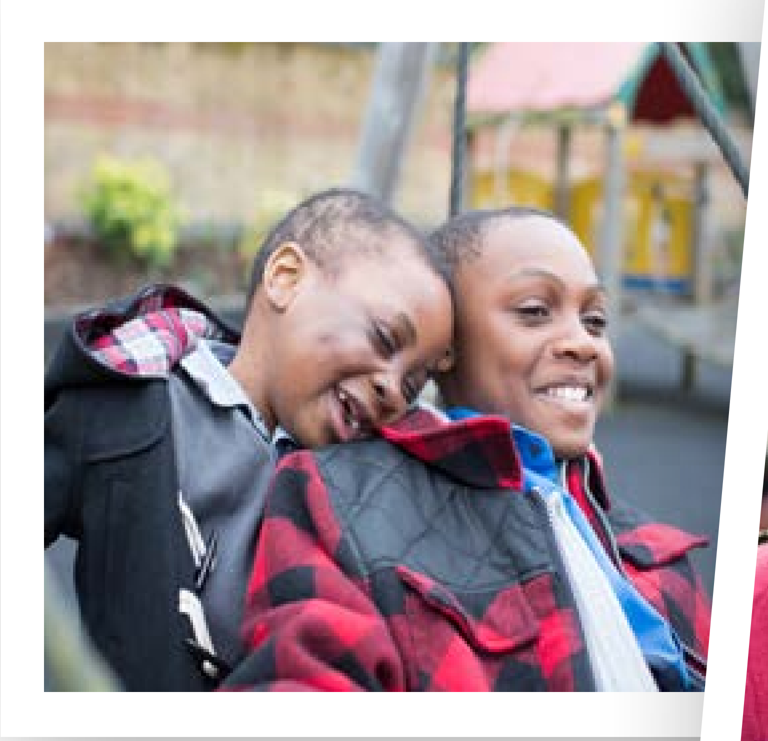

Jointly commissioning palliative care for children and young people aged 0-25 including short breaks

A guide for local areas in England

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The relatively small number of children and young people with life-limiting conditions can make it difficult for clinical commissioning groups (CCGs) and local authorities to jointly commission children's palliative care. As well as being inefficient, it can also prevent effective strategic care planning. This resource is designed to support CCGs and local authorities in England to effectively commission palliative care for children and young people. It also helps health and wellbeing boards to understand their role in the commissioning process. The resource is consistent with the new special educational needs and disability (SEND) system, the joint commissioning duty in the Children and Families Act 2014 and covers the following:

- What are life-limiting and life-threatening conditions? How do they affect children and young people?
- What do children and young people with life-limiting conditions need? What is children's palliative care?
- How many children and young people with life-limiting conditions should local areas expect to commission care for?
- Who provides services to children and young people with life-limiting conditions?
- What should CCGs, local authorities and health and wellbeing boards do to jointly commission children's palliative care?
- What outcomes can joint commissioners achieve by implementing these recommendations?
- Who else should be involved in commissioning for this population?

1. What are life-limiting and life-threateningconditions? How do they affect children and young people?

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 episodes 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.

Life-limiting and life-threatening conditions in children and young people can be defined by the following four categories[1]:

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 child is well – such as Duchenne muscular dystrophy.
3. Progressive conditions without curative treatment options, such as Batten disease.
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.

2. What do children and young people with life-limiting conditions need? What is children's palliative care?

Children and young people with life-limiting conditions need palliative care from the point at which their condition is diagnosed or recognised – often at birth – until the end of their lives.

Families also need care and support throughout the trajectory of their child's illness, including after they have died. Palliative care for children and young people should[2]:

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

Children's palliative care is different to palliative care for adults. Whereas the majority of adults only need palliative care at the end of their lives, children with life-limiting and life-threatening conditions require palliative care over a much longer period, often from birth as they live with the instability of their condition.

It is common for their conditions to fluctuate and, as such, it is often much more difficult to identify when a child is moving into their end of life phase.

Children with life-threatening and life-limiting conditions often have complex disabilities, while the range of health conditions which results in children requiring children's palliative care is more diverse. Children's palliative care is an approach to care in conjunction with curative treatments.

A comprehensive local children's palliative care service spans health, social care and education. Therefore joint commissioning is vital.

It is a whole-family approach and has the following characteristics:

- It is flexible and focused on children, their parents, their carers and their siblings.
- It is accessible 24 hours a day, seven days a week, 365 days a year – from diagnosis or recognition that a condition will shorten a child's life, to bereavement.
- It supports and enables children and families to choose the type, location and the provider of the care they receive and allows them to change their mind.
- It is not age, time or diagnosis specific – 15% of children who need children's palliative care have no definitive underlying diagnosis[3].
- It is multi-disciplinary and multi-agency.
- It is accessible to people of different faiths, culture, ethnicity and locations.
- It includes pre and post-bereavement support for families.
- It is able to manage symptoms.
- It supports parents in caring for their children according to their needs and wishes.
- It supports and enables smooth transitions for young people with life-limiting and life-threatening conditions who move from children's to adults' services.

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[1] 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.

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

[3] 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: bit.ly/11yjtVS.

Transition to adulthood for young people with life-limiting conditions

The needs of young people with life-limiting conditions and their families are complex. As a result, many 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[4].

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[4]. However, some young people will be cognitively impaired and will depend on their parents, carers or residential care until the end of their life.

For many young people with life-limiting conditions, transition into adult services often coincides with a rapid decline of their condition and eventual death. 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. There is a general dearth of age and developmentally appropriate short break services for young people with life-limiting conditions in England.

The Together for Short Lives Transition Taskforce has conceptualised the way that the five key agencies should work together as a 'pentagon of support' (see appendix two)[5]. 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.

3. How many children and young people with life-limiting conditions should local areas expect to commission care for?

Fraser et al[6] highlight the prevalence of life-limiting conditions in children and young people for every local authority district in England. Health and wellbeing boards should take note of this data as they conduct joint strategic needs assessments (JSNAs) – it is a strong indicator of the number of children and young people who need palliative care.

Health and wellbeing boards and joint commissioners should also take account of other data sources which include:

- their local registers of disabled children, which local authorities are obliged to hold
- GP registers: GPs have an incentive through the Quality and Outcomes Framework (QOF) to hold a complete register of all people who need palliative care and support regardless of their age
- hospital data: there is a summary hospital-level mortality indicator (SHMI) which measures the percentage of deaths with a palliative care coding

Overall, Fraser et al 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. The highest rate of increase between 2000 and 2010 was among those aged 16-19, who now account for 4,000, or one in ten, of 0-19-year-olds who need palliative care.

Fraser et al[7] estimate that there were 12,827 young adults aged 18-25 in England in 2009/10 who were living with a life-limiting or life-threatening condition. These numbers are also growing.

This is 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.

CCGs and local authorities should be aware that not all children and young people with life-limiting conditions have a special educational need (SEN).

Children with conditions such as cancer or leukaemia may not have a SEN.

4. Who provides services to children and young people with life-limiting conditions?

Universal, targeted and specialist children's palliative care is delivered by a web of providers; a significant proportion of children's palliative care is delivered by the voluntary sector. Voluntary sector providers, including children's hospices, bring social value to communities.

When the local commissioners remunerate these organisations for the children's palliative care they provide, the funding is matched and exceeded by charitable donations which also contribute to running services. Local volunteers also help to provide children's palliative care which are part-funded from statutory sources, further adding value.

Commissioning a comprehensive children's palliative care service will help CCGs to meet their duties under the Public Services (Social Value) Act 2012.

Commissioners should ensure that sustained and effective children's palliative care can be provided in their local areas. There should be no gap as young people move from children's to adults' services. At all times, locally available and community-led children's palliative care should be at the heart of provision to children. This should be supported by:

- specialist medical input (for example, medical consultants with expertise in the child's condition)
- sustainable community children's nursing teams
- children's hospice services
- specialised children's palliative care providers

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4. 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.

5. Transition Taskforce (2015). Stepping up: a guide to enabling a good transition to adulthood for young people with life-limiting and life-threatening conditions. Available to download from: http://bit.ly/1J0mMLA.

6. 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.

7. 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.

- access to secondary and tertiary care
- emotional and psychological support
- local authority children's services - practical care and support, including services providing equipment to disabled children, education, housing and leisure
- community paediatricians
- primary care

Joint commissioners should refer to Together for Short Lives' online directory of services[8] to understand which organisations are providing children's palliative care in their local area. Our directory includes maps, lists and a search function. The local offer may also be helpful.

5. What should CCGs, local authorities and health and wellbeing boards do to jointly commission children's palliative care?

Section three of the SEND Code of Practice[9] sets out in detail what local areas must and should do to jointly commission services for children and young people aged 0-25 with SEND. Preparing for Adulthood Joint Commissioning in Action describes joint commissioning as 'a method for two or more partner agencies to commission collaboratively to secure better outcomes for a defined population than either can achieve on their own'.[10]

There is no single model of integration and joint commissioning between local authorities and their partner clinical commissioning groups (CCGs). It requires genuine co-production with all partners, backed by clear governance arrangements and a commitment to operating in a much more integrated way.

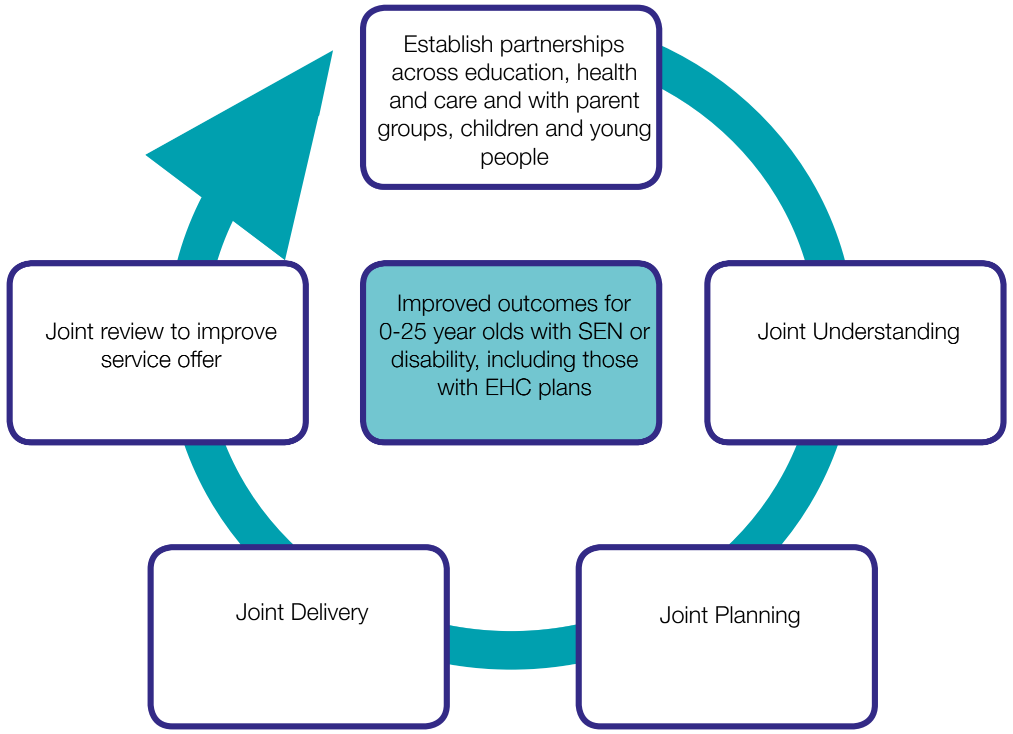
Local area learning has also demonstrated that the development of joint commissioning arrangements is often gradual and delivered in a phased, sustainable way. To commission effectively for children and young people with life-limiting conditions – as with all types of SEND – a joint approach is required. A list of all those who should be involved is provided in section 7 of this resource.

The joint commissioning cycle provides a continual cycle of review and improvement. It follows the same process as the commissioning cycle and is carried out jointly across organisational boundaries.

Establishing partnerships

Children and 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[11] to ensure an integrated service for children and young people with life-limiting conditions.

The joint commissioning cycle



The code of practice[9] describes how, under section 75 of the National Health Service Act 2006, local authorities and CCGs can pool resources and delegate certain NHS and local authority health-related functions to the other partner(s) if it would lead to an improvement in the way those functions are exercised.

CCGs and local authorities also need to be aware of their duties under the Children and Families Act 2014[12]. These **require** them to commission services for all disabled children and young people aged 0-25 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. EHC plans should focus on the outcomes which young people wish to achieve. This will include some children and young people with life-limiting conditions.

The SEND code of practice[9] explicitly states that joint commissioning must include services for 0-25 year old children and young people with SEN or disabilities, both with and without EHC plans. For example, children and young people with cancer or leukaemia may not have an SEN or EHC plan – but should still be able to access jointly commissioned children's palliative care.

The code also states that local authorities, NHS England and their partner CCGs must make arrangements for agreeing the education, health and social care reasonably required by local children and young people with SEN or disabilities.

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 have a right to a personal health budget.

The Care Act 2014 statutory guide and the *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*[13] 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.

Local areas must also offer a personal budget to children and young people aged 0-25 who have an EHC plan. Section 3.36 of the SEND Code of Practice[9] states that local authorities and CCGs have a statutory duty to consider the extent to which children and young people's needs could be met more effectively by integrating services and aligning or pooling budgets in order to offer greater value for money – and improve outcomes and/or better integrating services for children and young people with SEN or disabilities.

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

In complying with the Care Act, local authorities must 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 support plans and personal budgets for adults over the age of 18 with assessed needs[14].

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[8] Together for Short Lives (2015) Support in your area. Available online at: http://bit.ly/1N5r1Mo

[9] Department for Education (2014). Special educational needs and disability code of practice: 0 to 25 years. Available to download from: http://bit.ly/1kOCi5i

[10] Preparing for Adulthood (2015). Joint Commissioning in action. Available to download from: http://bit.ly/1du8oSU

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

[12] Great Britain. Children and Families Act 2014: Elizabeth II. Part 3 (2014). Available to download from: http://bit.ly/1rmlG7b

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

[14] Department of Health (2014). Care and support statutory guidance issued under the Care Act 2014. Available to download from: http://bit.ly/VrzH7i

More generally, the Care Act also states that local authorities must:

- promote wellbeing when carrying out any of their care and support functions in respect of a person
- take steps to prevent people or their carers from developing needs for support
- promote integrated care and support with health services and other types of provider
- establish and maintain a service for providing people in its area with information and advice relating to care and support for people and support for carers
- promote an efficient and effective market in services for meeting care and support needs
- co-operate with its relevant partners

CCGs and local authorities should also seek to work in partnership with:

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

The SEND Code of Practice[9] states that local offers must include information about palliative care for children with complex health needs. CCGs should also consider working in partnership with children's palliative care networks and providers in the statutory and voluntary sectors, including children's hospices.

The important role of health and wellbeing boards

The Department of Health[15] states that:

- the joint commissioning requirements give health and wellbeing boards the opportunity to act as a forum for strategic discussions between local authorities and CCGs
- some areas may also have existing multi-agency groups which lead or co-ordinate on issues relating to children and young people, which the health and wellbeing board can link with as appropriate
- where there are existing formal joint commissioning arrangements between a local authority and CCG or CCGs (for example, under a section 75 agreement), the health and wellbeing boards can again act as system driver

The SEND code of practice[9] states that local authorities, CCGs and other partners must work together in local health and wellbeing boards to assess the health needs of local people, including those with SEN or who are disabled.

If they have not yet done so, health and wellbeing boards should sign the Every Disabled Child Matters 'Disabled Children's Charter for Health and Wellbeing Boards'[16].

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15. Department for Health (2014). Children with special educational and complex needs: guidance for health and wellbeing boards. Available to download from: http://bit.ly/1RQRxr0

16. Every Disabled Child Matters (2013). Disabled Children's Charter for Health and Wellbeing Boards. Available to download from: http://www.edcm.org.uk/hwbcharter

Joint understanding

Joint commissioning should be informed by a clear assessment of local needs. Health and wellbeing boards are required to develop JSNAs and joint health and wellbeing strategies.

The JSNA is an opportunity for stakeholders and partners across social care, health, education, public health, housing and employment (and across age groups) to share their understanding of the evidence about the needs and views of young people and their families.

The SEND Code of Practice[9] states that children who need palliative care should be included in JSNAs. The Department of Health[15] also states that health and wellbeing boards:

- will want to consider also how local health services are meeting the needs of children and young people with acute, life-limiting conditions, such as cancer and leukaemia
- should consider long-term conditions, such as diabetes, asthma, epilepsy and cerebral palsy. It sets out nine questions for health and wellbeing boards to consider
- will need to ensure that they are aware of the complexity of local children and young people's needs, and have a good understanding of the key implications for children and their families of complex and special educational needs
- will want in particular to consider how integrated approaches to meeting local need can provide better outcomes for the child and their family, and remove avoidable use of resources
- will want to agree how detailed it makes its assessment of the needs of local children with special educational and complex needs, and how this is reflected in the local joint health and wellbeing strategy; this should be done with regard to their role in influencing CCGs in making commissioning plans, and their role in providing a benchmark against which CCG commissioning can be measured

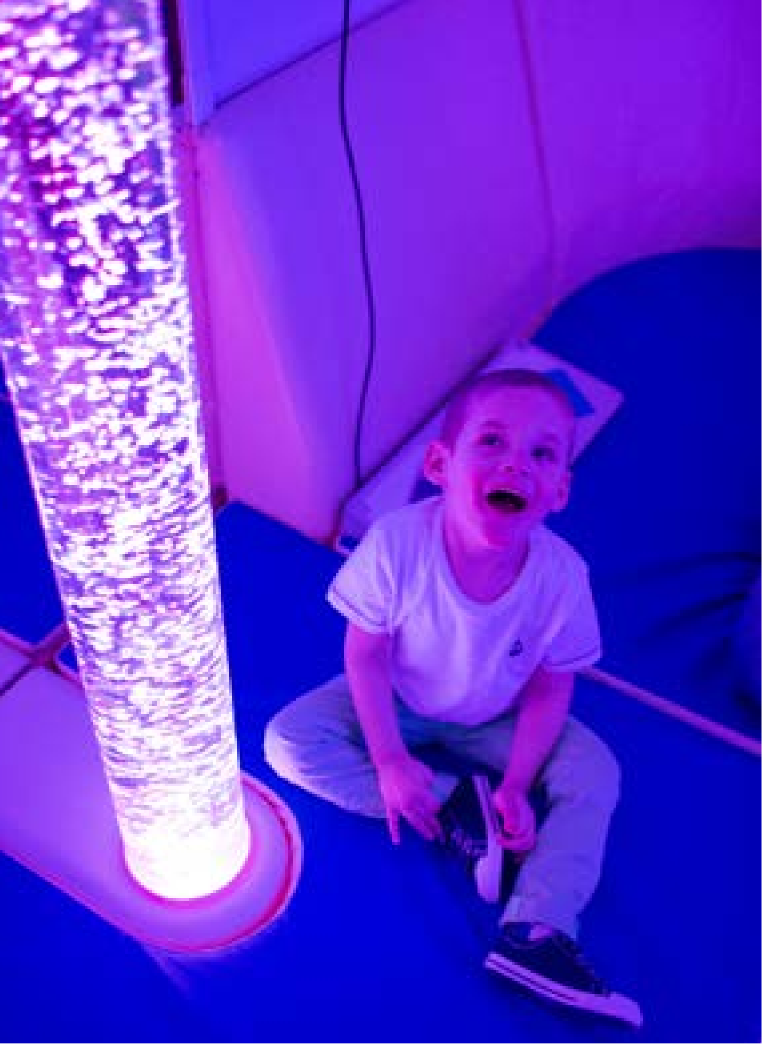
The Department of Health states that the biggest challenge the health and wellbeing board will face in building up a picture of local needs is obtaining the right information; for children and young people with life-limiting conditions, it should refer to data from those sources described in section three of this guide.

GPs should use their knowledge of children and young people with life-limiting conditions who are registered with their practice to inform the joint commissioning process.

Joint planning

The SEND reforms focus on enabling children and young people to achieve the best they can, with an emphasis on outcomes rather than processes. CCGs and local authorities should work together to deliver integrated support that improves outcomes for children with life-limiting conditions. Outcomes are the benefit or difference made as a result of an intervention at three levels:

- **Individual outcomes** such as might be set out in an EHC plan: e.g. Jordan can attend school, make friends and maintain his social networks.
- **Service level outcomes:** e.g. paternal mental health has improved in 10 families.
- **Strategic outcomes:** e.g. there has been a 10% increase in the number of children and young people who were able to receive end of life care in the place they chose.



To achieve such outcomes, children's palliative care services have to be commissioned and provided. In the scenarios next to the outcomes above, the right wheelchair, equipment and support in school, a short breaks programme and a community children's nursing team commissioned to provide 24/7 end of life care, respectively.

It is important that local areas jointly commission short breaks for children with life-limiting and life-threatening conditions and their families. Their needs are often complex and should be taken into account when contracting short break services.

Why short breaks are important for children and young people with life-limiting conditions

Children with life-limiting conditions – and their families – rely on frequent short breaks to enable them to spend time as a family, doing the things that other families do. However, not all families of children and young people with life-limiting conditions can access short breaks because commissioners do not always commission services which meet their complex care needs. CCGs and local authorities should jointly commission short breaks for this group of children, young people and families.

Short breaks away from home for children and young people with life-limiting conditions are provided by a range of organisations, including children's hospices. Short breaks for children and 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.

The Short Breaks Regulations[17] set out how local authorities in England must provide breaks from caring for carers of disabled children. Breaks should support carers to continue to care for their children at home and to allow them to do so more effectively.

The regulations require local authorities to do three things:

1. Ensure that, when providing short breaks, they have regard to the needs of different types of carers, not just those who would be unable to continue to provide care without a break.
2. Provide a range of breaks, as appropriate, during the day, night, at weekends and during the school holidays.
3. To provide parents with a short breaks services statement detailing the range of available breaks and any eligibility criteria attached to them.

Section 2.10 of the 'Short breaks for carers of disabled children: departmental advice for local authorities'[17] states that health services directly provide and commission short breaks for children with complex health needs including children's hospice care and support local authority and voluntary and community sector provision.

In 2011, an Independent Palliative Care Funding Review was commissioned by the government. On page 59, the team recommends:

1. Short breaks which represent planned in-patient and/or community care (for example, to monitor the clinical needs of the patient and to make any necessary adjustments to their care) fall under clinical care as outlined above and should be funded through the palliative care tariff, according to the needs of the child or young person.
2. Short breaks which provide respite for the carers and families of children requiring palliative care should be funded by local authorities and the NHS under their respective legal short breaks duties.

The review report also states that these "duties" refer to the short breaks duty on local authorities and the legal precedence which establishes that the NHS is responsible for short breaks where the 'scale and type of nursing care' is such that it is outside that which can be provided by the local authority (R (T, D and B) v Haringey LBC).

Although there is no equivalent short breaks duty for adults, under the Care Act 2014, local authorities **must** ensure:

- the provision of preventative services
- the diversity and quality of care and support services for adults
- the provision of information and advice on care and support locally

Local authorities should recognise the difference, and the need for phased and timely transitions, between children's and adult's palliative care pathways. From April 2015, they **must** comply with the transition duties included within the Care Act 2014. These mean that local authorities will need to assess the future adult social care needs of young people under the age of 18 – and their carers – where:

- it becomes apparent to the local authority that the young person or their carer is likely to have needs once they reach adulthood
- an assessment is in the young person's best interest; and
- the young person consents to being assessed

Where a local authority identifies that an adult lacks mental capacity and that carrying out a needs assessment would be in the adult's best interests, the local authority is required to do so.

Young people and their carers will also have the right to request assessments should they wish to do so. Statutory guidance to help local authorities implement the duties was published by the Department of Health during 2014[14].

Creating economies of scale

A report from the York Health Economics Consortium to inform the Craft-Killen review of children's palliative care[18] 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'[19].

A CCG should seek to work with its neighbouring CCG(s) at a sub-regional level in order to determine how many children and 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.

Planning the local journey for children and young people with life-limiting conditions

Commissioners should refer to the Together for Short Lives *Core Care Pathway for Children with Life-limiting and Life-threatening Conditions*[1]. This is a critical tool for linking children and their families to community services, hospital-based services, social services, education, children's hospices and other voluntary providers in one, joined-up planning process.

There are three stages to children's palliative care as highlighted in the pathway: diagnosis or recognition that a child's care is going to be palliative rather than curative; ongoing care; and end of life and bereavement care.

CCGs should recognise the difference, and the need for phased and timely transitions, between children's and adult's palliative care.

Children's palliative care pathways should integrate with pathways for disabled children to ensure a whole service approach.

Specialised children's palliative care includes services which manage complex symptoms and prescribe unlicensed medicines. It is commissioned directly by NHS England[3]. CCGs and local authorities should take this into account and work with NHS England to make sure that the commissioning of general and specialised children's palliative care services correlate in local areas.

Once a child or young person's need has been identified, it is important that the service to meet this need is made available – even if ongoing assessments are continuing, or if different commissioners disagree about who should pay for it. This principle is set out in the *National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care*[13].

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[17] Department for Education (2011). Short breaks for carers of disabled children: departmental advice for local authorities. Available to download at: http://bit.ly/1EmRyvM

[18] 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.

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

Commissioners should also refer to *Stepping up: A guide to enabling a good transition to adulthood for young people with life-limiting and life-threatening conditions*[5]. This is a template for transition 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 be integral to 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 the care and support they need to enable them to achieve good outcomes.

CCGs may wish to incorporate transition plans for young people with life-limiting conditions into wider transition plans for young people with a 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 with life-limiting conditions.

Delivering jointly

Dialogue between commissioners, service providers and universal services is essential to achieve changes in response to evidence on children and young people's, and their families, needs and wishes[20]. Commissioners should make sure that a flexible range of services are available in their local area which can be commissioned to support this group of children and young people.

NHS South East Strategic Clinical Networks illustrates how responsibility for commissioning health services and public health for children and young people is divided across CCGs, local authorities and NHS England[21]. This states that joint commissioners are responsible for the following services which may be needed by a child with a life-limiting condition:

- childrens community nursing
- special school nursing
- community peadiatrics
- speech and language
- physiotherapy
- occupational therapy
- continence services
- wheelchair services
- home oxygen services
- learning disabilities
- child and adolescent mental health services (CAMHS) tier 2 and 3
- looked after children (LAC) medical and nursing

NHS England is responsible for commissioning specialised health services. Joint commissioners should take care to ensure that their own specifications for local, general children's palliative care services closely correlate with the specialised children's palliative care service specification E03/S/h3, 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 4. It encompasses functions including complex symptom management and prescribing unlicensed medicines.

Public Health England is responsible for the Healthy Child Programme for children aged 0-5 which includes:

- health visiting
- immunisation programmes
- national screening programmes
- antenatal and new-born screening programmes
- the Family Nurse Partnership (for young parents under the age of 19 (this is commissioned by the Department of Health; local authorities will be responsible for commissioning public health for children aged 0-5 from October 2015)

For young people, 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.

Local areas should specify in their contracts and agreements with providers that they 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[9] – and the recommendations of CQC's recent thematic inspection *From the pond into the sea: children's transition to adult health services*[22]; 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.

Local areas should also specify that providers of care to children, young people and adults with life-limiting conditions:

- offer services suitable for young people – possibly as a distinct discipline separate to children's and adults' services
- offer services focused on bringing about smooth transitions for young people
- offer training for staff working with young people
- have an organisational transition policy in place, which has been jointly developed by those providing care to children, young people and adults, as well as young people themselves
- have a nominated transition co-ordinator or key worker who is known to young person
- offer access to peer support.
- have systems to collect data on the number of young people in transition and on the care which is provided to them; this should be used to stimulate improvements in services
- have systems to measure young people's experiences of services – and to act on findings where necessary
- provide young people with access to training to help them self-advocate and make decisions about their care

In particular, adult services should be commissioned to work with children's services to bring about smooth transitions – and to provide age and developmental appropriate services.

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[23]. It has also developed a local Commissioning for Quality and Innovation (CQUIN) scheme for transition[24]. Both provide a template which should be considered by CCGs to support providers to improve transition.

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[20] Mott Macdonald (2015). SEND Pathfinder Information Pack: Version 6, March 2015 - Joint Commissioning. Available to download from: http://bit.ly/1Jn6tLs

[21] NHS South East Strategic Clinical Networks (2015). Who are the commissioners for children and young people? Available to download from: http://bit.ly/1L7GQ57

[22] 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

[23] http://bit.ly/1ibif3e

[24] http://bit.ly/1ibigUR

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.

Local areas 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*[22].
- The Preparing for Adulthood programme[25], 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's services and expects to publish in February 2016[26]; it is also developing a clinical guideline on end of life care for infants, children and young people[27].
- The *Bridging the Gap: Transition from Children's to Adult Palliative Care* project[28], funded by Together for Short Lives, describes the core elements that should be provided by services during transition.

CCGs should make themselves aware of any local short break services which can meet the needs of young people with life-limiting conditions and their families.

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 upper age limits for their services.

Many palliative care settings designed for babies and children are unsuitable for young people.

Funding children's palliative care services

In 2011, a government-commissioned review of funding arrangements for palliative care recommended that an NHS tariff for palliative care should be developed[29]. 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 adults' palliative care sectors. The programme has now published a new approach to palliative care funding for both children and adults[30] which is available for CCGs and providers to use. NHS England aims for the currency to be used in 2016/17 and to have a final currency by April 2017. The currency is based on a series of units which reflect the variables that affect the cost of providing children's palliative as identified during the pilot phase.

These are:

- the child's age
- the phase of their illness (stable, unstable, deteriorating and dying)
- the setting in which they are receiving care (acute inpatient, hospice inpatient and community)
- the severity of their condition

The full currency units for both adults and children are set out in appendix three.

During 2015/16, NHS England will collect further data from providers 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.

In commissioning children's palliative care, CCGs, local authorities and other commissioners should use contracting arrangements with voluntary sector providers which are proportionate to the contribution which they are making towards care costs. For CCGs – and consistent with NHS England guidance[31], this should include grants.

Joint review to improve service offer

Learning from individual plans and experiences can inform strategy and plans for change. Learning from the experiences of others is a powerful influence on young people and families, as well as operational staff and commissioners[11]. 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.

Other useful resources

Version six of the SEND Pathfinder Information Pack[11] includes two case studies which may be useful for local areas to refer to in jointly commissioning children's palliative care:

- Southampton City Council Joint Commissioning Project for Residential Overnight Short Breaks.
- Nottinghamshire Children's Integrated Commissioning Hub (ICH).

The *Preparing for Adulthood* programme has a guide to joint commissioning for CCGs, local authorities and other partners[32]; this includes links to other useful resources.

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[29] highlights that hospital admissions in the last year of life for children who need palliative care cost an estimated £18.2m.

Research has also shown that short breaks provided by children's hospices – which may include healthcare interventions – help to reduce stress on families and demand on public services[33].

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.

6. What outcomes can commissioners achieve by implementing these recommendations?

Commissioning a comprehensive care pathway for children and 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)

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)

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25. Preparing for Adulthood: http://www.preparingforadulthood.org.uk.

26. The National Institute for Health and Care Excellence (NICE): Transition from children's to adult services. http://bit.ly/1yjeadz.

27. The National Institute for Health and Care Excellence (NICE): End of life care for infants, children and young people: http://bit.ly/1yRNaEV.

28. 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.

29. 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: http://bit.ly/XQBIE7.

30. NHS England (2015). Developing a new approach to palliative care funding. Available to download from: http://bit.ly/1Fdxqyd

31. NHS England. 2015. A bite sized guide to grants for the voluntary sector. Available to download at: http://bit.ly/1LY0hdk

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

33. NEF Consulting (2009). The social and economic value of short breaks. Available to download at: http://bit.ly/10VnUAG.

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 children's palliative care 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[34]:

- The experience of care for children and young people at the end of their lives.*
- The number of children and young people with end of life plans who die in the place of their choice.*
- Access to a quality multi-disciplinary assessment that reflects all the child's or young person's needs, in addition to those of their family.
- Access to 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.
- A review of the care plan at key points of transition particularly transition to adult life and services.
- A whole family approach which helps to maintain the health and wellbeing of family (carers) – on the basis that this has a direct impact on children and young people and their resilience.

Joint commissioners can also help children and families to realise the outcomes they wish to achieve; these could include:

- Better quality of life of the child or young person and their family members or carers.*
- Satisfaction of the child or young person with their care.*
- Satisfaction with care of the family members, carers (as appropriate) to the child or young person.*
- Psychological well-being, for example resilience, depression or anxiety in the child or young person and their family members or carers (as appropriate).*
- Pain and other distressing symptoms such as restlessness or agitation prevented or managed.*
- Access care which is appropriate to the child or young person's age.
- Access education or training.

* Reflected in the National Institute for Health and Care Excellence's (NICE) draft scope of the clniical guideline 'End of life care for infants, children and young people: the planning and management of end of life care for infants, children and young people with life-limiting conditions'. Available online at: http://bit.ly/1INzaz3.

- Start or maintain a job.
- Start or maintain a hobby.
- Live independently.
- Build and maintain a social life and social networks.
- Have relationships.
- Access a regular short break.
- Access the treatments and equipment they need.
- Be aware of the children's palliative care services available to them.
- Access information in a language which they can understand.
- Minimise the number of times that families have to tell their story to professionals and agencies across health, social care and education in order to secure the care and support they need.
- Access to a key worker.
- Access to generalist professionals who understand how to support and care for children with life-limiting and life-threatening conditions.
- Experience a smooth and well-planned transition to adult services.

Commissioning a comprehensive care pathway for children and young people with life-limiting conditions can also help CCGs to implement the Ambitions for Palliative and End of Life Care[35].

7. Who else should be involved in commissioning for this population?

- The child or young person.
- Their family.
- Professionals providing palliative care.
- The range of providers described in figure one on page three.
- The regional palliative care networks for children and adults and the Transition Taskforce Regional Action Groups (RAGs); CCGs and local authorities 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.
- 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.

Section 19 of the Children and Families Act[13] states that if a child or young person has a special educational need or a disability, a local authority in England must have regard to the following matters in particular:

(a) the views, wishes and feelings of the child and his or her parent, or the young person

(b) the importance of the child and his or her parent, or the young person, participating as fully as possible in decisions relating to the exercise of the function concerned

(c) the importance of the child and his or her parent, or the young person, being provided with the information and support necessary to enable participation in those decisions

(d) the need to support the child and his or her parent, or the young person, in order to facilitate the development of the child or young person and to help him or her achieve the best possible educational and other outcomes.

Specifically, the SEND Code of Practice[9] states that local authorities must:

- ensure the child's parents or the young person are fully included in the EHC needs assessment process from the start, are fully aware of their opportunities to offer views and information, and are consulted about the content of the plan
- consult children with SEN or disabilities, and their parents and young people with SEN or disabilities when reviewing local SEN and social care provision
- consult them in developing and reviewing their local offer
- make arrangements for providing children with SEN or disabilities, and their parents, and young people with SEN or disabilities with advice and information about matters relating to SEN and disability

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[34] 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/Zqlirl.

[35] Ambitions for Palliative and End of Life Care (2015). Available to download from: http://endoflifecareambitions.org.uk/

Appendix one: case study - short breaks at Naomi House Children's Hospice are vital for the Carroll family

The Carroll family's world was turned upside down nine years ago when their GP told them their four year old son had Duchenne Muscular Dystrophy. Duchenne Muscular Dystrophy is a life-limiting condition that causes progressive muscle weakness. The condition, which is only present in males, causes muscle fibres to break down and the body to gradually weaken. There is no cure available and the condition means that Lloyd is unlikely to live into his 30s. The average life expectancy for boys with Duchenne Muscular Dystrophy is around 25.

For Mum, Tanya, the news came like a bolt from the blue: "The news was utterly devastating. No family should have to hear that their child's life will be shortened. It took at least six months for the news to sink in and it took even longer to uncover all the support that was out there."

Being the parent of a life-limited child is incredibly stressful: in many cases, it involves providing round the clock care and being forced to come to terms with the emotional impact of knowing that their child has a life-limiting condition. On top of this, families often have to deal with an endless stream of health visitors, doctors and consultants. Being able to take a break while your child is cared for is hugely important to families. Without this, families can reach breaking point.

Lloyd was referred to Naomi House Children's Hospice by his GP when he was six years old. The family's preconceptions of hospice care were quite different to what they found at Naomi House.

Tanya says: "I thought hospices were sad places; places for death and dying. I hadn't realised that children's hospices offered short breaks and I definitely hadn't expected them to be so full of life, laughter and love. Walking through the doors at Naomi House was such a pleasant surprise. We instantly felt welcome.'

For Lloyd's Dad, Neil, family life now wouldn't be the same if the hospice wasn't around: "Without Naomi House, you just wouldn't be able to take a break. There isn't anywhere else that offers the care and support we get there.'

"Naomi House has had a major impact on our family. Lloyd is a growing boy and Naomi House gives him the independence that boys at his age need. The fact that there are male carers and nurses around is really important and the hospice is so flexible; it is great that they are able to take in and care for so many different children with diverse conditions and needs."

"Naomi House allows us to have a more normal life and the same is true for Lloyd. He met his best friends at the hospice. He loves catching up with them and they have such a great time together. They couldn't do that without Naomi House. He can't have his friends stay over like normal children do; there simply isn't space for all of the wheelchairs."

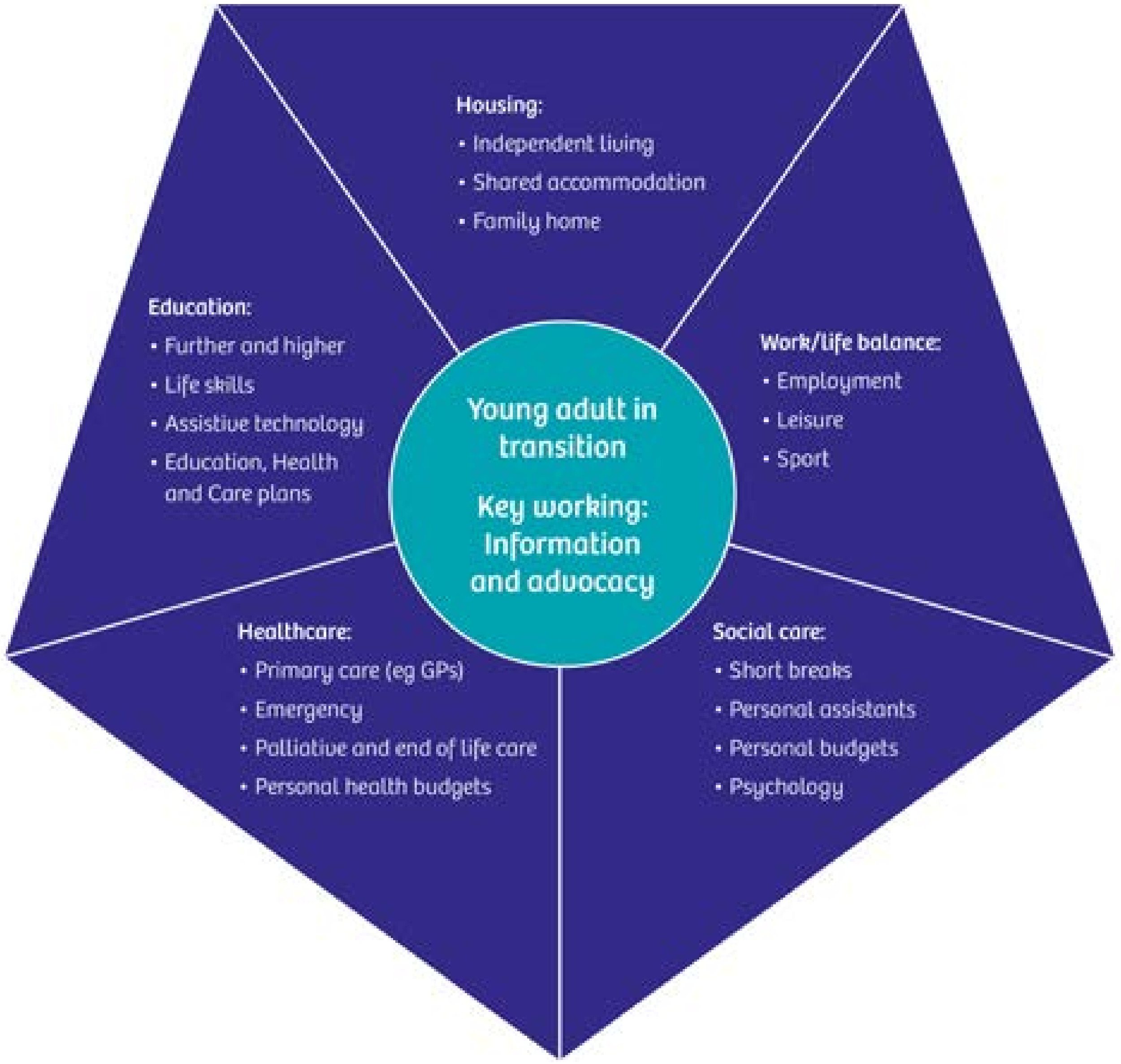
For Tanya, it is the whole package of services that Naomi House offers that makes the hospice so special.

"Short breaks are really important to us and we really need it. At Naomi House, our whole family is supported and we have access to a counsellor. Lloyd's 5 year old brother, Louie, gets to take part in lots of exciting activities that he wouldn't be able to do if the hospice didn't exist."

"The brothers and sisters of life-limited children have a lot to deal with in their lives and it is great that the hospice looks after them and ensures they have lots of fun things to do. It also gives them the opportunity to befriend other children in the same situation and ultimately give each other mutual support."

Naomi House has no formal agreements for funding in place with any Hampshire clinical commissioning group or local authority. The charity relies on the generosity of local people and businesses to generate the income it needs to sustain services.

Appendix two: The pentagon of support



Appendix two: Palliative care currency funding units

Adult acute inpatient settings

Currency unit	Phase	Other
AW_1	Stable	1 diagnosis
AW_2	Stable	1+ diagnosis <75yrs
AW_3	Stable	1+ diagnosis 75+yrs
AW_4	Unstable	1 diagnosis
AW_5	Unstable	1+ diagnosis
AW_6	Deteriorating	1 diagnosis
AW_7	Deteriorating	1+ diagnosis, <75yrs
AW_8	Deteriorating	1+ diagnosis, 75+yrs
AW_9	Dying	1 diagnosis
AW_10	Dying	1+ diagnosis

Children acute inpatient settings

Currency unit	Phase	Age group/other
CW_1		<1
CW_2		1-4
CW_3	Stable	5-9
CW_4	Unstable	5-9
CW_5	Deteriorating/dying	5-9
CW_6	Stable	10+
CW_7	Unstable	10+
CW_8	Deteriorating/dying	10+

Adult hospice inpatient settings

Currency unit	Phase	Other
AH_1	Stable	Low function
AH_2	Stable	Med/high function
AH_3	Unstable	Low function
AH_4	Unstable	Med/high function
AH_5	Deteriorating	Low function
AH_6	Deteriorating	Med/high function
AH_7	Dying	Low function
AH_8	Dying	Med/high function

Children's hospice inpatient settings

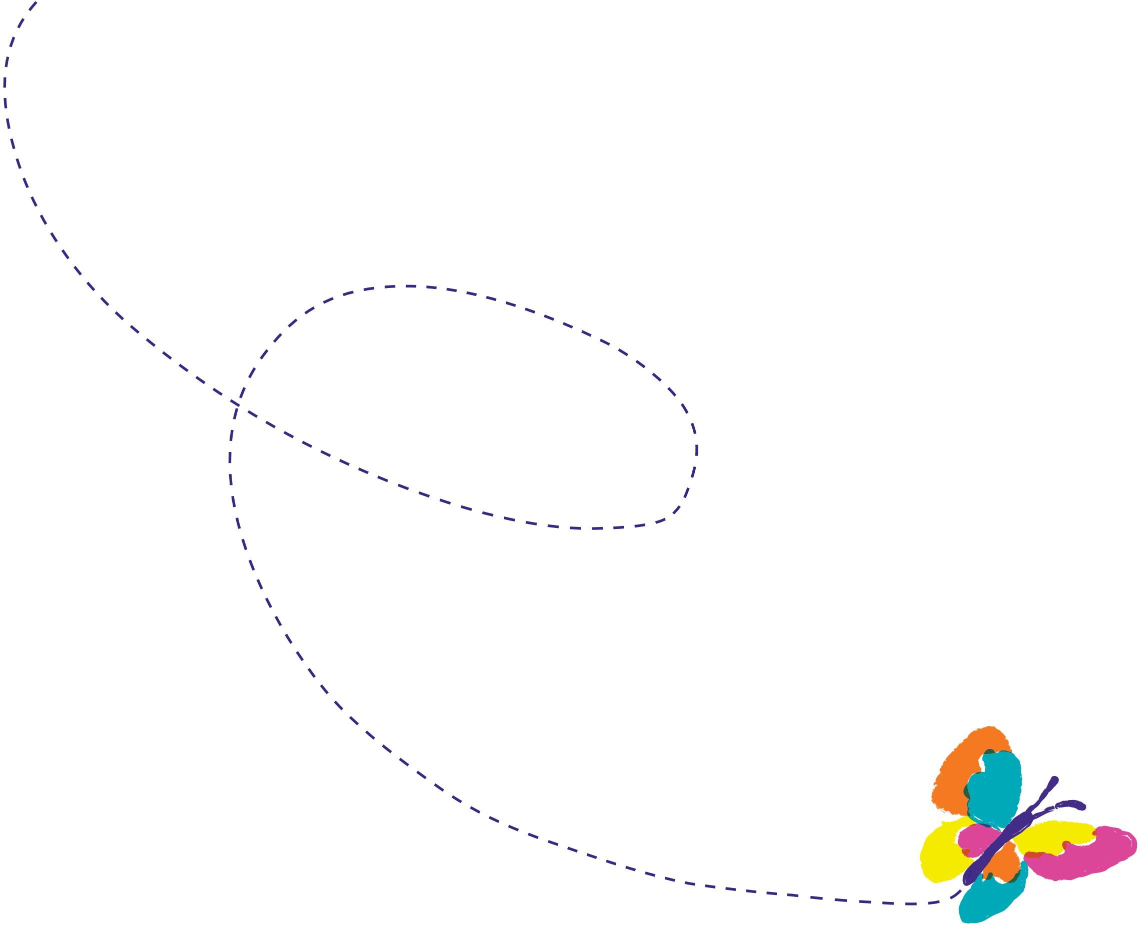
Currency unit	Phase	Age group/other
CH_1		<1
CH_2		1-4
CH_3	Stable	5-9
CH_4	Unstable	5-9
CH_5	Deteriorating/dying	5-9
CH_6	Stable	10+
CH_7	Unstable	10+
CH_8	Deteriorating/dying	10+

Adult community settings

Currency unit	Phase	Other
AC_1	Stable	Low function
AC_2	Stable	Med function
AC_3	Stable	High function
AC_4	Unstable	Low function
AC_5	Unstable	Med function
AC_6	Unstable	High function
AC_7	Deteriorating	Low function
AC_8	Deteriorating	Med function
AC_9	Deteriorating	High function
AC_10	Dying	

Children community settings

Currency unit	Phase	Other
CC_1	Stable	Low physical severity
CC_2	Stable	Med/high physical severity
CC_3	Unstable	<1
CC_4	Unstable	1-4
CC_5	Unstable	5-9
CC_6	Unstable	10+
CC_7	Deteriorating	<1
CC_8	Deteriorating	1-4
CC_9	Deteriorating	5-9
CC_10	Deteriorating	10+
CC_11	Dying	0-9
CC_12	Dying	10+



together for short lives

Jointly commissioning palliative care for children and young people – a guide for local areas in England
September 2015

Together for Short Lives
4th Floor, Bridge House, 48-52 Baldwin Street
Bristol BS1 1QB
T: 0117 989 7820
E: info@togetherforshortlives.org.uk

www.togetherforshortlives.org.uk
www.twitter.com/Tog4ShortLives
www.facebook.com/togetherforshortlives

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