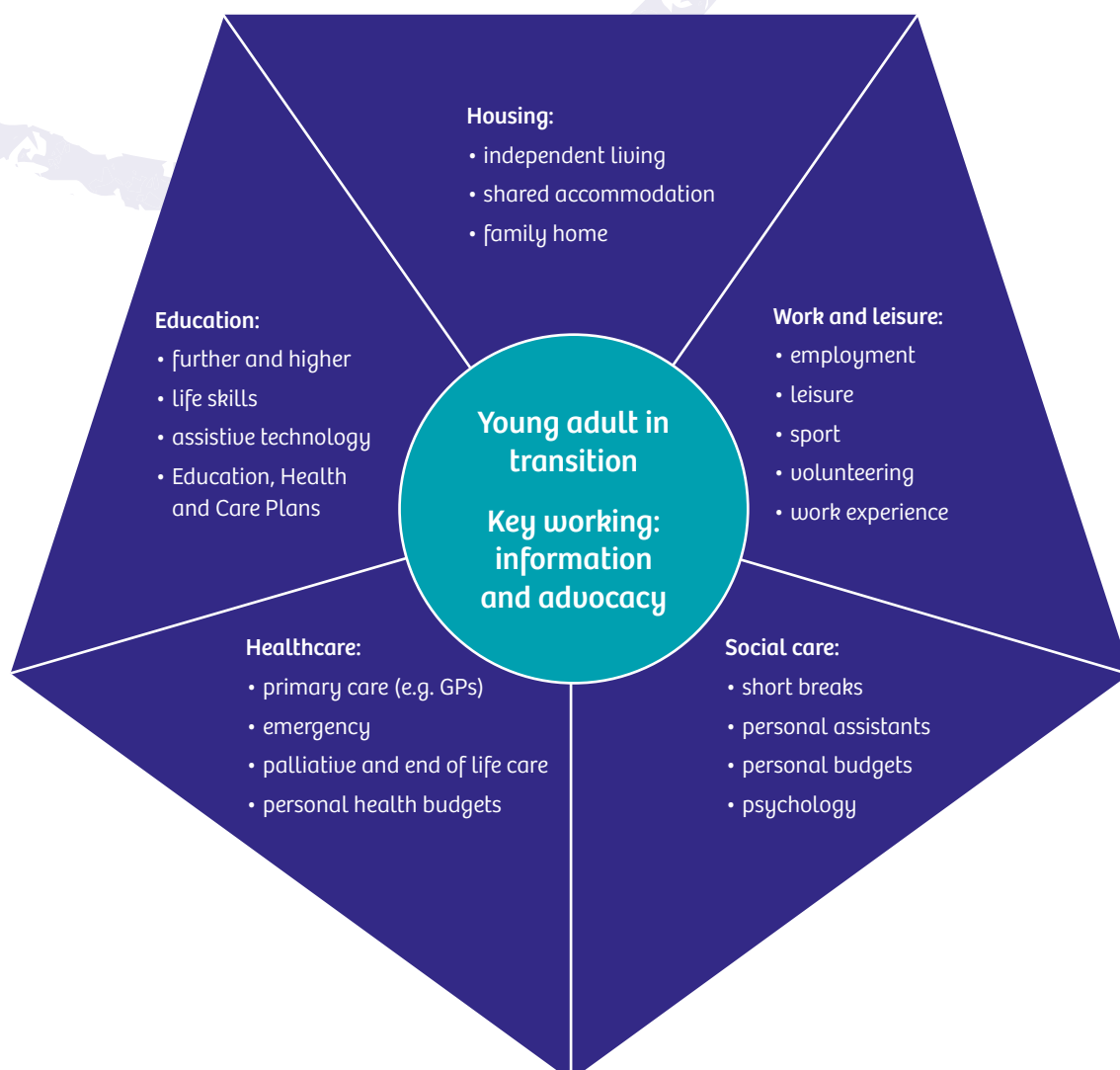
We are now seeing a greater number of young adults living into adulthood with life-limiting conditions. These young adults struggle to access short breaks in an age-appropriate environments with care provided by staff that understand and can respond to their complex care needs. The growth of this population is also hugely impacting on their family's health and wellbeing, many of which are the main care provider, and who are older themselves. Initial feedback has allowed us to consider what worked well, what needs to be changed or refined, what service model (including skill mix), is required for this, and what the service will cost per year. It is hoped that the above knowledge will support the service moving safely from a proof-of-concept to a core service that young adults can access and pay for via their own Self-Directed Support or respite budget.





The roles of different agencies in adult services

This 'Pentagon of Support' conceptualises the way that five key agencies should work together, with the young person at the centre. The 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 housing/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 changes. District nursing teams are often small and may be based within GP surgeries, which 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. This 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 are expected to undertake, rather than just those 'with a special interest' or additional training in palliative care.

A key function of general practice is to provide a safety net so that service provision gaps are identified and filled. 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 healthcare from parents to the young person (or an advocate), and informing young people about their rights to receive confidential healthcare, independently of their parents (subject to capacity) 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.

Peer Support

Peer support helps to foster reciprocal relationships, to facilitate emotional, social and practical help. It can help to reduce feelings of isolation for young people and their families. Peer support may be formal or informal: it can be delivered by trained peer support staff and volunteers, or through more informal, ad-hoc support among peers with lived experience. www.england.nhs.uk/personalisedcare/supported-self-management/peer-support

Transition in practice

Royal College of General Practitioners: Developing positive transitions into primary care – development of e-learning modules for GPs

Aim

This project aimed to support GPs to make improvements to the service they are able to offer to seriously ill young adults, to ensure good communication between the primary care team, patients, carers and secondary care professionals.

What they did

- Engaged with key stakeholders, including young people and their families, to design a solution for improving care within primary care.
- Developed processes to integrate the care between health professionals and the community, and provide safe and supportive outcomes for the young person.
- Engaged and linked GPs and the wider primary care team with wider support services in their locality supporting young people with life-limiting conditions.
- Developed two new e-learning modules to inform and support GPs and the wider primary care team.

What they learned

- Planned transition for young people in primary care is a new concept and commissioners need to recognise that funding is essential for continuous professional development.
- A mechanism needs to be developed to identify and support children with life-limiting conditions within GP practices.
- The project identified areas which can be neglected if primary care is not involved, for example sexual health, dealing with common conditions seen in primary care, co-ordination and rationalisation of referrals, and medication management.

The benefits/impact of the project

Some of the learning from the project will be beneficial for other GP practices to take forward, for example building relationships with services such as Children's Hospices, Community Paediatrics, and hospital-based Transitions Teams, with a view to ensuring that general practice is included in local transition planning meetings. The practices who worked on the project have been able to develop a register of high-need patients and plan in 6 monthly reviews for these young people.

The eLearning modules provide practical information for GPs which can be accessed free of charge by RCGP members: <https://elearning.rcgp.org.uk/course/info.php?id=485>

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.

You can find hospice services in your area via these links:

www.togetherforshortlives.org.uk/get-support/supporting-you/find-a-service

www.hospiceuk.org/hospice-care-finder

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 (Pilkington et al, 2019; Young et al, 2018).

Adult hospices tend to have a very different role to children's hospices and do not usually provide planned short breaks, although this is changing. 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.

Social prescribing

Social prescribing is a fundamental aspect of the NHS Long Term Plan. It enables GPs, nurses and other primary care professionals to refer people to a range of local, non-clinical services to support their health and wellbeing. Most models involve a link worker such as community connector or navigator. www.kingsfund.org.uk/publications/social-prescribing

Youth Work

Youth workers play a valuable role in helping to provide a range of information and support to young people. Their role helps to build young people's self-esteem and confidence, which may enable them to make informed choices about how to manage their health, wellbeing and social relationships. Often learning opportunities and the development of new skills can be a positive outcome for young people who access this support. Interactions may be face-to-face, by telephone or via other media (or a combination approach).

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.

Transition in practice

Futures Midlands

Volunteering Matters led a project aiming to support young people in their last year of school and match them with a trained volunteer to explore opportunities for them to sample life in the workplace through skills training and/or work placements.

What they did

The project was a partnership with the Acorns Hospices in the West Midlands, based in Birmingham, Walsall and Worcester, and schools and colleges in the West Midlands. The target group was young people with life-limiting conditions aged 17 to 19. The mentors worked alongside the young people to engage them in skills development, volunteering and social action, and work placements. The project organised training workshops, volunteering opportunities, work experience placements, and mentoring opportunities.

What they learned

Volunteering Matters put together a checklist of factors for a successful volunteering or work experience placement:

- ✓ an accessible building
- ✓ an appropriate and accessible working environment, which should be risk assessed
- ✓ access to accessible toilets
- ✓ access to personal care where needed
- ✓ induction and training for the young person
- ✓ a contact person that the young person can go to at any time
- ✓ provision of a buddy
- ✓ a clear but simple role for the young person
- ✓ structured and achievable activities
- ✓ opportunities for the young person to suggest their own ideas and co-produce their own project, where possible
- ✓ flexibility in case a first option does not go to plan

Benefits/Impact

Futures Midlands supported 12 young people to recognise their skills and positively shape their futures through volunteer mentor support.

Read the evaluation from the project:

www.togetherforshortlives.org.uk/app/uploads/2021/06/Volunteering-Matters-Futures-Midlands-Evaluation-August-2019.pdf

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 Further and Higher Education (FHE) settings needs 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 healthcare 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.

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) 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/home

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, a young person 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 a young person who wants to continue living where they are, or move elsewhere – either to their own property, or a hostel, or a form of shared accommodation. 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

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 some 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.

www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/shared-lives-schemes

Appendices

Appendix one: National Guidance and Policy

UK Government policy

- Department for Education. 2011. Short breaks for carers of disabled children: departmental advice for local authorities. www.gov.uk/government/publications/short-breaks-for-carers-of-disabled-children
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NHS England and NHS Improvement: policy published on the FutureNHS platform

- Palliative and End of Life Care Children and Young People's National Service Specification
- Palliative and End of Life Care Adult National Service Specification
- Palliative and End of Life Care Contract & Specification Requirements
- Palliative and End of Life Care Commissioning Investment Framework April 2022
- Palliative and End of Life Care Funding & Contracting Approaches LIVE Draft

National Institute for Health and Care Excellence guidance

- The National Institute for Health and Care Excellence. 2016. Transition from children's to adults' services for young people using health or social care services – NICE guideline [NG43]. www.nice.org.uk/guidance/ng43
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Emma Powell, Regional Nurse Advisor for Young People's Healthcare Transition (Northeast & Yorkshire and Northwest England)

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Stepping Up: A Transition Pathway to enable a good transition to adulthood for young people with life-limiting and life-threatening conditions

This pathway 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 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

Suite 1b, Whitefriars, Lewins Mead, Bristol BS1 2NT

T: 0117 989 7820

E: info@togetherforshortlives.org.uk

Helpline: 0808 8088100

www.togetherforshortlives.org.uk

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