



**Commissioning for smooth  
transitions and age-appropriate care  
for young people with life-limiting  
conditions in England**

**A guide for Clinical  
Commissioning Groups**

**This resource is designed to support clinical commissioning groups (CCGs) to effectively commission smooth and well-planned transitions to adulthood for young people with life-limiting and life-threatening conditions between the ages of 13 and 25. It is also intended to help CCGs commission age-appropriate health services for this population group. It covers the following:**

- What do young people with life-limiting conditions need?
- How does this differ from children or older adults?
- How many young people with life-limiting conditions should CCGs expect to commission care for?
- Who provides services to young people with life-limiting conditions?
- What should CCGs do?
- Who else should be involved in commissioning for this population?
- What outcomes can CCGs improve by implementing these recommendations?

## **1. What do young people with life-limiting conditions need? How does this differ from children or older adults?**

Life-limiting conditions are those for which there is no reasonable hope of cure and from which people are expected to die. Life-threatening conditions or events are those for which curative treatment may be feasible but can fail. People with life-limiting conditions need continuing palliative care throughout the trajectory of their illness.

Young people with life-limiting conditions need palliative care from the point at which their condition is diagnosed or recognised, throughout life, death and beyond. Palliative care for young people should:

- meet their physical, emotional, social and spiritual needs
- aim to enhance their quality of life and support their family in coming to terms with their condition and the care they will need
- help families understand how the young person's condition and their needs may change over time
- include managing distressing symptoms, providing short breaks and care through death and bereavement<sup>1</sup>

- be provided in ways which are appropriate to their age; this means care provided in age-appropriate settings by professionals who are skilled in working with them.

Whereas the majority of adults only need palliative care at the end of their lives, young people with life-limiting conditions require palliative care over a much longer period. Many will have needed palliative care from birth.

It is common for young people's conditions to fluctuate and, as such, it is often much more difficult to identify when they are moving into their end of life phase.

Young people with life-limiting conditions often have complex disabilities. The range of health conditions which results in young people needing palliative care is diverse. They can be defined by the following four categories<sup>2</sup>:

1. Life-threatening conditions for which curative treatment may be feasible but can fail – such as cancer or congenital heart disease.
2. Conditions where premature death is inevitable but where there may be prolonged periods where the young person is well - such as Duchenne muscular dystrophy.
3. Progressive conditions without curative treatment options, such as Batten disease.

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1. Together for Short Lives (2013). Definitions. Available to download from: [bit.ly/Z34i5s](http://bit.ly/Z34i5s).

2. Together for Short Lives (2013). A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions. Available to download from: [bit.ly/18Vd3JV](http://bit.ly/18Vd3JV).

4. Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death - such as severe brain injury.

Many young people with life-limiting conditions and their families find transition daunting. On leaving the comprehensive care offered by children's services, they will often have to deal with and establish important relationships with a range of unfamiliar agencies and professionals. The result can be gaps in services or fewer or less appropriate services<sup>3</sup>.

Studies show that there are number of distinct characteristics which young people with life-limiting conditions demonstrate and which commissioners and providers should take into account<sup>4</sup>. Although they will have fully outgrown childhood, young people's brains are still developing – meaning they won't have fully attained certain characteristics that are usually associated with being an adult. Their emotional and psychological maturity, as well as some key skills, will still be developing. Young adults with life-limiting conditions diagnosed in childhood may well be less mature than their healthy peers.



Many view their parents as their main source of support. Unlike other adults, the majority of young people are not at the stage at which parental support has been replaced with another source of committed support, such as a long-term partner.

Young adults want choice and control over how their parents are involved in decisions about their care. They often find their first appointments with adult health services daunting. They do not want health professionals to assume that their parents should not be involved.

Like all young people, many of those with life-limiting conditions want to establish their independence; some want to be able to spend time away from older adults; some hope to go into further or higher education and attain qualifications and skills; some wish to get a job, move into their own home, develop a social life and have relationships. Some young people also want to use their experiences to make things easier for other people in similar situations.

For many young people with life-limiting conditions, transition into adult services often coincides with a rapid decline of their condition and eventual death. As such, they have specific health needs which differ from both younger children and older adults who need palliative care.

These include advance care planning (ACP) and end of life planning. Young people should have plans in place where it is unclear whether their condition will stabilise, deteriorate or enter the end of life phase; this is known as 'parallel planning'.

Young people with life-limiting conditions require holistic support from a range of providers spanning health, social care, education, leisure and housing services. CCGs should partner other organisations – including local authorities and housing providers – which commission these services.

The Transition Taskforce has conceptualised the way that the five key agencies should work together as a 'pentagon of support' (see overleaf).

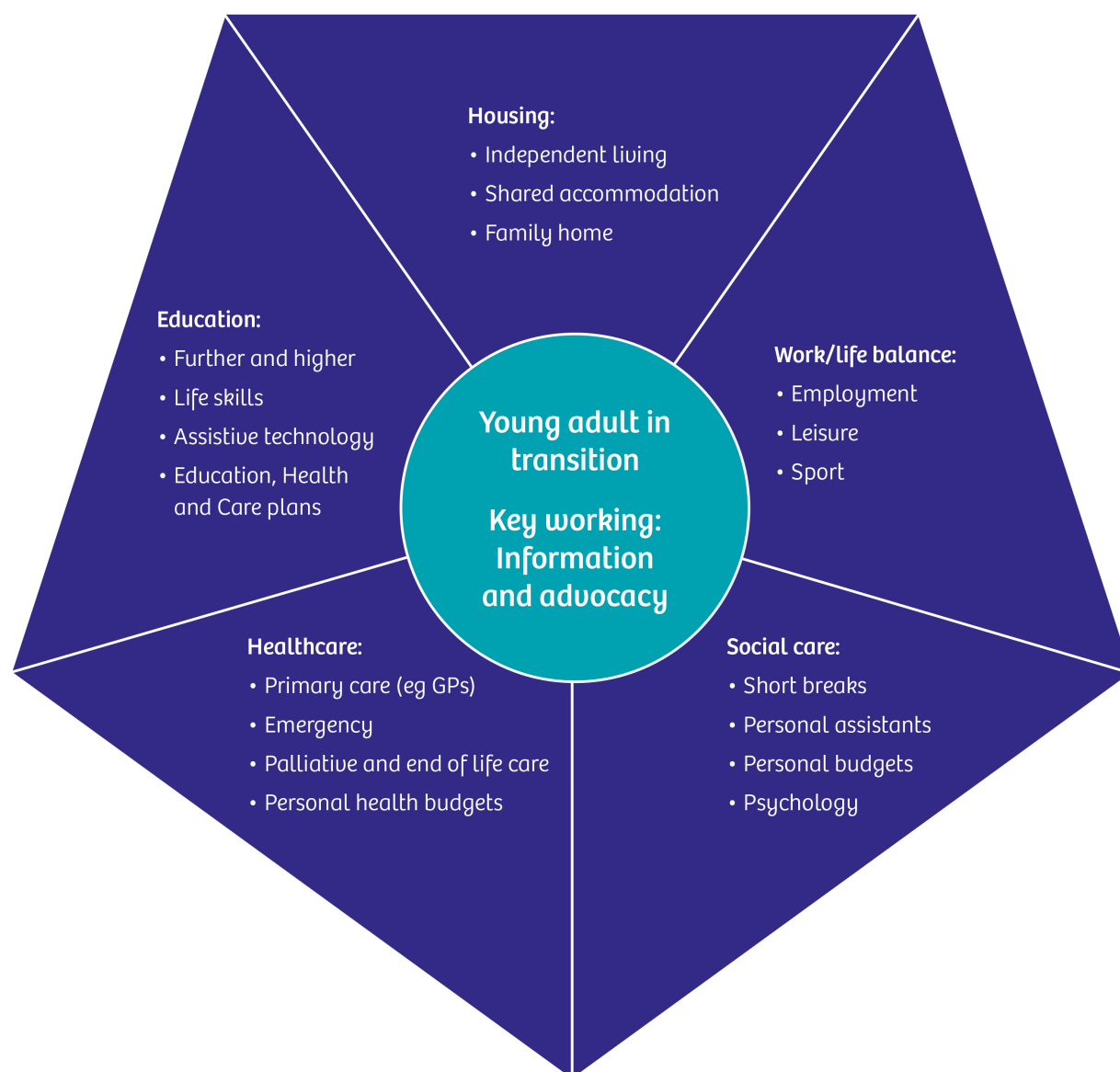
This pentagon is underpinned by health and social care working closely together to provide a foundation for all the other provision, with work, leisure and education being the two 'enabling agencies' on either side and independent living as the 'capstone' at the top.

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3. Marie Curie Cancer Care and Together for Short Lives (2012). Don't let me down: ensuring a good transition for young people with palliative care needs. Available to download from: <http://bit.ly/1uRYCey>.

4. Beresford B (2013). Supporting health transitions for young people with life-limiting conditions: researching evidence of positive practice (STEPP): making a difference for young adult patients practice prompts - key messages from research. Available to download from: <http://bit.ly/1FBGN9Y>.

**Figure one: The pentagon of support**



Working together, services which successfully help young people to move from children's to adult services:

- develop their skills of self-management and self-determination
- support their psychosocial development
- involve young people
- involve young people's peers
- support young people's changing relationships with their parent carers

- provide choice
- provide information
- focus upon young people's strengths for their future development<sup>5</sup>.

Services which successfully help parents:

- help them to adjust to their changing relationships with young people
- involve them in service planning
- offer a family-centred approach
- provide information.

5. Beresford B (2004). On the road to nowhere: Young disabled people and transition. London.



**Please note that this guide refers to general children's palliative care.** It sets out what CCGs should commission and how they should work with other local commissioners and providers. **CCGs should be aware that specialised children's palliative care is commissioned by NHS England<sup>6</sup>.** This includes services which manage complex symptoms and prescribe unlicensed medicines. **Specialised children's palliative care is different to specialist palliative care for adults.**

The latter is defined as the active, total care of patients with progressive, advanced disease and their families<sup>7</sup>. It is provided by a multi-professional team who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support.

**A service specification for adult's specialist palliative care is currently being developed by NHS England and is due to be published by September 2015<sup>8</sup>.**

## 2. How many young people with life-limiting conditions should CCGs expect to commission care for?

Published studies show the prevalence of life-limiting conditions in children and young people for every local authority district in England<sup>9</sup> and the prevalence of life-limiting conditions in young adults for every government office region<sup>10</sup>.

It is estimated that more than 40,000 children (0-19 years) in England in 2009/2010 were living with a life-limiting or life-threatening condition<sup>9</sup>. The highest rate of increase between 2000 and 2010 was among those aged 16-19, who accounted for 4,000, or one in ten of 0-19-year-olds who needed palliative care.

This was due to increasing life expectancy and improving quality of life resulting from advances in treatment and support. Children living with a life-

limiting condition may survive to an age where they will need to transition to adult services.

There are 56,000 young adults aged 18 to 40 in England who are currently living with life-limiting conditions<sup>10</sup>. This number is also growing. Between 2000 and 2010, the prevalence of life-limiting conditions in young adults in England rose from 26.0 to 34.6 per 10,000 population.

Young people with life-limiting conditions represent a very small population in healthcare commissioning terms; evidence shows that these small populations make commissioning appropriate services difficult. As well as often being inefficient, it can also prevent effective strategic care planning.

## 3. Who provides services to young people with life-limiting conditions?

Universal, targeted and specialist palliative care is delivered by a web of providers. They include children's and adult services – and some services which have been specifically designed for young people. General palliative care may be commissioned from the statutory and voluntary sectors using collaborative commissioning arrangements.

A significant proportion of palliative care is delivered by the voluntary sector. Voluntary sector organisations, including hospices which provide palliative care to young people, bring social value to communities. When the NHS remunerates these organisations for the palliative care they provide, the funding is matched and frequently exceeded by charitable donations which also contribute to the running of services.

Local volunteers also help to provide palliative care which are part-funded from statutory sources, further adding value. Commissioning comprehensive health services for young people with life-limiting conditions will help CCGs to meet their duties under the Public Services (Social Value) Act 2012.

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6. NHS England (2013). E03/S/h - 2013/14 NHS standard contract for paediatric medicine: palliative care particulars, schedule 2 – the services, A - service specifications. Available to download from: <http://bit.ly/11yjtVS>.

7. National Council for Palliative Care (2012). Commissioning Guidance for Specialist Palliative Care: helping to deliver commissioning objectives. Available to download from: <http://bit.ly/1BH8JN4>.

8. NHS England (2014). Actions for End of Life Care: 2014-16. Available to download from: <http://bit.ly/1BH9CFt>.

9. Fraser LK, Parslow RC, McKinney PA, Miller M, Aldridge JM, Hain R, Norman P (2012) Life-limiting and life-threatening conditions in children and young people in the United Kingdom; final report for Together for Short Lives. Available to download from: <http://bit.ly/1z24ZQw>.

10. Fraser LFK, Miller M, Aldridge J, PA, Parslow RC (2013). Prevalence of life-limiting and life-threatening conditions in young adults in England 2000-2010; final report for Together for Short Lives. Available to download from: <http://bit.ly/1z24VQQ>.

Commissioners should ensure that sustained, effective and age-appropriate health services are provided to young people with life-limiting conditions. There should be no gap as young people move from children's to adult services. At all times, locally available and community-led care should be at the heart of this.

## 4. What should CCGs do?

### 4.1 Actions for CCGs

The NHS Institute for Improvement and Innovation identifies a number of key actions which CCGs should follow as part of the commissioning process<sup>11</sup>. CCGs should take the following action immediately to bring about smooth transitions and age-appropriate services.

#### 4.1.1 Build partnerships

Young people with life-limiting conditions require holistic support from a range of providers spanning health, social care, education, leisure and housing services. CCGs should commission in partnership with local authorities using agreements under section 75 of the National Health Services Act 2006<sup>12</sup> to ensure an integrated service for young people with life-limiting conditions.

CCGs also need to be aware of their duties under the Children and Families Act 2014. These require them to commission services for all disabled children and young people aged 0 to 25 jointly with local authorities.

They must also co-operate with local authorities in ensuring that single assessments and education, health and care (EHC) plans are put in place. EHC plans are for children who have learning difficulties and disabilities which result in special educational needs. This will include some young people with life-limiting conditions.

CCGs should be aware that, from April 2015, local authorities are duty-bound under the Care Act 2014 to assess children's future social care needs before they reach adulthood.

Local authorities must also focus on the outcomes that adults wish to achieve; promote their wellbeing; work jointly with relevant partners (such as CCGs); and put in place care and care and support plans and personal budgets for adults over the age of 18 with assessed needs<sup>13</sup>.

CCGs should work with local authorities and other agencies to develop integrated transition plans across health, education, social care, housing and leisure, focussed on the outcomes which young people wish to achieve. These should form part of EHC plans. CCGs and local authorities should consider pooling budgets to help them offer personal budgets to young people in transition.

The Preparing for Adulthood programme has a guide to joint commissioning for CCGs, local authorities and other partners<sup>14</sup>; this includes links to other useful resources.

CCGs should also seek to work in partnership with:

- children's and adult palliative care networks
- providers in the statutory and voluntary sectors
- Transition Taskforce Regional Action Groups (RAGs).

#### 4.1.2 Analyse and plan

A report from the York Health Economics Consortium to inform the Craft-Killen review of children's palliative care<sup>15</sup> concluded that "the relatively small numbers of children and the specialist nature of the services points to the advisability of planning these services for a larger population of at least one million"<sup>16</sup>.

This principle also applies to the population of young people with life-limiting conditions. A CCG should seek to work with its neighbouring CCG(s) at a sub-regional level in order to determine how many young people with life-limiting conditions it is responsible for commissioning for.

CCGs should also work together to create the economies of scale necessary to commission services effectively.

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11. NHS Institute for Innovation and Improvement (2013). Supporting integrated care and integrated commissioning. Available to download from: [bit.ly/ZPKWFi](http://bit.ly/ZPKWFi).

12. Great Britain. National Health Services Act 2006: Elizabeth II. Part 3 (2006). Available to download from: [bit.ly/11lcfQo](http://bit.ly/11lcfQo).

13. Department of Health (2014). Care and Support statutory guidance issued under the Care Act 2014. Available to download from: <http://bit.ly/VrzH7i>.

14. Preparing for Adulthood (2015). Guide to joint commissioning resources. Available to download from: <http://bit.ly/1DZlcKF>

15. Craft A and Killen S (2007). Palliative care services for children and young people in England: an independent review for the Secretary of State for Health. Available to download from: [bit.ly/YHZjsA](http://bit.ly/YHZjsA).

16. York Health Economics Consortium (2007) Independent review of palliative care services for children and young people: An economic report.



CCGs should work with local authorities to ensure that local populations of young people with life-limiting conditions are included within Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies as recommended in the special educational needs and disability (SEND) code of practice<sup>17</sup>.

GPs should use their knowledge of young people with life-limiting conditions who are registered with their practice to inform their CCG's commissioning.

#### 4.1.3 Design pathways

Commissioners should refer to the *Transition Guide: A framework for the development of an integrated approach to improve the transition journey for young people with life-limiting and life-threatening conditions*<sup>18</sup>. This includes a diagram of a transition journey (see appendix one). This is a template for local transition care journey which can be adapted according to local need and the capacity of local services.

These can be effectively planned by local strategic level networks which should include commissioners and professionals from both adult and children's services. Young people should also be involved in this planning process.

Effective local transition journeys can help young people and their families clearly identify what should happen (and when) during their transition to adult services. This can help empower young people to take part in planning their care.

CCGs may wish to incorporate a transition journey for young people with life-limiting conditions into a wider journey which plans transitions for young people with all types of long-term conditions.

Where CCGs take this approach, they should ensure that their pathway is flexible enough to meet the unique needs of young people who need palliative care.

#### 4.1.4 Specify and procure

CCGs and local authorities should jointly oversee how a local pathway for transition is functioning – and make sure that a number of important elements of the pathway are implemented by the web of organisations providing care to young people. CCGs should help to bring about a joined-up approach without overlap or duplication – and where different providers are clear about their roles and responsibilities.

CCGs should specify in their contracts and agreements that providers plan transitions with young people and professionals consistent with person-centred planning principles. The plan

- should set out the transition support the young person will receive
- could take the form of a communication or 'health passport' to ensure relevant professionals – including GPs – have access to essential information about the young person
- should be developed by the time a young person reaches the age of 14; this is consistent with the transition process beginning in year nine as set out in the SEND code of practice<sup>17</sup> – and the recommendations of CQC's recent thematic inspection *From the pond into the sea: children's transition to adult health services*<sup>19</sup>; a rolling plan should be in place by the age of 16
- should form part of a young person's education, health and care (EHC) plan if they have a special educational need and are in education or training.

CCGs should also specify that providers of care to young people with life-limiting conditions offer:

- services suitable for young people – possibly as a distinct discipline separate to children's and adult services
- services focussed on bringing about smooth transitions for young people
- systems to collect data on the number of young people in transition and on the care

17. Department for Education (2014). Special educational needs and disability code of practice: 0 to 25 years. Available to download from: <http://bit.ly/1kOCi5j>.

18. Transition Taskforce (2014). *Transition Guide: A framework for the development of an integrated approach to improve the transition journey for young people with life-limiting and life-threatening conditions*. To be published in 2015.

19. Care Quality Commission. 2014. *From the pond into the sea: children's transition to adult health services*. Available to download from: <http://bit.ly/1uKT4Yf>.



which is provided to them; this should be used to stimulate improvements in services

- young people's experiences of services measured and acted on where necessary
- young people having access to training to help them self-advocate and to adapt to consenting their own treatment
- staff working with young people who can access training; this should help professionals provide services appropriate to young people which can help them achieve the outcomes they want from their lives
- an organisational transition policy, pathway and operational guide in place, which has been jointly developed by those providing care to children, young people and adults, as well as young people themselves
- a nominated health care transition co-ordinator or key worker who is known to the young person
- access to multi-media transition support resources
- access to peer support.

The NHS South West Maternity & Children's Strategic Clinical Network has developed a framework to assess the extent to which NHS trusts are ready to implement standards of care for young people in transition. It has also developed a local Commissioning for Quality and Innovation (CQUIN) scheme for transition. Both provide a template which should be considered by CCGs to support providers to improve transition. Both are attached to this guide as appendices.

The *Bridging the Gap: Transition from Children's to Adult Palliative Care* project<sup>20</sup>, funded by Together for Short Lives, describes the core elements that should be provided by services during transition. The project report also describes:

- gaps in current transition plans and pathways
- symptoms that young people may experience and need proactive support to manage
- key policies and guidance relating to palliative care during transition
- how and why key working is important

- the views of young people, families and professionals
- person-centred care planning tools.



CCGs should also be aware of the following resources when developing transition specifications:

- Recommendations for good transition planning for children with complex needs are set out in the report of CQC's recent thematic inspection entitled *From the pond into the sea: children's transition to adult health services*<sup>19</sup>.
- The *Preparing for Adulthood* programme<sup>21</sup>, funded by the Department for Education to help implement the SEND reforms, is developing outcomes resources for young people undergoing transition.
- The National Institute for Health and Care Excellence (NICE) is developing a clinical guideline for transitions from children's to adult services and expects to publish in February 2016<sup>22</sup>; it is also developing a clinical guideline on end of life care for infants, children and young people<sup>23</sup>.

There is a general dearth of age-appropriate short break services for young people with life-limiting conditions in England: CCGs should make themselves aware of any local short break services which can meet the needs of this group. As the population of children with life-limiting conditions increases, demand for children's palliative care services is growing.

Voluntary sector children's palliative care services are, in increasing number, being forced to introduce

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20. Noyes J, Pritchard A, Rees S, Hastings R, Jones K, Mason H, Hain R, Lidstone V (2014). *Bridging the gap: transition from children's to adult palliative care - final report*. Available to download from: <http://bit.ly/1yj1PpL>.

21. *Preparing for Adulthood*: <http://www.preparingforadulthood.org.uk/>

22. The National Institute for Health and Care Excellence (NICE): *Transition from children's to adult services*. <http://bit.ly/1FFpNTA>.

23. The National Institute for Health and Care Excellence (NICE): *End of life care for infants, children and young people*: <http://bit.ly/1yjeadz>.



upper age limits for their services. Many palliative care settings designed for babies and children are also unsuitable for young people.

Short breaks for young people with life-limiting conditions should include clinical care to meet their often complex health needs. Therefore, CCGs have a specific role in jointly commissioning these services with local authorities.

CCGs should take care to ensure that their own specifications for local, general transition services closely correlate with the specialised children's palliative care service specification E03/S/h6<sup>6</sup> which is the responsibility of NHS England. The latter focuses on a multi-professional specialist palliative care team, led by a medical consultant working at Paediatric Palliative Care Competency Level Four.

It encompasses functions including complex symptom management and prescribing unlicensed medicines. In contrast, for example, a CCG's responsibilities include commissioning community children's nursing teams and district nursing teams, many of which provide the bulk of general children's palliative care within their local areas.

NHS England is currently developing a service specification for specialised palliative care for adults. In 2011, a government-commissioned review of funding arrangements for palliative care recommended that an NHS tariff for palliative care should be developed<sup>24</sup>. The Department of Health and subsequently NHS England has run a Palliative Care Funding Programme.

This set up pilots to collect activity and cost data across both the children's and adult palliative care sectors. The programme has now published a new approach to palliative care funding for both children and adults<sup>25</sup> which is available for CCGs and providers to use.

During 2015/16, NHS England will collect further data and will oversee practical testing of the currency by groups of commissioners and providers. CCGs should use the age cut-offs between the adult and children's classification flexibly to best suit the needs of young people in transition.

CCGs should take account of the relatively high proportion of young people with life-limiting conditions who are eligible for NHS children's

continuing care and subsequently continuing healthcare – and who have a right to a personal health budget. The Care Act 2014 statutory guide<sup>13</sup> and the *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*<sup>26</sup> both set out how CCGs and local authorities should work together to ensure a smooth transition for young people from children's continuing care to continuing healthcare.

#### 4.1.5 Deliver and improve

CCGs should support palliative care services in: collecting and measuring data on the outcomes they are achieving; continually evaluating their performance; and innovating to improve the service they provide.

#### 4.2 Cost-effectiveness

Effectively commissioned and delivered services can play a cost-effective role in supporting early discharge for young people from acute care settings through step-down care. It can also help to reduce unplanned admissions among young people to acute care settings.

The government-commissioned funding review<sup>24</sup> highlights that hospital admissions in the last year of life for children who need palliative care cost an estimated £18.2m. Short breaks provided by hospices – which may include healthcare interventions – help to reduce stress on families and demand on public services.

Bereavement services for parents and siblings offered by voluntary sector palliative care providers before and following the death of a young person can help to mitigate the need for other service interventions later in their lives.

#### 4.3 What outcomes can CCGs improve?

Commissioning a comprehensive care pathway for young people with life-limiting conditions can contribute to improving the following indicators set out in the Clinical Commissioning Group Outcomes Indicator Set (CCG OIS):

#### Domain one: Preventing people from dying prematurely

**C1.1:** Combined indicator on potential years of life lost (PYLL) from causes considered amenable to healthcare adults and children and young people (NHS OF 1a i & ii)

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24. Hughes-Hallett T, Craft A and Davies C (2011). Palliative care funding review - creating a fair and transparent funding system; the final report of the palliative care funding review. Available to download from: [bit.ly/XQBIE7](http://bit.ly/XQBIE7).

25. NHS England (2014). Developing a new approach to palliative care funding: a first draft for discussion. Available to download from: <http://bit.ly/1Fdxqyd>.

26. Department of Health (2012). National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care (Revised). Available to download from: <http://bit.ly/1fZ3714>.

## Domain two: Enhancing quality of life for people with long term conditions

**C2.1** Health-related quality of life for people with long term conditions (NHS OF 2)

**C2.2** People feeling supported to manage their condition (NHS OF 2.1)

**C2.6** Unplanned hospitalisation for chronic ambulatory care sensitive conditions (adults) (NHS OF 2.3.i)

**C2.7** Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s (NHS OF 2.3.ii)

## Domain three: Helping people to recover from episodes of ill health or following injury

**C3.1** Emergency admissions for acute conditions that should not usually require hospital admission (NHS OF 3a).

**C3.2** Emergency readmissions within 30 days of discharge from hospital (NHS OF 3b).

**C3.4** Emergency admissions for children with lower respiratory tract infections (NHS OF 3.2)

## Domain four: Ensuring that people have a positive experience of care

All indicators.

A comprehensive local CPC service can also deliver improvements against indicators suggested for the NHS Outcomes Framework and the CCG OIS by the Children and Young People's Health Outcomes Forum Long-term Conditions, Disability and Palliative Care Subgroup<sup>27</sup>:

- Getting a quality multi-disciplinary assessment that reflects all the child's or young person's needs, in addition to those of their family.
- Getting a quality package of care (including a health care plan for emergency situations or an end of life care plan where appropriate) fully integrated across health, education and social care with access to key working support, information to enable the child or young person and family to manage the condition and ensure timely provision of equipment to support maximum participation.
- Ensuring review of the care plan at key points of transition particularly transition to adult life and services.
- Ensuring that the outcome indicators promote a whole family approach because the health and

wellbeing of family (carers) directly impacts on children and young people and their resilience.

## 4.4 Who else should be involved in commissioning for young people who need palliative care?

- the young person
- their family
- professionals providing palliative care
- the range of providers described in the pentagon support on page three
- the regional palliative care networks for children and adults and the Transition Taskforce Regional Action Groups (RAGs); CCGs should develop formal partnerships with existing local networks
- delivery organisations, including children's hospices, young people's hospices and adult's hospices; other voluntary palliative care providers should also be involved
- the local CCG(s) - specifically commissioning leads for children's services, end of life care, continuing healthcare and long-term conditions
- local forums of parent-carers, young people and disabled people.



27. Children and Young People's Health Outcomes Forum - Report of the Long-term Conditions, Disability and Palliative Care Subgroup (2012). Available to download from: [bit.ly/ZqIrlr](http://bit.ly/ZqIrlr)

# Appendix one: diagram of a transition journey

Parallel Planning for end of life care

Standard 3: Every young person has an end of life plan which is developed in parallel to planning for ongoing care and support in adult services.

Phase 1: Preparing for adulthood	
Young Person 14+	
Young person	Service goals
<div>At the centre</div> <div>Developmentally appropriate information</div> <div>Supported to make decisions</div> <div>Parents involved as young person wishes</div> <div>Key worker</div> <div>Friends Relationships</div> <div>School</div>	<div>1. Young person at the centre of planning, using person-centered planning approaches.</div> <div>2. Parallel planning takes place.</div> <div>3. Initial conversations about transition take place with the young person and their family at a time and in a place that suits them.</div> <div>4. A follow-up meeting with the young person and family takes place.</div> <div>5. The first multi-agency/multi-disciplinary team meeting takes place.</div>

Standard 1

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

Phase 2: Preparing for moving on	
Young person 14-18	
Young person	Service goals
<div>At the centre</div> <div>Friendships Relationships Sexuality</div> <div>Developmentally appropriate information</div> <div>Advocacy Self-advocacy</div> <div>Self-management of condition</div> <div>Short breaks</div>	<div>1. Young people and their parents are helped with the transition from family-centered to young person centered care.</div> <div>2. Every young person has a key worker to facilitate continuity of care and prepare the way into adult services.</div> <div>3. Every young person is supported to consider future plans, supported by ongoing multi-agency assessement.</div> <div>4. Every young person is supported to identify adult services which can meet their needs.</div>

Standard 2

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



Phase 2: Preparing for moving on Young person 14-18	
Able to talk about wishes	<ol style="list-style-type: none"> <li>1. Transition planning continues to take place even during times of uncertainty.</li> <li>2. Every young person has a documented end of life plan running alongside their plan for future life.</li> <li>3. The young person's pain and other symptoms are dealt with effectively.</li> <li>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.</li> <li>5. Family members and other carers are supported, informed and involved.</li> <li>6. The young person has the best quality of life and care to the end.</li> <li>7. Parents should retain their parenting role after the death of the young person.</li> <li>8. Siblings should be supported and included in all decisions.</li> <li>9. All professionals/agencies should be informed of the death with the parents' consent.</li> <li>10. All family members should be supported according to their individual needs for as long as they need it.</li> </ol>
Keyworker supporting all aspects of the move to adult services.	<ol style="list-style-type: none"> <li>1. Child and adult services within health work together so that there is an overlap of care planning and care provision.</li> <li>2. Services within all agencies should be engaged in planning for the specific needs of the young person.</li> <li>3. Ongoing reviews (at least annually) with the young person take place.</li> </ol>

### Standard 3

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

*This standard applies to all stages of the transition journey.*

### Standard 4

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

Phase 3: Settling in to adult services	
Young adult 18+	
<p>Friendships Relationships Sexuality</p> <p>Self-management of condition</p> <p>Meaningful occupation (leisure, education, work)</p> <p>Short breaks and holidays</p> <p>Technology and adaptations</p> <p>Independent living</p> <p>Support in using personal budgets and managing personal assistants</p>	<ol style="list-style-type: none"> <li>1. A key working function is provided for every young person so that all the agencies providing care and support are co-ordinated.</li> <li>2. All agencies ensure that age and developmentally appropriate services are available that address the full range of a young person's needs.</li> <li>3. Palliative care services provide a single clinical overview for the young person and link with other specialists involved in their care.</li> <li>4. There is frequent review and communication across services about care plans and end of life decisions.</li> <li>5. Primary health care services, including GPs, develop a relationship with the young person and their families/carers.</li> <li>6. Adult services in secondary care ensure there is an appropriate lead clinician to take responsibility for young adults in their clinics and admissions processes.</li> <li>7. Short break or respite needs of young people and their parents/carers are considered and provided in the most appropriate setting.</li> <li>8. Parents are included as appropriate.</li> </ol>

### Standard 5

Every young person is supported in adult services with a multi-agency team fully engaged in facilitating care and support. Young person and their family have been equipped with realistic expectations and knowledge to ensure confidence in their care going forward



### Transition – A guide for clinical commissioning groups

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