



Children and Families
Programme

Needs Based Palliative Care Commissioning for Children, Young People and their Families

A Guide

(This guide applies to services for any child or young person who has been diagnosed as having a life limiting or life threatening condition)

To be read in conjunction with:

1. *National Framework for Children's Continuing Care DH 2010*
2. *NHS at Home: Community Children's Nursing Services DH 2011*
3. *Aiming High for Disabled Children (AHDC) HM Treasury / DfES 2007*
4. *National Transition Support Programme DCSF/ DH 2008*

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1. Introduction

This document is designed to assist commissioners in identifying the types of services they should consider when commissioning provision for children and young people with life-limiting and / or life-threatening conditions. Any commissioning should be based on an individual's holistic needs of support and care, and those of their families. These will include health, social care and general support, recognising that the emerging model for commissioning is one with a focus on localisation.

The health and social care landscape is changing, with a greater focus on local commissioning, and Public Health will align itself more closely with Local Authorities. It is anticipated that GPs will be very closely involved in decisions about NHS spending. Local Authorities will work with the NHS to undertake Joint Strategic Needs Assessments and identify the local healthcare needs, against which local decisions will be made about commissioning services. The increased emphasis on local population commissioning should enable enhanced recognition of children and young people with palliative care needs, and access to a varied range of services more responsive to their individual needs. Mapping of service provision and local needs, alongside Joint Strategic Needs Assessment should also inform the decision making process

At the same time, the Government has commissioned a Palliative Care Funding Review of adult and children's services, which is due to report in the summer of 2011. It will make recommendations in relation to children and young people's palliative care services, a national funding mechanism and tariff for end of life care.

The Fundamentals of Commissioning Health Services for Children (Andrews, 2011) refers specifically to the current service provision for children and makes recommendations regarding the commissioning of future provision. In particular, the need is identified for children with long term conditions to have "access to specialist community teams to minimise hospital admissions and keep them in education".

Further support is identified through *The Operating Framework for the NHS in England 2011-12* (DH 2010) which outlines service issues that all commissioners are required to take into account. This includes the provision of 24hr nursing care for patients, including children and young people with palliative care needs.

The intention of this Commissioners' Guide is to describe the commissioning considerations for all children and young people who are diagnosed with a life-limiting or life-threatening condition, based on a holistic needs-based approach.

There is a recognition that age-appropriate commissioning decisions will need to occur throughout the child / young person's whole journey from diagnosis and recognition, through to end of life care and death. The needs may differ in intensity, according to individual circumstances and will take into account the wider family and carers needs at any given point in time. It is therefore anticipated that varied packages of care will be required to meet the child / young person's changing needs at different times in their life journey.

This guide closely links with activity relating to Children's Continuing Care as the level of need may require care which is part of, or in addition to, the care provided as part of a continuing care package. It also recognises the very close links to the work outlined within the Transition Support Programme as part of the "Aiming High for Disabled Children" agenda and other relevant national initiatives. The ways in which these documents highlight areas of close association make it really important to ensure that a multi-agency joint assessment is undertaken when considering a child or young person's needs, rather than many un-coordinated individual assessments.

The *ACT Integrated Care Pathway (Appendix 1)* was first published in 2004 to provide a resource for professionals which identifies the many and complex needs families have in caring for a child with a life-limiting or life-threatening condition. It presents a pathway for professionals to engage with the child's and family's needs, which can be used to ensure that all families have access to the appropriate support at the appropriate time.

There has been a clear national focus on improvement of services for children and young people with life limiting and life threatening conditions over the past 5 years, alongside recognition of the central role that Community Children's Nurses play.

During a time of political change within the public sector it is vital that this momentum is not lost. Children's commissioners should continue to advocate for, and build on, any existing developments that will continue to support services for this group of children and their families.

2. What is Children’s Palliative Care?

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

ACT 2009

It is very important to recognise that, where a child or young person has a life limiting or life threatening condition, their needs and those of their family are not just based on medical care. A full range of support and care which may include nursing care and other general and social care support is needed.

2.1 ACT Groups: descriptions and typical disease progression

A wide range of definitions is used in relation to children’s palliative care and a definitions paper is included at **Appendix 2**.

Four broad groups of life-threatening and life-limiting conditions may be delineated. Categorisation is not easy and the examples used in the table below are not exclusive. Diagnosis is only part of the process; the spectrum of disease, severity of disease and subsequent complications and the needs of and impact on the child and family need to be taken into account. The table below describes the different categories of conditions which may affect children and young people.

<p>Category 1</p>	<p>Life-threatening conditions for which curative treatment may be feasible but can fail. Where access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life. On reaching long term remission or following successful curative treatment there is no longer a need for palliative care services. <i>Examples: cancer, irreversible organ failures of heart, liver, kidney.</i></p>
<p>Category 2</p>	<p>Conditions where premature death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities. <i>Examples: cystic fibrosis, Duchenne muscular dystrophy.</i></p>
<p>Category 3</p>	<p>Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. <i>Examples: Batten disease, mucopolysaccharidosis.</i></p>
<p>Category 4</p>	<p>Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. <i>Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury, complex health care needs and a high risk of an unpredictable life-threatening event or episode.</i></p>

ACT 2009

2.2 Diagnostic Codes

Hain et al (2010) have compiled a list of ICD10 diagnoses that have been judged by professionals working in paediatric palliative care to be life-limiting. It is largely drawn from admissions to children's hospices on the one hand, and referrals to specialist paediatric palliative medicine on the other. The list can never be exhaustive, but it already encompasses the large majority of such diagnoses. Expansion of the list as new diagnoses become apparent is important and should be the basis for further studies. The first version of this list is included at **Appendix 3**. A range of supporting resources is included at **Appendix 8**.

2.3 Pathway Stages

Emerging work from Dr L Brook et al is developing an approach which will help to clarify the numbers of children at different stages of the care pathway. This is included at **Appendix 4**.

It is important to recognise that the identification of function for an individual child or young person is crucial in determining the level and type of care and support that they will require.

Often it is difficult to recognise the starting point of palliative care but in children's palliative care, it is acknowledged that this starts with the diagnosis or recognition that the child's condition means they are expected to die from the condition they have during childhood. However some conditions such as Duchenne Muscular Dystrophy and Cystic Fibrosis can now be managed with the affected young people living to adulthood – bringing the challenge of transition to adult services. The work undertaken through the National Transition Support Programme has enabled local areas to develop clear processes for all young people with life limiting / life threatening conditions. These processes focus on personalised approaches, full participation in planning by the young people and joint multi-agency assessment - supported by coherent strategic planning. The process is typically initiated through a universal process, "the Year 9 Review" within schools.

3. What this means for Commissioners

One of the biggest challenges facing children's palliative care commissioners, providers and service users is a lack of uniform, regular and accurate information about the nature of life-limiting conditions and the services available to support them. This means that it is difficult to effectively plan, commission and deliver services to children and families where they are most needed. Equally, without this source of information, it is impossible to predict need, track prevalence or spot trends.

Better Care, Better Lives, Department of Health, 2008

3.1 Commissioning Process

The commissioning process is comprised of 4 stages, which are:

- **Understand** – commissioners should understand needs, resources and priorities and agree outcomes for children and young people with life-limiting / life-threatening conditions
- **Plan** – map and plan sustainable and diverse services to deliver outcomes
- **Do** – procure and develop services based on the plan
- **Review** – monitor service delivery of outcomes and take remedial action if necessary

The process of commissioning plays a vital role in identifying local palliative care needs and models of effective delivery. It also enables transparency and agreements on levels of investment to meet those needs (DH 2006).

3.2 Relevant National Commissioning Frameworks

The following are commonly in use within children's services:

- HM Government (2006): Joint planning and commissioning framework for children, young people and maternity services
- Department of Health (2007): Commissioning framework for health and well-being
- Department of Health (2010): National Framework for Children and Young People's Continuing Care (DH 2010)

A range of support tools such as the Needs Assessment Tool from the ChiMat Data Atlas (www.chimat.org.uk), the Minimum Data Set from the ACT National Mapping Project (www.act.org.uk) and the Commissioning Support Programme (www.commissioningsupport.org.uk) are also available to help commissioners identify the numbers of children and young people with life-limiting / life-threatening conditions throughout the care pathway.

3.3 Local Palliative Care Commissioning Arrangements

There is an expectation that commissioners will locally agree a commissioning framework with their partners, which will underpin future discussion and the planning of commissioning palliative care services. There may be slight variation between models, but the fundamental elements are similar.

A local Children's Palliative Care Commissioning Strategy should have been developed with partners to identify the current and future service requirements, linked closely to the local Children's Strategy for Children with a Disability.

3.4 Responsibility of PCT and partners

The National Framework for Children and Young People's Continuing Care (DH 2010) clarifies that PCTs are responsible for leading the continuing care process. There is recognition that a child or young person with continuing care needs may require services commissioned not only by the PCT, but also by the Local Authority and other partners. Where a child or young person requires services commissioned by multiple organisations, the PCT is responsible for leading the commissioning care process, involving the local authority and other partners as appropriate.

3.5 Parental and Carer Need

Parents and carers play a vital role in the care of children and young people with life-limiting and life-threatening conditions, but also have their own needs and the Carers & Disabled Children Act 2000 aims to ensure the rights of carers including the right for a carer to request an assessment of their needs.

3.6 Flexible Range of Services

Commissioners will need to consider the development and maintenance of their local provider market, to ensure that there is a sufficient range of suitable services that can be commissioned to support this group of children and young people. Core flexible community provision will include those services delivering community nursing, psychological, social and respite care near to the children's homes and schools.

Commissioning recognition of the central role that Community Children's Nurses play in the lives of children with disabilities and those with complex health needs is key (DH, 2009).

The report details clear expectations that commissioners will continue to advocate for and support these services to provide 'all round care packages including end-of-life care for 24 hours a day, seven days a week' (Carter and Coad, 2009) alongside further development of joint health and social care wrap-around services.

"For an average district with a child population of 50,000 a minimum number of 20 WTE Children's Community Nurses are required, in addition to any child specific continuing care investment"

RCN: A child's right to care at home 2009

4. Commissioning Standards Framework

Commissioners, from both health and Local Authority services, have the responsibility to ensure the provision of care services throughout various stages of the child's palliative care journey.

4.1 Stages and Required Standards

Stage 1: Diagnosis / Recognition

All children, young people and families require the same service standards regardless of their condition, or where they receive that information. Special consideration may be needed to consider how tertiary, secondary and primary care services work together to ensure that planning for going home provides seamless, effective transfer. Commissioners need to consider the provision of information – and whether this is equally accessible or whether other resources are needed e.g. for those unable to read or those whose first language is not English. They also need to recognise that for some families the process of bereavement starts at this time.

The first standard: Breaking news *Every family should receive the disclosure of their child's prognosis in a face-to-face discussion in privacy and should be treated with respect, honesty and sensitivity. Information should be provided both for the child and family in language that they can understand*

The second standard: Planning for going home *Every child and family diagnosed in the hospital setting, should have an agreed transfer plan involving the hospital, community services and the family, and should be provided with the resources they require before leaving hospital.*

Suggested Service Provision	Level of Service	Examples of Services
<ul style="list-style-type: none"> specialist investigations to enable accurate diagnosis recognition of when active treatment is no longer an option and appropriate referral to palliative care services <p><i>These are highly specialist services, involving the care and psychosocial support of patients with more complex needs. They require specialist expertise.</i></p>	Specialised	<p><i>Specialist services are analogous to secondary or tertiary health care services but may be provided in a range of settings including the child's home, school or other community setting, hospice or hospital.</i></p> <p><i>There is a major contribution at this level from disease-specific voluntary sector agencies such as CLIC Sargent, Debra, Local Authority specialist children's teams e.g. disability services, hospice and other voluntary organisations as well as specialist CCN Services, and psychological services</i></p>
<ul style="list-style-type: none"> Provision of appropriate investigations to enable accurate diagnosis and referral to specialist services 	Core	<p><i>Practical support to facilitate discharge home, such as transport or equipment provision.</i></p>

Suggested Service Provision	Level of Service	Examples of Services
<p><i>if required</i></p> <ul style="list-style-type: none"> • <i>Provision of emotional and psychological support to family members during time of diagnosis and investigation</i> • <i>Provision of physical support</i> • <i>Provision of any appropriate equipment</i> 		<p><i>These services may include input from health care professionals with additional training and experience in palliative care (such as GPs/Nurses with special interest), Local Authority specialist short break services, some aspects of provision from children's hospice services and from other voluntary sector agencies such as the Jessie May Trust and Rainbow Trust; paediatric services (hospital/community), public health nurses; CCN services, pathology services, psychological support, specialist education and Early Years programmes, interpreters, specialist housing workers, bereavement services</i></p>
<ul style="list-style-type: none"> • <i>A clear recognition and referral process to enable diagnosis and subsequent referral to required services</i> <p><i>These services should be able to provide a palliative approach to their care, without referral to specialist palliative care units or personnel and deal with grief issues</i></p>	<p>Universal</p>	<p><i>Primary Health Care Services including GP Services, health visiting, school nursing, opticians, pharmacy, midwifery services, new born screening, audiology services, leisure and play services, housing, education, Surestart, Early Years programmes</i></p>

Based on: ACT and Children's Hospices UK, 2009

Stage 2: Living with the Condition

It should be recognised that the child / young person's condition has a real impact on the provision of services during this phase of the condition. In addition to the clinical aspects of the child's condition, the psycho-social and environmental factors will have an impact. It is essential that carers' needs are formally considered and there should be a link to carers' assessments. Partnership working with other services is essential and planning should involve education, social care, leisure and housing agencies.

Key working or care co-ordination is a service, involving two or more agencies that provide disabled children and young people and their families with a system whereby services from different agencies are co-ordinated. It encompasses individual tailoring of services based on assessment of need, inter-agency collaboration at strategic and practice levels and a named key worker for the child and their family. Families with disabled children should only have a key worker if they want one. (Care Co-Ordination Network UK, 2006).

Jessie May Trust use an innovative, evaluated tool for the Family Assessment of Short Break Care needs – further information is included at **Appendix 7**.

The progression of different conditions should take into account regular reviews of needs. Some children have gradual deterioration with increasing dependency and need for support, whereas others may have sudden crises and resultant increased dependency for short periods. Flexibility in service provision is key to successfully meeting child / family needs during this phase of care.

The third standard: Multi-agency Assessment of Family's Needs *every family should receive a multi-agency assessment of their needs as soon as possible after diagnosis or recognition, and should have their needs reviewed at appropriate intervals.*

The fourth standard: Multi-agency Care Plan *every child and family should have a multi-agency care plan agreed with them for the delivery of co-ordinated care and support to meet their individual needs. A key worker to assist with this should be identified and agreed with the family.*

Services should provide	Level of Service	Examples of service
<i>Services should contribute specialist information to multi-agency assessments and reviews and may provide a keyworker</i>	Specialised	<i>Specialist support e.g. supported short breaks provided by children's hospice services and other voluntary sector agencies. Services may also include disease- specific specialists, specialist CCN services, specialist children's teams e.g. disability services, specialist symptom management and psychosocial support teams / professionals.</i>
<i>Services should contribute to multi-agency assessments and reviews. They may provide a keyworker and offer ongoing emotional support to child and family</i>	Core	<i>Services may include paediatrics, pathology, psychological support, specialist Education and Early Years Programmes, interpreters, specialist housing workers, 24 hour advice on management of pain and symptom management, therapy services, CCN services, specialist outreach services such as oncology, continuing care packages, CAMHS, Special Education Services, short breaks, specialist housing, social care, hospice and other voluntary organisations.</i>
<i>Services should contribute to multi-agency assessments and reviews and offer ongoing emotional support.</i>	Universal	<i>Services may include: Primary health care services including GP services, health visiting, school nursing, opticians, pharmacy, midwifery services, new born screening, leisure and play services, housing; Surestart; education and Early Years programmes.</i>

Stage 3: End of Life Care and Bereavement

Service need is similar for all children and young people, regardless of diagnosis although there may be a need for 2 different approaches to deal with different needs:

- **Recognised / predicted End of Life** – with advance planning and gradual progression

Frequently these children are cared for at home with support from community and specialist services, including children’s hospices.

- **Rapid response** – e.g. sudden deterioration / acute conditions / trauma
Usually these children are being cared for in hospital, often in tertiary centres, away from home. The challenge is to enable the child to be cared for in the location of choice, which involves partnership working, through protocols, with the emergency and out of hour services. One such example of a rapid discharge protocol is included at **Appendix 6**.

The fifth standard: End of Life Plan: *Every child and family should be helped to decide on an end of life plan and should be provided with the care and support to achieve this as closely as possible.*

Continuing bereavement support: Bereavement frequently starts at the moment of diagnosis, so support should be provided throughout the care pathway. The need to continue and possibly provide intense support to the whole family, during the child’s death and beyond should also be recognised.

Services should provide	Level of Service	Examples of service
<i>Services should provide 24 hour access to specialist ‘hands on’ care and advice as required by children, families and carers, including professional members of the care team. This may be included within CCN services and be able to deal with complex grief and loss issues</i>	Specialised	<i>Services may include: specialist palliative care teams / professionals, disease specific / specialist palliative care, such as neuro-disability, cystic fibrosis and muscular dystrophy, to enable effective psychosocial support and management of severe symptoms, chronic pain and other distressing symptoms, specialist CCN services and bereavement services</i>
<i>Services should provide day-to-day care of the child and family and should have access to 24 hour specialist advice through effective clinical networks</i>	Core	<i>Services may include paediatric services, psychological support, interpreters, therapy services, CCN services, special education services, specialist housing, social care, hospice and other voluntary organisations, foster care and bereavement services</i>
<i>Services should support the whole family emotionally and practically. Services to support the siblings of children and young people who are dying are an important part of supporting the whole family through the bereavement process</i>	Universal	<i>Services may include primary health care services including GP services, health visiting, school nursing, opticians, pharmacy, midwifery services, new born screening, leisure and play services, housing, Surestart, Early Years programmes and education services</i>

4.2 Framework

4.2.1 Assessment

Assessing and prioritising the needs of the child / young person, alongside establishing the wishes of the child / young person and their family will provide an indication of the child / young person's level of palliative care need, indicated in the table below. It is essential to remember that the movement through the framework is not necessarily sequential; children's conditions and needs can change on a daily, weekly, monthly or yearly basis – or even sometimes from hour to hour. This means that dependency can go down as well as up and regular assessment is required, based on the individual child and family's need.

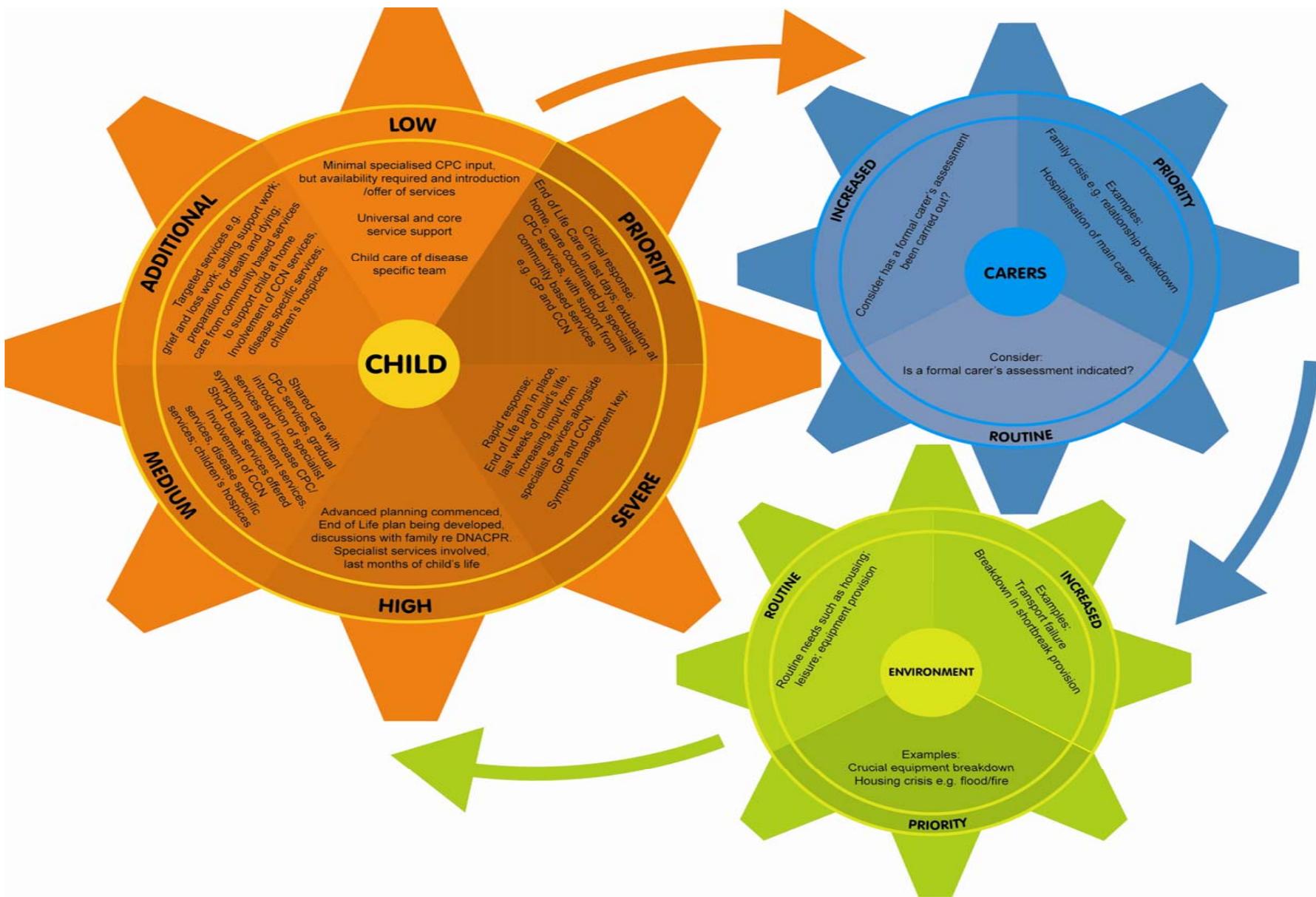
It is imperative that there is recognition that children and young people dip into and out of the stages described and there is a need to consider the level of service required for a child / young person at a specific point in time, with this informing the whole package of care. The individual child / young person will have different needs at different points in time throughout their care journey and these needs are impacted on by their carer's needs and care environment issues e.g. housing crisis or transport provision.

Existing services currently use their own child / family dependency scoring and an example of that used by Children's Hospice South West is included at **Appendix 5**.

4.2.2 Interdependencies

The interdependence of the child's needs, carer's needs and environmental factors needs to be considered as a whole. The figure on the following page demonstrates these interdependencies.

Please note: it is necessarily rather small within this document but can be made larger by viewing in "zoom" online, or by printing onto A3 size paper.



When commissioning services for an individual child and family, it is essential that the total needs are considered, including the interdependency of the additional factors. When considering the level of need, this should be the highest level of need for either the child, or carer, or environment, although this level may only be required for a matter of hours, or days. The interchangeable aspects of need require a flexible approach to the commissioning of services.

Recognising the dual responsibility of Local Authorities to consider both the environmental and carers' needs and also public health needs, it is essential that commissioners from across health and social care work together to ensure that children and their families receive the flexible, high quality standards of care they require. This can be better achieved by the use of a single multi-agency assessment based on individual needs and should not be viewed as an "eligibility assessment".

4.2.3 Framework for Commissioning Service Models

Carers Issues	Priority needs	Increased needs	Routine needs
	Examples: Family crisis e.g. relationship breakdown. Hospitalisation of main carer	Consider has a formal carer's assessment been carried out?	Consider: Is a formal carer's assessment indicated?

Children may rapidly move in & out of different levels according to need at any specific time, and based on level of support available	Level of Need	Child/Young Person's Issues
	Priority	<p>Critical response End of Life Care in last days; extubation at home, care coordinated by specialist CPC services, with support from community based services e.g. GP and CCN Examples of situation: Child/young person (CYP) at End of Life. CYP discharged from high dependency/ICU situation. CYP has compassionate extubation planned. Expected prognosis: days / hours</p>
	Severe	<p>Rapid response End of Life plan in place, last weeks of child's life, increasing input from specialist services alongside GP and CCN. Symptom management key. Examples of situation: CYP approaching End of Life, condition deteriorating Expected prognosis: weeks / days</p>
	High	<p>Advanced planning commenced End of Life plan being developed, discussions with family re DNACPR. Specialist services involved, last months of child's life Examples of situation: DMD with increasing chest infections/ respiratory demand increasing</p>

		Some newly diagnosed children/young people with life-limiting/life-threatening conditions when coming to terms with diagnosis Expected prognosis: months / weeks
	Medium	Shared care with CPC services, gradual introduction of specialist services and increased CPC/symptom management services. Short break services offered Involvement of CCN services, disease specific services, children’s hospices Examples of situation: DMD post-spinal surgery, Neonatal diagnosis Expected prognosis: years / months
	Additional	Targeted services e.g. grief and loss work; sibling support work, preparation for death and dying, care from community based services to support child at home Involvement of CCN services, disease specific services, children’s hospices Examples of situation: CYP may be on phase 3 trials, realisation from family that curative care no longer an option, e.g. “well” Duchenne Muscular Dystrophy, Antenatal diagnosis, Expected prognosis: years
	Low	Minimal specialised CPC input, but availability required and introduction/offer of services Universal and core service support Child c/o disease specific team Examples of situation: All newly diagnosed CYP with life-limiting/life-threatening conditions Expected prognosis: years

Environmental Issues	Priority needs	Increased needs	Routine needs
	Examples: Crucial equipment breakdown. Housing crisis e.g. flood/fire	Examples: Transport failure. Breakdown in short break provision	Consider needs such as housing; leisure; equipment provision

4.2.4. Case Examples

Case example 1: a child who is ventilator-dependent, but stable, with family and professional carers delivering care at home (child = additional needs, carers = routine needs). If the ventilator breaks down, then the level of need would increase to priority until the equipment is replaced. From a commissioning perspective this may require funding for alternative accommodation with available equipment e.g. hospital or possibly hospice beds.

Case example 2: a child who has 24hr care needs, met through a care package which involves non-family carers delivering care in the family home (child = additional needs, environment = routine needs), severe weather prevents the carers getting to the home, the level of need would increase to priority until the care package can be delivered by the carers again, when environment issues and carers issues revert to routine again. From a commissioning perspective this may require funding for additional staff to be brought in e.g. bank/agency staff.

5. Conclusion

It is recognised that commissioning services for children and young people with palliative care needs is highly complex. The very nature of their illness and the course it may take, means that a broad range of responsive and flexible services could be required.

It is hoped that this guide will help by drawing together the holistic issues of the child and their family that require consideration, indicating the relevant national guidance and providing tools and relevant information to support both the commissioning and provision of services.

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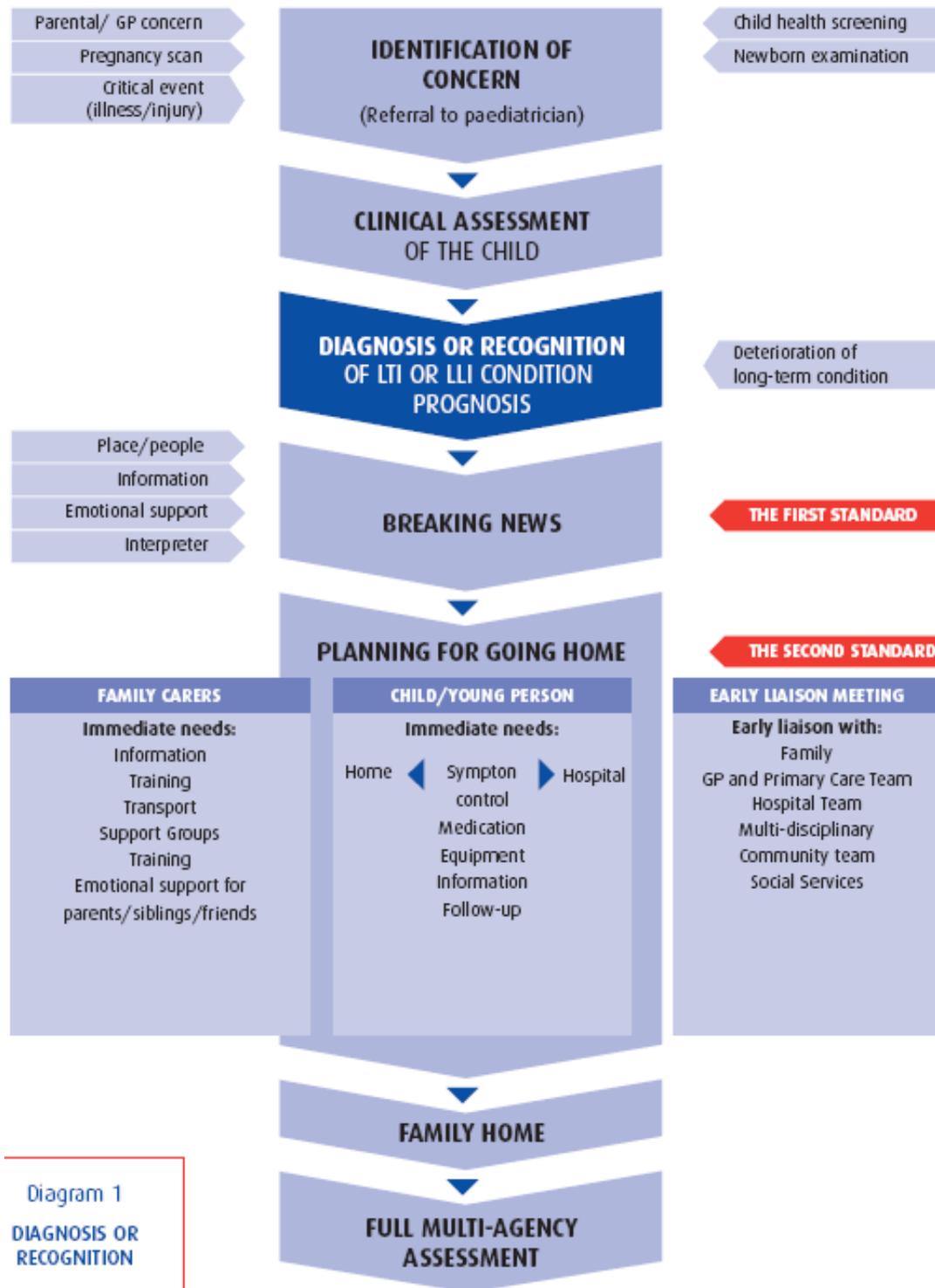
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Appendix 1: ACT Care Pathway



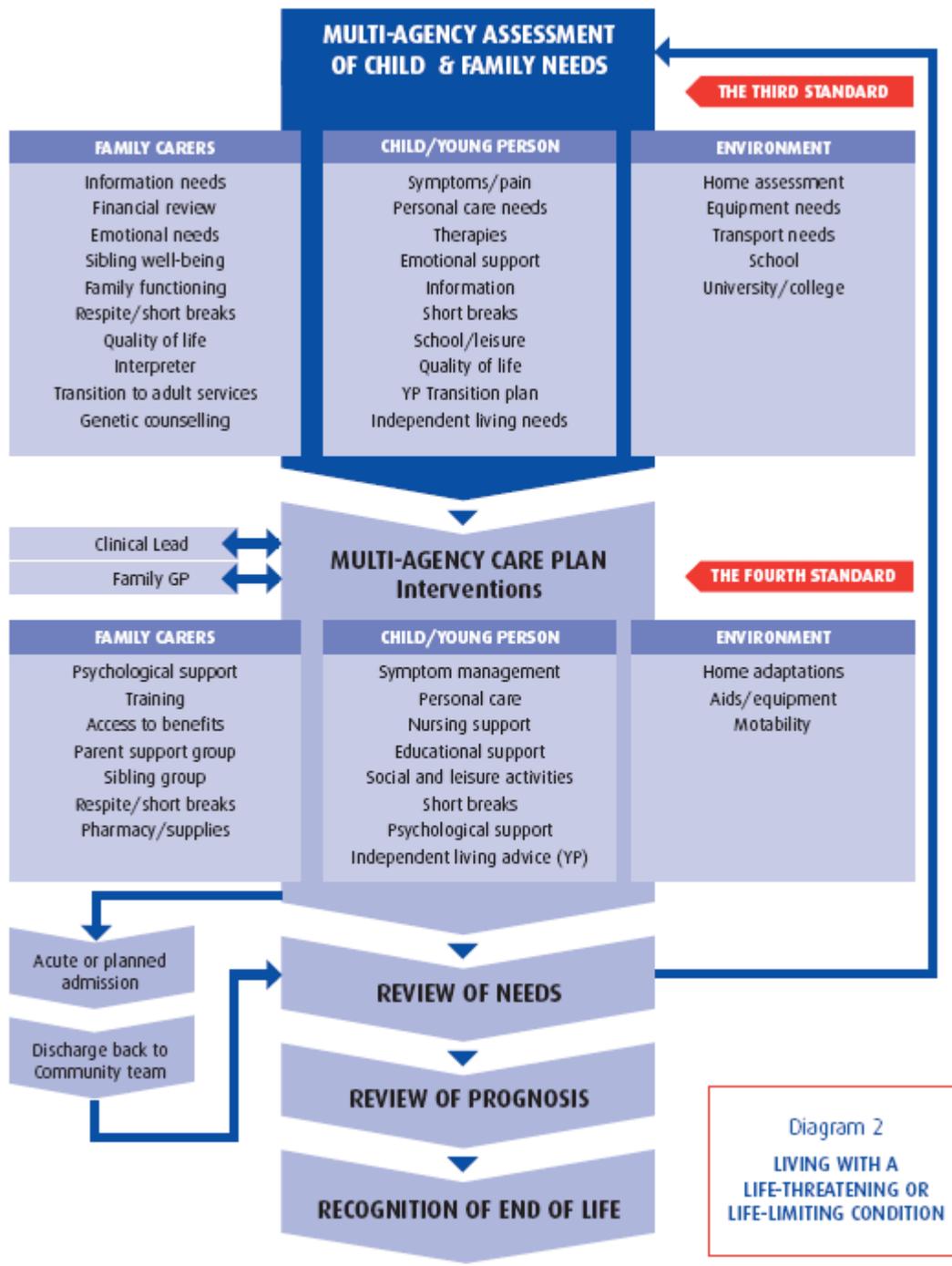
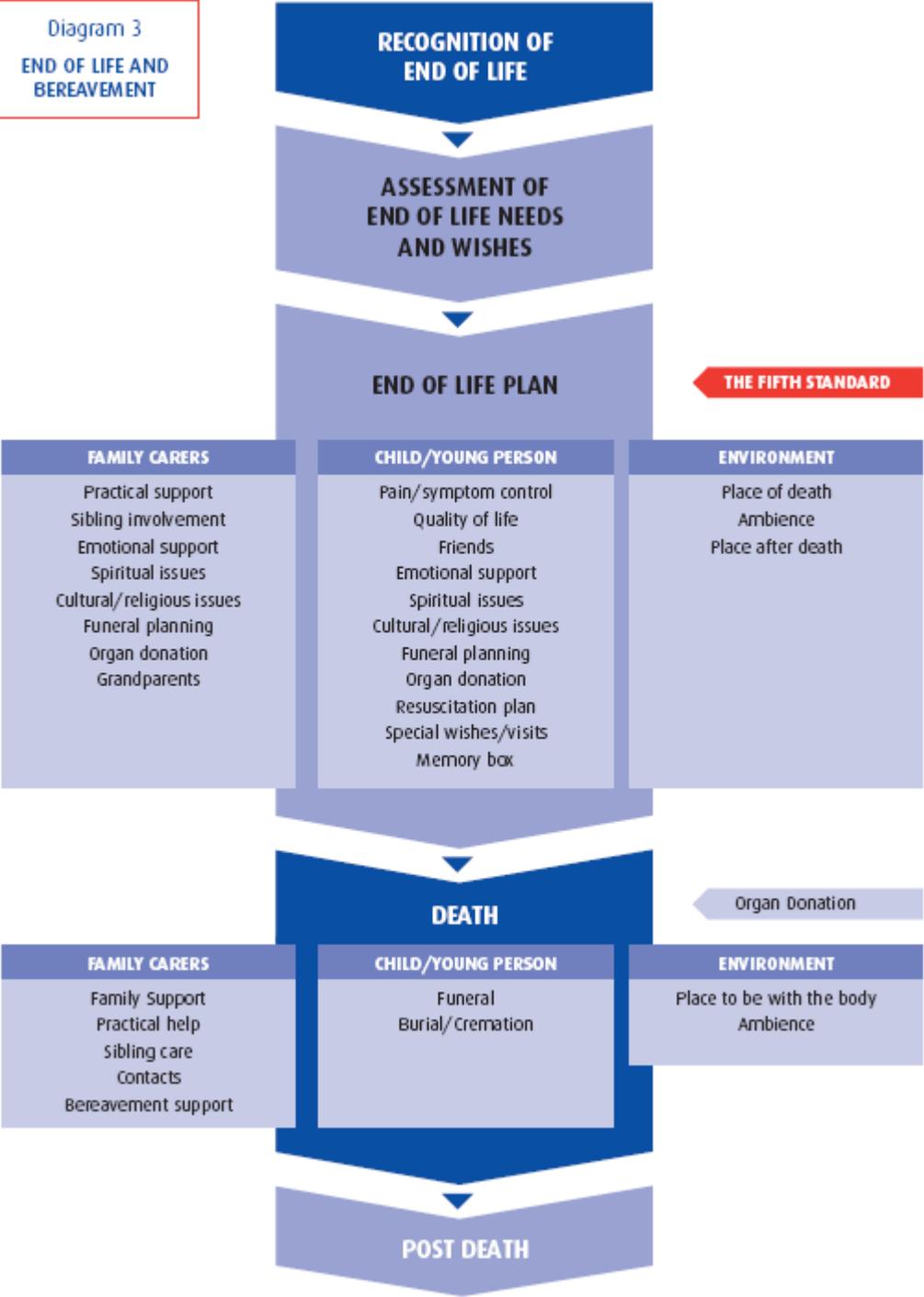


Diagram 3
**END OF LIFE AND
 BEREAVEMENT**



Appendix 2: Definitions

Children's palliative care

Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement. ACT (2009)

Care of the dying

Care of the dying is the care of the patient and family in the last hours and days of life. It incorporates four key domains of care: physical, psychological, social and spiritual, and supports the family at that time and into bereavement.

Child

A child is defined as a young person aged up to their 19th birthday

Children's hospice services

Children's hospice services provide palliative care for children and young people with life-limiting conditions and their families. Delivered by a multi-disciplinary team and in partnership with other agencies, children's hospice services take a holistic approach to care, aiming to meet the needs of both child and family - physical, emotional, social and spiritual - through a range of services. These include:

- 24 hour end of life care
- Support for the entire family (including siblings, grandparents and the extended family).
- Bereavement support.
- 24 hour access to emergency care.
- Specialist short break care.
- 24 hour telephone support.
- Practical help, advice and information.
- Provision of specialist therapies, including physiotherapy as well as play and music therapy.
- Provision of information, support, education and training where needed to carers.

Children's hospice services deliver this care in the home (commonly termed 'hospice at home service') and/or in a purpose built building.

Children's palliative care networks

Children's palliative care networks are linked groups of multi-agency professionals and organisations from primary, secondary and tertiary care, social services, education and other statutory and voluntary services working together in a co-ordinated manner. They provide the forum in which:

- Better integrated and more effective commissioning models can be developed and shared.
- Statutory and voluntary agencies will work together to provide an agreed and comprehensive range of services.
- Local needs can be assessed, through mapping of affected children and young people and available services (this would be via children's trust arrangements).
- Skills, knowledge and expertise can be exchanged.
- Local service users can be involved and included in service development.

Commissioner

A commissioner is a person with responsibility for commissioning services from service providers in either the public, private or voluntary sector.

Commissioning

Commissioning is the process of improving outcomes and meeting the needs of the population within the local health community with the resources available.

Complex care/continuing care

Complex/continuing care is a bespoke package of care beyond what is available through core and universal services. It is provided to children with high levels of complexity or intensity of nursing care needs.

End of life

The end of life phase begins when a judgement is made that death is imminent. It may be the judgement of the health/social care professional/team responsible for the care of the patient, but it is often the child/young person or family who first recognises its beginning.

End of life care

End of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It focuses on preparing for an anticipated death and managing the end stage of a terminal medical condition, this includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both child/young person and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family into bereavement.

End of life care services

End of life care services are services to support those with advanced, progressive, incurable illness to live as well as possible until they die. These are services that enable the supportive and end of life care needs of both child/young person and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. This is not confined to discrete specialist services but includes those services provided as an integral part of the practice of any health or social care professional in any setting.

Family

The term 'family' includes parents, other family members involved in the care of the young person, or other carers who are acting in the role of parents. Family includes informal carers and all those who matter to the child/young person.

Hospice at Home

Hospice at Home is a term commonly used to describe a service which brings skilled, practical children's palliative care into the home environment. Hospice at Home works in partnership with parents and families and other carers.

Key working

Key working or care co-ordination is a service, involving two or more agencies that provide disabled children and young people and their families with a system whereby services from different agencies are co-ordinated. It encompasses individual tailoring of services based on assessment of need, inter-agency collaboration at strategic and practice levels and a named key worker for the child and their family. Families with disabled children should only have a key worker if they want one. (Care Co-ordination Network UK, 2006).

Life-limiting/life-shortening conditions

Life-limiting /life-shortening conditions are those for which there is no reasonable hope of cure and from which children or young people will die. Some of these conditions cause progressive deterioration rendering the child increasingly dependent on parents and carers.

Life-threatening conditions

Life-threatening conditions are those for which curative treatment may be feasible but can fail, such as children with cancer. Children in long-term remission or following successful curative treatment are not included.

Needs-led

Need-led is the term used to describe how services should be provided on the basis of the needs of the patient and family and not as a result of assessing the resources that are available. To deliver a

needs-led service it is important to assess and thoroughly understand the needs of the children, young people and families first.

Parents

The term 'parents' has been used throughout the text, and it is used to mean any carer for a child whether that is a married or unmarried couple, a single parent, guardian or foster parent.

Primary care organisation

A primary care organisation is the NHS body responsible for providing primary health services and improving health within their local community through commissioning. Primary care organisations have taken on many of the responsibilities of planning and purchasing health services that were formerly undertaken by health authorities and in addition they can also provide services themselves e.g. Primary Care Trusts and Local Health Boards.

Primary healthcare team

A primary healthcare team comprises the general practitioner, practice nurse and community staff (such as community children's nurses or physiotherapists) who work with the practice staff.

Service level agreement

A service level agreement is an agreement between the commissioner and any organisation providing a service. They specify standards to which the service should be provided, for what sum of money and for how long.

Short breaks (Respite Care)

Short break care has three main functions:

- To provide the child or young person an opportunity to enjoy social interaction and leisure facilities.
- To support the family in the care of their child in the home or an alternative community environment such as a children's hospice.
- To provide opportunities for siblings to have fun and receive support in their own right.

Short breaks may offer the whole family an opportunity to be together and to be supported in the care of their child or it may offer care solely for the child or young person.

Specialist short break care

Specialist short break care refers to a setting of care, a programme of care or a service that provides additional care for highly complex or technology dependent children who may otherwise be excluded from short breaks provided by social care. It may take place in the child's home or in a setting outside of the home such as a hospital, long-term care facility or hospice. Specialist short break care provides the support required to meet the child's holistic care needs and enables children and families to be able access short break services. Specialist short breaks will often address some aspects of symptom management. Specialist short breaks should also meet the functions described under general short breaks.

Supportive care

Supportive care is an 'umbrella' term for all services, both generalist and specialist, that may be required to improve the quality of life for people with life-threatening illness. It recognises that people need some forms of care that are not directed towards cure from the time that the possibility of a life-threatening condition is raised.

Symptom management

Symptom management is the management of common symptoms associated with life-limiting conditions. It is often used to refer to symptoms that are primarily physical, but in palliative care symptom management also includes attention to psychosocial and spiritual aspects of symptoms where appropriate.

Technology dependent children

Technology dependent children are those who need both a medical device to compensate for the loss of a vital bodily function and substantial and on-going nursing care to avert death or further disability.

Transition

Transition is the term used when the child is moving from childhood into adulthood. The transfer of service provision around this time should be well planned and ensure as little disruption to the young person and their family as possible

Young adult

The term young adult describes a person from their 19th birthday.

Young person

The term young person describes a person from their 13th – 19th birthday.

Appendix 3: Hain Dictionary (May 2010 edition)

ICD10 code	Diagnostic label
A81.0	Creutzfeld-Jakob disease
A81.0	Subacute spongiform encephalopathy
A81.1	Subacute Sclerosing Panencephalitis/SSPE
B20	HIV - Congenital infection
B20.8	HIV infection resulting in other infectious and parasitic diseases
B20-24	Human Immunodeficiency Virus infection / HIV positive
C02.9	Carcinoma of the tongue
C22.0	Hepatoblastoma
C22.0	Hepatocellular Carcinoma
C22.0	Liver Cancer
C22.2	Hepatoblastoma - metastatic
C22.3	Angiosarcoma
C22.9	Malignant neoplasm: Liver, unspecified
C38.4	Malignant neoplasm: Pleura
C40	Osteosarcoma - hip
C40.2	Malignant neoplasm: Long bones of lower limb
C40-C41	Cancer of the bone
C41.4	Malignant neoplasm: Pelvic bones, sacrum and coccyx
C41.8	Ewing's sarcoma
C41.9	Osteosarcoma
C41.9	Malignant neoplasm: Bone and articular cartilage, unspecified
C43	Malignant Melanoma
C49.2	Malignant neoplasm: Connectiva and soft tissue of lower limb, including hip
C49.9	Desmoplastic round cell tumour with metastases
C49.9	Rhabdomyosarcoma
C49.9	Malignant neoplasm: Connectiva and soft tissue, unspecified
C52	Carcinoma - vaginal

C56	Malignant neoplasm of ovary
C62	Mixed Germinoma/Teratoma
C62.9	Malignant neoplasm: Testis, unspecified
C64	Wilm's Tumour - stage 4
C64	Wilm's tumour - relapsed
C64	Malignant neoplasm of kidney, except renal pelvis
C65	Renal Carcinoma
C65	Renal Cell Carcinoma - relapsed
C69.2	Retinoblastoma
C71	Astrocytoma
C71	Astrocytoma -Anaplastic
C71	Astrocytoma - gemistocytic
C71	Ependymoma
C71	Glioma
C71	Glioma - high grade left thalamic
C71	Glioma - pontine
C71	Glioma of Cerebellar Vermis - grade 3
C71	Glioma - Brain Stem
C71	Gliomatosis cerebri
C71	Glioblastoma
C71.0	Malignant neoplasm: Cerebrum except lobes and ventricles
C71.0	Malignant neoplasm: Supratentorial NOS
C71.6	Malignant neoplasm: cerebellum
C71.6	Medulloblastoma - anaplastic
C71.7	Malignant neoplasm: Brainstem
C71.7	Malignant neoplasm: Fourth ventricle
C71.7	Malignant neoplasm: Infratentorial NOS
C71.9	Malignant neoplasm: Brain, unspecified
C72.0	Malignant neoplasm: Spinal cord
C72.1	Cauda Equina Tumour
C72.3	Glioma - optic nerve

C72.3	Malignant neoplasm: Optic nerve
C72.9	Malignant neoplasm: Central nervous system, unspecified
C72.9	Malignant neoplasm: Nervous system NOS
C74.9	Neuroblastoma
C74.0	Adrenocortical carcinoma
C74.9	Malignant neoplasm: adrenal gland, unspecified
C75.3	Pineoblastoma
C76.1	Malignant neoplasm of other and ill-defined sites: Thorax
C76.1	Malignant neoplasm of other and ill-defined sites: Axilla NOS
C76.1	Malignant neoplasm of other and ill-defined sites: Intrathoracic NOS
C76.1	Malignant neoplasm of other and ill-defined sites: Thoracic NOS
C80	Malignant neoplasm without specification of site
C80	Cancer unspecified site (Primary)(Secondary)
C80	Carcinoma unspecified site (Primary)(Secondary)
C80	Carcinomatosis unspecified site (Primary)(Secondary)
C80	Generalised cancer unspecified site (Primary)(Secondary)
C80	Generalised malignancy unspecified site (Primary)(Secondary)
C80	Malignancy unspecified site (Primary)(Secondary)
C80	Multiple cancer unspecified site (Primary)(Secondary)
C80	Malignant cachexia
C80	Malignant neoplasms primary site unknown
C81	Hodgkin's Lymphoma
C81.9	Hodgkin's disease, unspecified
C82	Lymphoma - non Hodgkins
C83.7	Burkitt's tumour
C84.5	Other and unspecified T-cell lymphomas
C85.1	B Cell Lymphoma
C85.9	Non-Hodgkin's lymphoma, unspecified type
C85.9	Lymphoma NOS
C85.9	Malignant Lymphoma NOS
C85.9	Non-Hodgkin's lymphoma NOS

C91	Acute Lymphoblastic Leukaemia/ALL - relapsed
C91.0	Acute lymphoblastic leukaemia
C92	Chronic Myeloid Leukaemia - juvenile
C92.0	Acute myeloid leukaemia
C92.7	Other myeloid leukaemias
C93	Juvenile Myelomonocytic Leukaemia/JMML
C95.0	Acute leukaemia of unspecified cell type
C95.0	Blast cell leukaemia
C95.0	Stem cell leukaemia
D18	Cavernous Haemangioma in Brainstem
D21.9	Benign neoplasm: connective and other soft tissue, unspecified
D33	Brain Tumour
D43.0	Neoplasm of uncertain or unknown behaviour: Brain, supratentorial
D43.0	Neoplasm of uncertain or unknown behaviour: cerebral ventricle
D43.0	Neoplasm of uncertain or unknown behaviour: cerebrum
D43.0	Neoplasm of uncertain or unknown behaviour: frontal lobe
D43.0	Neoplasm of uncertain or unknown behaviour: occipital lobe
D43.0	Neoplasm of uncertain or unknown behaviour: parietal lobe
D43.0	Neoplasm of uncertain or unknown behaviour: temporal lobe
D43.2	Neoplasm of uncertain or unknown behaviour: Brain, unspecified
D48.0	Neoplasm of uncertain or unknown behaviour: Bone and articular cartilage
D48.2	Peripheral nerve sheath tumour - malignant
D48.7	Neoplasm of uncertain or unknown behaviour: Other specified sites
D48.7	Neoplasm of uncertain or unknown behaviour: eye
D48.7	Neoplasm of uncertain or unknown behaviour: heart
D48.7	Neoplasm of uncertain or unknown behaviour: peripheral nerves of orbit
D48.9	Neoplasm of uncertain or unknown behaviour: unspecified
D48.9	Neoplasm of uncertain or unknown behaviour: "Growth" NOS
D48.9	Neoplasm of uncertain or unknown behaviour: neoplasm NOS
D48.9	Neoplasm of uncertain or unknown behaviour: new growth NOS
D48.9	Neoplasm of uncertain or unknown behaviour: tumour NOS

D61.9	Medullary hypoplasia
D61.9	Panmyelophthisis
D70	Chronic Neutropenia - severe
D70	Neutropenia
D75.9	Disease of blood and blood-forming organs, unspecified
D76.1	Haemophagocytic lymphohistiocytosis
D76.1	Familial haemophagocytic reticulosis
D76.1	Histiocytoses of mononuclear phagocytes other than Langerhans' cells NOS
D82.1	Di George syndrome
D82.1	Pharyngeal pouch syndrome
D82.1	Thymic alymphoplasia
D82.1	Thymic aplasia or hypoplasia with immunodeficiency
D83	Common Variable Immunodeficiency
D84.9	Immunodeficiency
D89.1	Cryoglobulinemia
E31.0	Autoimmune polyglandular failure
E31.0	Schmidt's syndrome
E71.1	Other disorders of branched chain amino acid metabolism
E71.1	Hyperleucine-isoleucinaemia
E71.1	Hypervalinaemia
E71.1	Isovaleric acidaemia
E71.1	Methylmalonic acidaemia
E71.1	Propionic acidaemia
E71.3	Adrenoleukodystrophy - X-linked
E71.3	Adrenoleukodystrophy - Autosomal
E71.3	Leukodystrophy
E71.3	Disorders of fatty acid metabolism
E71.3	Adrenoleukodystrophy [Addison-Schilder]
E71.3	Muscle carnitine palmityltransferase deficiency
E72.0	Fanconi's Syndrome

E72.1	Homocystinuria
E72.2	Disorders of urea cycle metabolism
E72.2	Argininaemia
E72.2	Argininosuccinic aciduria
E72.2	Citrullinaemia
E72.2	Hyperammonaemia
E72.3	Glutaric Aciduria Type 1
E72.5	Glycine encephalopathy
E72.9	Aminoaciduria
E74.0	Glycogen Storage Disease Type 1B
E74.0	Pompe's Disease
E74.2	Galactosaemia
E75.0	Gangliosidosis
E75.0	GM2 Gangliosidosis (Tay Sachs)
E75.0	Tay Sachs Disease - infantile
E75.1	GM1 Gangliosidosis - early infantile
E75.1	GM1 Gangliosidosis - late infantile
E75.1	Other Gangliosidosis
E75.1	Gangliosidosis: NOS
E75.1	Gangliosidosis: GM1
E75.1	Gangliosidosis: GM3
E75.1	Mucopolipidosis IV
E75.2	Gauchers Disease - Type 2
E75.2	Metachromatic Leukodystrophy - juvenile
E75.2	Niemann-Pick disease - type a
E75.2	Niemann-Pick disease - type b
E75.2	Niemann-Pick Disease - type c
E75.2	Other Sphingolipidosis
E75.2	Fabry(-Anderson) Disease
E75.2	Gaucher Disease
E75.2	Krabbe Disease

E75.2	Niemann-Pick Disease
E75.2	Farber's syndrome
E75.2	Metachromatic leukodystrophy
E75.2	Sulfatase deficiency
E75.4	Batten Disease/Neuronal Ceroid Lipofuscinosis - Infantile
E75.4	Batten Disease/Neuronal Ceroid Lipofuscinosis - Late Infantile
E75.4	Neuronal ceroid lipofuscinosis
E75.4	Batten disease
E75.4	Bielschowsky-Jansky disease
E75.4	Kufs disease
E75.4	Spielmeier-Vogt disease
E75.5	Other lipid storage disorders
E75.5	Cerebrotendinous cholesterosis [van Bogaert-Scherer-Epstein]
E75.5	Wolman's disease
E75-77	Lysosomal Storage Disorder
E76.0	Mucopolysaccharidosis type 1/MPS1 - Hurler Syndrome
E76.1	Mucopolysaccharidosis Type 2/MPS 2 - Hunter Syndrome
E76.2	Other mucopolysaccharidose
E76.2	Beta-glucuronidase deficiency
E76.2	Mucopolysaccharidosis, types III, IV, VI, VII
E76.2	Maroteaux-Lamy syndrome (mild)(severe)
E76.2	Morquio syndrome (-like)(classic)
E76.2	Sanfilippo syndrome (type B)(type C)(type D)
E77.0	I Cell Disease / Mucopolipidosis type 2
E77.0	Pseudo-Hurler Polydystrophy / Mucopolipidosis type 3
E77.0	Defects in post-translational modification of lysosomal enzymes
E77.0	Mucopolipidosis II [I-cell disease]
E77.0	Mucopolipidosis III [pseudo-Hurler polydystrophy]
E77.1	Fucosidosis
E77.8	Other disorders of glycoprotein metabolism
E79.1	HPRT Deficiency/Lesch-Nyhan Syndrome

E79.1	Lesh-Nyhan Syndrome/HPRT deficiency
E83.0	Disorders of copper metabolism
E83.0	Menkes' (kinky hair)(steely hair) disease
E84	Cystic Fibrosis
E84.0	Cystic fibrosis with pulmonary manifestations
E84.1	Cystic fibrosis with intestinal manifestations
E84.1	Meconium ileus+
E84.8	Cystic fibrosis with other manifestations
E84.8	Cystic fibrosis with combined manifestations
E84.9	Cystic fibrosis, unspecified
E88.0	Disorders of plasma-protein metabolism, not elsewhere classified
E88.0	Alpha-1-antitrypsin deficiency
E88.0	Bisalbuminaemia
E88.9	Metabolic disorder, unspecified
F00-F07	Dementia
F84.2	Rett's syndrome
G10	Huntington's chorea/Disease - juvenile onset
G10	Huntington's disease
G10	Huntington's chorea
G11	Spinocerebellar Ataxia
G11.1	Friedreich's ataxia
G11.3	Ataxia Telangiectasia
G12.0	Werdnig Hoffman Disease
G12.2	Motor neurone disease/MND
G12.9	Spinal muscular atrophy, unspecified
G20	Parkinson's Disease
G23.0	Hallervorden Spatz Disease/Pantothenate kinase-associated neurodegeneration
G23.8	Olivopontocerebellar Atrophy
G31.8	Leigh Syndrome
G31.9	Cerebellar degeneration - progressive

G31.9	Degenerative disease of nervous system, unspecified
G35	Multiple Sclerosis
G40.4	Lennox/Gastaut Syndrome
G40.5	Epilepsia partialis continua [Kozhevnikof]
G60.0	Charcot-Marie-Tooth Syndrome
G60.0	Hereditary motor sensory neuropathy/HMSN
G60.1	Infantile Refsum Disease
G70.0	Myasthenia Gravis
G70.9	Myoneural disorder, unspecified
G71	Muscular Dystrophy - Emery-Dreifuss type
G71	Myopathy - familial
G71	Myopathy - unknown origin
G71.0	Duchenne Muscular Dystrophy/DMD
G71.0	Gamma Sarcoglycanopathy/Limb girdle muscular dystrophy/Type 2C gamma Sarcoglycaopathy?
G71.0	Limb girdle muscular dystrophy/Type 2C gamma sarcoglycanopathy/Gamma Sarcoglycanopathy
G71.0	Type 2C gamma sarcoglycanopathy/Gamma Sarcoglycanopathy/Limb girdle muscular dystrophy/
G71.0	Muscular Dystrophy - non specific
G71.0	Muscular dystrophy
G71.0	Muscular dystrophy: autosomal recessive, childhood type, resembling Duchenne or Becker
G71.0	Muscular dystrophy: distal
G71.0	Muscular dystrophy: facioscapulohumeral
G71.0	Muscular dystrophy: limb-girdle
G71.0	Muscular dystrophy: oculopharyngeal
G71.0	Muscular dystrophy: scapuloperoneal
G71.0	Muscular dystrophy: severe [Duchenne]
G71.1	Myotonic disorders
G71.1	Dystrophia myotonica [Steinert]
G71.1	Myotonia: chondrodystrophic

G71.1	Myotonia: drug-induced
G71.1	Myotonia: symptomatic
G71.1	Myotonia congenita: NOS
G71.1	Myotonia congenita: dominant [Thomsen]
G71.1	Myotonia congenita: recessive [Becker]
G71.1	Neuromyotonia [Isaacs]
G71.1	Paramyotonia congenita
G71.1	Pseudomyotonia
G71.2	Myopathy - congenital
G71.2	Muscular Dystrophy - congenital - merosin negative
G71.2	Congenital myopathies
G71.2	Congenital muscular dystrophy: NOS
G71.2	Congenital muscular dystrophy: with specific morphological abnormalities of the muscle fibre
G71.2	Congenital myopathies: disease central core
G71.2	Congenital myopathies: disease minicore
G71.2	Congenital myopathies: disease multicore
G71.2	Congenital myopathies: Fibre-type disproportion
G71.2	Myopathy: myotubular (centronuclear)
G71.2	Myopathy: nemaline
G71.3	Mitochondrial myopathy, not elsewhere classified
G80.0	Spastic quadriplegic cerebral palsy
G80.0	Spastic tetraplegic cerebral palsy
G80.3	Cerebral Palsy - Athetoid
G80.3	Cerebral Palsy - dyskinetic
G80.4	Cerebral Palsy - Ataxic
G80.8	Other cerebral palsy
G80.8	Mixed cerebral palsy syndromes
G82.4	Spastic tetraplegia
G82.5	Tetraplegia, unspecified
G82.5	Quadriplegia NOS

G91.9	Hydrocephalus, unspecified
G93.4	Encephalopathy, unspecified
G93.6	Cerebral oedema
H35.5	Retinitis pigmentosa
I27.0	Persistent pulmonary hypertension
I27.0	Primary pulmonary hypertension
I42	Cardiomyopathy
I42.0	Dilated cardiomyopathy
I42.0	Congestive cardiomyopathy
I42.1	Cardiomyopathy - hypertrophic
I42.2	Other hypertrophic cardiomyopathy
I42.2	Nonobstructive hypertrophic cardiomyopathy
I42.4	Endocardial fibroelastosis
I42.4	Congenital cardiomyopathy
I42.8	Other cardiomyopathies
I42.9	Cardiomyopathy, unspecified
I42.9	Cardiomyopathy (primary)(secondary) NOS
I61.3	Intracerebral haemorrhage in brain stem
I68.7	Cerebral ischaemia (chronic)
J47	Bronchiectasis
J47	Bronchiolectasis
J84.1	Fibrosing Alveolitis
J84.9	Interstitial pulmonary disease, unspecified
J96	Respiratory failure
J98.0	Diseases of bronchus, not elsewhere classified
J98.0	Broncholithiasis
J98.0	Calcification of bronchus
J98.0	Stenosis of bronchus
J98.0	Tracheobronchial collapse
J98.0	Tracheobronchial dyskinesia
J98.2	Interstitial emphysema

J98.2	Mediastinal emphysema
J98.4	Calcification of lung
J98.4	Cystic lung disease (acquired)
J98.4	Pulmolithiasis
K55.0	Acute fulminant ischaemic colitis
K55.0	Acute intestinal infarction
K55.0	Acute small intestine ischaemia
K55.0	Mesenteric (artery)(vein) embolism
K55.0	Mesenteric (artery)(vein) infarction
K55.0	Mesenteric (artery)(vein) thrombosis
K55.0	Subacute ischaemic colitis
K55.9	Ischaemic colitis NOS
K55.9	Ischaemic enteritis NOS
K55.9	Ischaemic enterocolitis NOS
K72.9	Liver Failure
K72.9	Liver Failure - chronic
K72.9	Hepatic failure, unspecified
K74.6	Other and unspecified cirrhosis of liver
K74.6	Cirrhosis (of liver) NOS
K74.6	Cirrhosis (of liver) cryptogenic
K74.6	Cirrhosis (of liver) macronodular
K74.6	Cirrhosis (of liver) micronodular
K74.6	Cirrhosis (of liver) mixed type
K74.6	Cirrhosis (of liver) portal
K74.6	Cirrhosis (of liver) postnecrotic
M31.1	Thrombotic microangiopathy
M31.1	Thrombotic thrombocytopenic purpura
M8824/1	Myofibromatosis - Locally Invasive
M9401/3	Astrocytoma - anaplastic
N11.9	Chronic tubulo-interstitial nephritis, unspecified
N11.9	Chronic interstitial nephritis NOS

N17	Renal failure - end stage
N18	Chronic renal failure
N18.0	Renal Failure - dialysis
N18.0	End-stage renal disease
N18.9	Chronic renal failure, unspecified
N19	Unspecified renal failure
N19	Uraemia NOS
P10.1	Cerebral haemorrhage due to birth injury
P11.2	Unspecified brain damage due to birth injury
P20.0	Intrauterine hypoxia first noted before onset of labour
P20.1	Intrauterine hypoxia first noted during labour and delivery
P21.0	Severe birth asphyxia
P21.0	Pulse less than 100 per minute at birth and falling or steady, respiration absent or gasping, colour poor, tone absent.
P21.0	Asphyxia with 1-minute Apgar score 0-3
P21.0	White asphyxia
P21.9	Birth asphyxia, unspecified
P21.9	Anoxia NOS
P21.9	Asphyxia NOS
P21.9	Hypoxia NOS
P27.1	Bronchopulmonary dysplasia originating in the perinatal period
P27.9	Unspecified chronic respiratory disease originating in the perinatal period
P28.0	Primary atelectasis of newborn
P28.0	Primary failure to expand terminal respiratory units
P28.0	Pulmonary hypoplasia associated with short gestation
P28.0	Pulmonary immaturity NOS
P28.5	Respiratory failure of newborn
P29.0	Neonatal cardiac failure
P29.3	Persistent fetal circulation
P29.3	Pulmonary hypertension of newborn (persistent)
P35.1	Cytomegalovirus infection - congenital

P52.3	Unspecified intraventricular (nontraumatic) haemorrhage of fetus and newborn
P52.4	Intracerebral (nontraumatic) haemorrhage of fetus and newborn
P52.5	Subarachnoid (nontraumatic) haemorrhage of fetus and newborn
P52.9	Intracranial (nontraumatic) haemorrhage of fetus and newborn, unspecified
P78.8	Other specified perinatal digestive system disorders
P78.8	Congenital cirrhosis (of liver)
P83.2	Hydrops fetalis not due to haemolytic disease
P83.2	Hydrops fetalis NOS
P91.2	Periventricular Leukomalacia / PVL
P91.6	Hypoxic brain damage
P91.6	Hypoxic ischaemic encephalopathy/HIE - grade 1
P91.6	Hypoxic ischaemic encephalopathy/HIE - grade 3
P96.0	Congenital renal failure
P96.0	Uraemia of newborn
P96.8	Other specified conditions originating in the perinatal period
Q00.0	Anencephaly
Q00.0	Acephaly
Q00.0	Acrania
Q00.0	Amyelencephaly
Q00.0	Hemianencephaly
Q00.0	Hemicephaly
Q02	Microcephaly
Q02	Hydromicrocephaly
Q02	Micrencephalon
Q03.1	Dandy Walker Syndrome
Q03.9	Congenital hydrocephalus, unspecified
Q04.0	Corpus callosum - absent/agenesis
Q04.0	Congenital malformations of corpus callosum
Q04.0	Agenesis of corpus callosum
Q04.2	Holoprosencephaly

Q04.3	Other reduction deformities of brain
Q04.3	Absence of part of brain
Q04.3	Agenesis of part of brain
Q04.3	Aplasia of part of brain
Q04.3	Hypoplasia of part of brain
Q04.3	Agyria
Q04.3	Hydranencephaly
Q04.3	Lissencephaly
Q04.3	Microgyria
Q04.3	Pachygyria
Q04.4	Septo-optic dysplasia
Q04.6	Suprasellar Arachnoid Cyst
Q04.9	Congenital malformation of brain, unspecified
Q04.9	Congenital anomaly NOS of brain
Q04.9	Congenital deformity NOS of brain
Q04.9	Congenital disease or lesion NOS of brain
Q04.9	Congenital multiple anomalies NOS of brain
Q05	Myelomeningocele
Q07.0	Arnold Chiari Malformation - type 1
Q07.0	Arnold Chiari Malformation - type 2
Q07.0	Arnold Chiari Malformation - type 3
Q07.0	Arnold Chiari Malformation - type 4
Q20.0	Common arterial trunk
Q20.0	Persistent truncus arteriosus
Q20.3	Discordant ventriculoarterial connection
Q20.3	Dextrotransposition of aorta
Q20.3	Transposition of great vessels (complete)
Q20.4	Double inlet ventricle
Q20.4	Common ventricle
Q20.4	Cor triloculare biatriatum
Q20.4	Single ventricle

Q20.6	Isomerism of atrial appendages
Q20.6	Isomerism of atrial appendages with asplenia or polysplenia
Q21.2	Atrioventricular septal defect
Q21.2	Common atrioventricular canal
Q21.2	Endocardial cushion defect
Q21.2	Ostium primum atrial septal defect (type I)
Q21.3	Tetralogy of Fallot
Q21.3	Ventricular septal defect with pulmonary stenosis or atresia, dextroposition of aorta and hypertrophy of right ventricle.
Q21.8	Other congenital malformations of cardiac septa
Q21.8	Eisenmenger's defect
Q21.8	Pentalogy of Fallot
Q22.4	Tricuspid Atresia
Q22.5	Ebstein's anomaly
Q22.6	Hypoplastic right heart syndrome
Q23.0	Congenital stenosis of aortic valve
Q23.0	Congenital aortic atresia
Q23.0	Congenital aortic stenosis
Q23.2	Congenital mitral stenosis
Q23.2	Congenital mitral atresia
Q23.4	Hypoplastic left heart syndrome
Q23.4	Atresia, or marked hypoplasia of aortic orifice or valve, with hypoplasia of ascending aorta and defective development of left ventricle (with mitral valve stenosis or atresia).
Q23.9	Congenital malformation of aortic and mitral valves, unspecified
Q24.0	Dextrocardia
Q24.5	Anomalous coronary artery
Q25.1	Co-arcuation aorta
Q25.4	Absence of aorta
Q25.4	Aplasia of aorta
Q25.4	Congenital aneurysm of aorta
Q25.4	Congenital dilatation of aorta

Q25.4	Aneurysm of sinus of Valsalva (ruptured)
Q25.4	Double aortic arch [vascular ring of aorta]
Q25.4	Hypoplasia of aorta
Q25.4	persistant convolutions of aortic arch
Q25.4	Persistent right aortic arch
Q25.5	Atresia of pulmonary artery
Q25.6	Stenosis of pulmonary artery
Q26.2	Total anomalous pulmonary venous connection
Q26.4	Anomalous pulmonary venous connection, unspecified
Q26.8	Other congenital malformations of great veins
Q26.8	Absence of vena cava (inferior)(superior)
Q26.8	Azygos continuation of inferior vena cava
Q26.8	Persistent left posterior cardinal vein
Q26.8	Scimitar syndrome
Q27.9	Congenital malformation of peripheral vascular system, unspecified
Q27.9	Anomaly of artery or vein NOS
Q32.1	Atresia of trachea
Q32.1	Congenital stenosis of trachea
Q33.6	Hypoplasia and dysplasia of lung
Q39.8	Absent oesophagus
Q41.0	Duodenal Atresia
Q41.9	Congenital absence, atresia and stenosis of small intestine, part unspecified
Q41.9	Congenital absence, atresia and stenosis of intestine NOS
Q44.7	Congenital absence of liver
Q61.4	Renal Dysplasia
Q61.9	Cystic kidney disease, unspecified
Q61.9	Meckel-Gruber syndrome
Q77.2	Short rib syndrome
Q77.2	Asphyxiating thoracic dysplasia [Jeune]
Q79.2	Exomphalos

Q79.2	Omphalocele
Q79.3	Gastroschisis
Q81	Dystrophic Epidermolysis Bullosa
Q81	Epidermolysis Bullosa
Q81	Epidermolysis Bullosa - junctional
Q81	Epidermolysis Bullosa - Herlitz's junctional
Q82.1	Xeroderma pigmentosum
Q82.4	Ectodermal Dysplasia
Q86.0	Foetal Alcohol Syndrome
Q87.0	Pierre Robin Syndrome
Q87.0	Acrocephalopolysyndactyly
Q87.0	Acrocephalosyndactyly [Apert]
Q87.0	Cryptophthalmos syndrome
Q87.0	Cyclopia
Q87.0	Goldenhar syndrome
Q87.0	Moebius syndrome
Q87.0	oro-facial-digital syndrome
Q87.0	Robin syndrome
Q87.0	Whistling face
Q87.1	Cornelia de Lange Syndrome
Q87.1	Aarskog syndrome
Q87.1	Cockayne syndrome
Q87.1	De Lange syndrome
Q87.1	Dubowitz syndrome
Q87.1	Robinow-Silverman-Smith syndrome
Q87.1	Russell-Silver syndrome
Q87.1	Seckel syndrome
Q87.1	Smith-Lemli-Opitz syndrome
Q87.8	Alport syndrome
Q87.8	Laurence-Moon(-Bardet)-Biedl syndrome
Q87.8	Zellweger syndrome

Q90.9	Chromosomal abnormality - Trisomy 21/Down's Syndrome
Q90.9	Down's syndrome, unspecified
Q90.9	Trisomy 21 NOS
Q91.3	Edwards Syndrome - Trisomy 18
Q91.3	Edwards' syndrome, unspecified
Q91.7	Patau Syndrome
Q91.7	Patau's syndrome, unspecified
Q92	Chromosomal abnormality - Trisomy 22
Q92	Chromosomal abnormality - Trisomy 9
Q92.4	Chromosomal abnormality - Duplication of X chromosome
Q92.8	Other specified trisomies and partial trisomies of autosomes
Q93.3	Deletion of short arm of chromosome 4
Q93.3	Wolff-Hirschorn syndrome
Q93.4	Deletion of short arm of chromosome 5
Q93.4	Cri-du-chat syndrome
Q93.5	Jacobsen Syndrome (11q deletion)
Q93.5	Angelman syndrome
Q93.8	William's Syndrome
T86.0	Chronic Graft vs Host Disease /chronic GVHD
T86.0	Bone marrow failure

Appendix 4: Mapping Paper

ACT and Children's Hospice UK Children's Palliative Care Mapping Initiative Making Life Limited Children Count

New definitions of children that may have palliative care needs

Summary

As a result of the work of the ACT and Children's Hospices UK children's palliative care mapping initiative, definitions of children who may have palliative care needs have been revised. The overarching definition of children's palliative care, and the four ACT groups remain unchanged. However a new "Rainbow of Children's Palliative Care Needs" is proposed. This identifies children who may have palliative care needs at different stages of their illness journey. This article outlines how the new "Rainbow of Children's Palliative Care needs" and supporting definitions, were developed and the next stages in the validation process.

ACT Groups of children who may require palliative care (2009)

Group 1	Life-threatening conditions for which curative treatment may be feasible but can fail. Where access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life. On reaching long term remission or following successful curative treatment there is no longer a need for palliative care services. e.g. cancer, irreversible organ failure of heart, liver, kidney.
Group 2	Conditions where premature death is inevitable, where there may be long periods of intensive treatment, aimed at prolonging life and allowing participation in normal activities. e.g. cystic fibrosis, Duchenne muscular dystrophy.
Group 3	Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. e.g. Batten disease, mucopolysaccharidoses
Group 4	Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. e.g. severe cerebral palsy, multiple disabilities such as following severe brain or spinal cord injury, complex healthcare needs and a high risk of an unpredictable life-threatening event or episode.

Background

Collection of the ACT and Children's Hospices UK Children's Palliative Care Minimum Dataset began in Merseyside and Cheshire in 2005. The original aim was to use the standard ACT definition of "life threatening" and "life limiting" conditions to identify those children who may have palliative care needs. However during the earliest stages of awareness-raising for the Minimum Dataset pilot it became clear that there was a need for more robust and unambiguous definitions of children who may have palliative care needs to be adopted across the UK. In particular it became apparent that

- Different teams and services were counting differently
- There was subjectivity and variation within teams and districts

- Wider variations were likely when comparing different areas of UK

It was recognised that there was a need to define more precisely children to be identified through the Minimum Dataset in order to compare figures

- In different areas of country
- Consistently over time

A Delphi study was commissioned to resolve these issues

The Delphi study

The Delphi study comprised two Delphi survey rounds followed by a Delphi consensus building one-day conference.

The Delphi questionnaire was designed to

- Accept and not alter the standard definition of palliative care for children
- Review definitions for
 - Life threatening condition
 - Life limiting condition
- Enable greater precision with regard to
 - Age
 - Meaning of key words and phrases
- Evaluate alternative methods for identifying children with palliative care needs

Analysis of rounds 1 and 2 of the Delphi study identified areas of broad agreement but also highlighted significant areas of dissension and concern. The results from rounds 1 and 2 were therefore used as the basis for discussion for a Delphi workshop. This was followed by a stepwise discussion evaluating potential methods for identifying children with palliative care needs:

Fundamental principles

It was recognised that palliative care is different to other long term conditions as palliative care implies an increased risk of dying compared with the general population.

Palliative and end of life care

It was agreed that the term “End of life care” should be used to describe care during the last hours and days of life: anyone who dies may require end of life care. End of life care falls into the spectrum of palliative care, however not all end of life care is provided by palliative care services

Children with palliative care needs

It was agreed that the aim of the Delphi work was to define and hence facilitate identification of children with palliative care needs. Scope of children’s palliative care extends from antenatal diagnosis or recognition, through childhood and adolescence to end of life. Definitions of adulthood vary across the UK and worldwide. It was decided to keep to the proposed diagnosis or recognition before the child’s 18th birthday

Palliative care and transition

Two groups of young people with palliative care needs were recognised: “survivors” who are diagnosed in childhood and live unexpectedly into adulthood and a “new cohort” of young people who are diagnosed in early adulthood. This latter group are not normally eligible for children’s hospice or paediatric palliative medicine. It was acknowledged that the needs of these two groups were not the same and that recognising the needs of these two groups was extremely important. However it was agreed that this work was beyond the immediate scope of the Delphi study.

The options for identifying children with palliative care needs were then explored in more detail

- Prognosis

This was the original approach taken in Delphi study. However consensus decreased on the second round and there were significant numbers of conflicting responses. It was recognised that palliative care needs do not necessarily increase proportionately as prognosis decreases. A number of respondents also commented on “an over emphasis on life expectancy and a medical (disease based) model”

The group acknowledged that prognostication and predicting dying or end of life is difficult and that “None of us can accurately predict the future”.

Although accuracy of prognosis improves with nearness to end of life, and when a multi-professional approach is used, delegates felt that using prognosis to identify children with palliative care needs for the purposes of the Minimum Dataset was inappropriate and potentially misleading. Statistics and survival curves apply only to populations, furthermore many of our children have rare disorders or a combination of conditions for which no accurate prognostic information is available. Finally professionals are often reluctant to give a poor prognosis and reluctant to label or identify children as “palliative”

- ACT groups

Current wording of the ACT groups was modified for the 2009 revision of the ACT Guide to the Development of Children’s Palliative Care Services to take into account ambiguities recognised through early discussions of definitions of children’s palliative care in 2008 – 2009. Specifically that:

- Children in Group 1 are all those diagnosed or recognised (not just those where curative treatment has failed).
- The reference is to curative treatment that has failed, not that the treatment itself is necessarily life-threatening.

The group concluded that the ACT group provides a useful descriptor of the child’s anticipated journey. The ACT groups also illustrate the scope of palliative care for children. This is particularly important to enhance understanding for non-specialists. Ideally the relevant ACT group would be identified from the point of diagnosis or recognition of possible palliative care needs. However the situation and the relevant ACT group may change as the child’s condition progresses. For some children with complex and multiple pathologies or rare conditions it may not be possible to identify a specific ACT group.

When applied to a cohort of children who have died, identification of one or more relevant ACT groups is likely to signify probable palliative care needs, and certainly end of life care needs. However identification of one or more relevant ACT groups only signifies possible palliative care needs when applied to a cohort of children who are currently living. Additional information is needed to identify children with active palliative care needs. Furthermore there are large numbers of children in groups 4, 1 and to a lesser extent group 2, who may have palliative care needs around the time of diagnosis or recognition but then do not have active palliative care needs for many years. Finally being able to identify one or more relevant ACT groups does not necessarily imply that the current range of palliative care services is the most appropriate services to support an individual child

- The “surprise” question

The surprise question: “Would you be surprised if the child died within a specified period of time?” is an approach adopted by the Adult Gold Standards Framework¹. The group recognised that professionals are generally more comfortable with the genuine degree of uncertainty implicit in “not being surprised” if a child died rather than “expecting” a child to

¹ Gold Standards Framework

die. It is appropriately less threatening to talk about and plan for a possibility rather than a certainty. With this in mind the group felt that asking for consent for registration of potential palliative care needs would be less threatening if the “surprise question” was the basis of identifying children with potential palliative care needs. However the group recognised the greater level of certainty required for a written versus a verbal statement of potential palliative care needs.

The main criticism of the “surprise question” is its subjectivity. However, for a significant proportion of children, there is no accurate prognostic information and any response to the “surprise question” is not necessarily any more subjective than other estimates. There is potential to improve the accuracy of the response to the “surprise question” through a multiprofessional approach. Accuracy should also improve with familiarity with child and experience over time

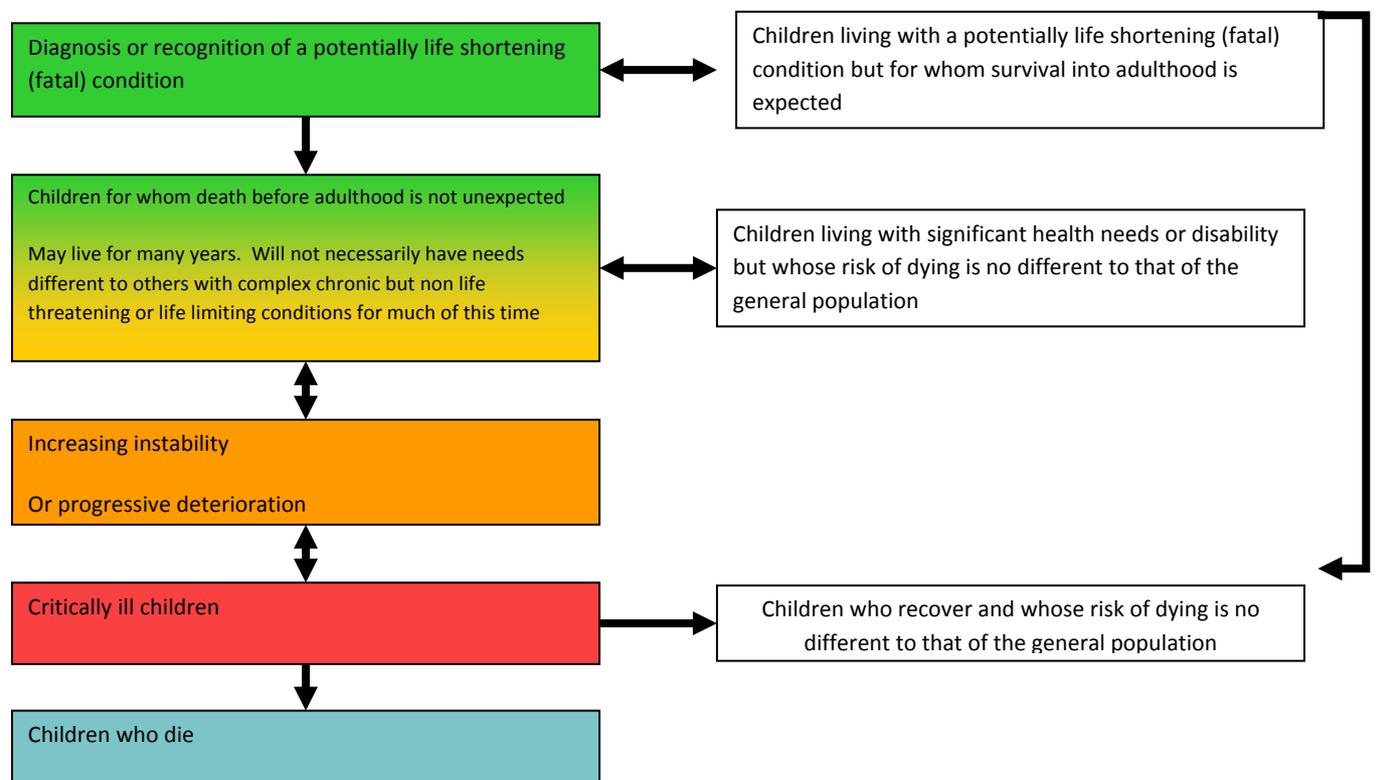
A rainbow of children’s palliative care needs

The use of colour groupings to describe different stages in the illness journey and types of palliative care need has been used before:

- Gold Standards Framework (adults and children)
- Colours of Life (N. Harris et al)
- Classification of children and young adults with life threatening and life limiting conditions (ACT 2009)

The group considered the use of colour groupings in conjunction with the “surprise question” to describe different groups of children who may have palliative care needs. The results are shown diagrammatically as a “rainbow of children’s palliative care needs”

Figure 1: A Rainbow of Childrne’s Palliative Care Needs



In order to support this model a range of possible “surprise questions” was proposed. The relevant surprise question may be different for different stages in illness journey or different types of conditions. There is potential to use “Would you be surprised if the child was alive in X amount of time?” for last few hours and days. Even when estimates prove subsequently to be inaccurate the strength of this approach is that it indicates “perceived” needs at that time and appropriate actions such as advance care planning to meet those perceived needs. A similar approach could be used for young people’s palliative care. There is also the potential for retrospectively reviewing accuracy and improving prognostication. The a series of “surprise questions were proposed in order to support the Rainbow of children’s palliative care needs

The revised definitions

Diagnosis or recognition before the child’s 18th birthday of a potentially life shortening (fatal condition) condition

- “Would you be surprised if this child died as a result of this condition or problem?”
- It is anticipated that diagnosis or recognition will facilitate identification of one or more relevant ACT groups

Death before adulthood is not unexpected

- “Would you be surprised if this child died before adulthood (18th birthday)?”

Children with Increasingly instability

- “Would you be surprised if this child died in the next few months to years?” Or “Would you be surprised if this child died in the next five years?”

Children experiencing Critical illness or end of life care

- “Would you be surprised if this child was alive in a few weeks time?”

Next steps

National consultation in order to raise awareness and explore the implications of the definitions

Consensus building for the definitions to be adopted to support children’s palliative care data collection

Formal validation of the definitions in terms of reliability and reproducibility of identifying children with potential palliative care needs

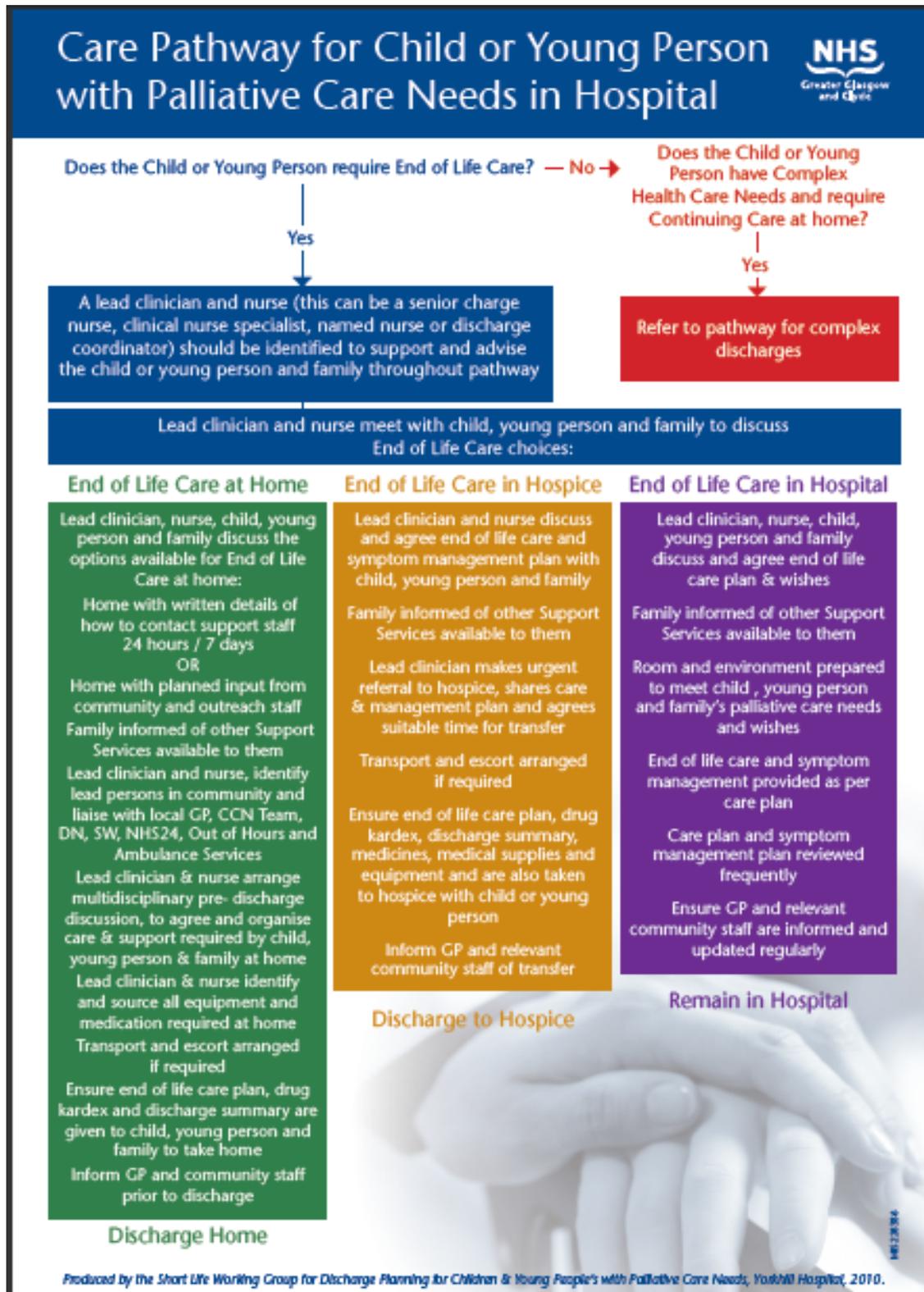
Lynda Brook, Chris Kerr and Sheila Hawker Sept 2010

Appendix 5: CHSW Dependency Assessment Tool

CHSW FAMILY DEPENDENCY ASSESSMENT TOOL			
DEPENDENCY DESCRIPTOR	DEPENDENCY SCORE		
Number of parents involved	HIGH	MED	LOW
Lone parent			
Two parents			
Parents with new partners			
Total number of children in family, including child with disability.	HIGH	MED	LOW
Up to 2			
3 – 4			
5 and above			
Number of children in family with a disability	HIGH	MED	LOW
1			
2 and above			
Does child's carer have physical health problems	HIGH	MED	LOW
No			
Yes, but does not impact on ability to care for child			
Yes, and does impact on ability to care for child			
Does child's carer have mental health problems	HIGH	MED	LOW
No			
Yes, but condition stable			
Yes, and condition unstable			
Does child's carer have a learning disability	HIGH	MED	LOW
No			
Yes			
Is there drug or alcohol dependency in the family	HIGH	MED	LOW
No			
Yes			
Are there social 'at risk' factors in the family	HIGH	MED	LOW
Child on 'at risk' register			
Child is 'in care'			
Are there any language/literacy issues	HIGH	MED	LOW
No			
Yes			
Does family receive respite support (other than Hospice)	HIGH	MED	LOW
No			
Yes			
OVERALL DEPENDENCY RATING	HIGH	MED	LOW
Number in each dependency category			
Overall dependency rating, (high, medium or low)			

Any one 'high' score gives an overall rating of HIGH
Two or more 'medium' scores give an overall rating of MEDIUM
Up to one 'medium' gives an overall rating of LOW

Appendix6: Scottish Care Pathway



Appendix 7: The Jessie May Trust Framework for Respite in Partnership with Parents and Carers (FRIPP)

The framework is used by the Trust in partnership with parents to help to work out how many hours of respite can be offered. The Jessie May Trust (JMT) and parents use the FRIPP chart as a guide when completing a care agreement to look at family respite needs. Together (the parent and JMT) they then use an allocation table to work out a “score” which is then converted into hours of respite care. Extra points are given if a temporary situation arises such as illness, pregnancy or other situations arising within the family life. Enabling an adjustment of hours offered. The age and health of siblings is taken into account here, how much attention they need and how the care needs of the child affects them.

The Care Agreement is regularly reviewed (minimum annually). This gives families a regular opportunity to discuss whether the service is meeting their needs. Although the date for next review may be preset, families are encouraged to contact JMT to discuss changes in circumstances and bring forward a review of the Care Agreement or negotiate a short-term change in service provision.

Overview of the factors and scores shown on the FRIPP framework

Factor	High (6 – 8)	Medium (3 –5)	Low (0 – 2)
Nursing care needs	Care of intravenous infusions Total Parenteral Nutrition Ventilated child	“Technical” support e.g. tracheostomy, gastrostomy or nasogastric feeding. Oxygen and suction Hoisting and/or problems due to weight and lack of mobility Time consuming medication regimes, nebulisers, physio	Dependent on carers for hygiene, feeding etc.
Supervision required on a day to day basis	Constant monitoring required due to age, health needs or behaviour	Frequent monitoring required	Regular monitoring – can be left for short periods in a safe area for that child.
Family’s perceived needs:			
Support	Unsupported main carer	Some family, social or statutory support	Supported by family, social network and/ or statutory services
Crisis	Significant illness of main carer(s) or other family members. Major life event e.g. house move, relationship breakdown, change to child’s care needs (e.g. application of hip spica). Emotional needs in the aftermath of stressful times.	Severe family problems requiring extra support. New equipment or care needs for the child where temporary extra support required.	Extra support needed.
Siblings	Siblings with chronic disability or illness or with acute illness or other problems.	Siblings needing attention due to age, health or behaviour.	Older siblings or siblings needing less parental attention.
Overall stability of child	Unstable	Potentially unstable	Stable

Framework for Respite in Partnership with Parents : allocation chart example

<i>Name</i>	<i>Date of birth</i>														
	<table border="1"> <thead> <tr> <th><i>Factors taken into account</i></th> <th><i>Score</i></th> </tr> </thead> <tbody> <tr> <td><i>Nursing care needs</i> Time-consuming feeding Often vomits, leading to large amounts of washing Often constipated, difficult to manage constipation.</td> <td style="text-align: center;">5</td> </tr> <tr> <td><i>Supervision</i> Frequent supervision needed due to epileptic seizures</td> <td style="text-align: center;">3</td> </tr> <tr> <td><i>Family's perceived needs</i> No statutory support but both parents are at home as carers. Stress related to managing feeding and washing. Two school age siblings</td> <td style="text-align: center;">5 2 2</td> </tr> <tr> <td><i>Overall stability</i> Potentially unstable, prone to chest infections</td> <td style="text-align: center;">4</td> </tr> <tr> <td><i>Extra points allocated</i> Not attending school due to health problems</td> <td style="text-align: center;">5</td> </tr> <tr> <td style="text-align: center;">Total</td> <td style="text-align: center;">26</td> </tr> </tbody> </table>	<i>Factors taken into account</i>	<i>Score</i>	<i>Nursing care needs</i> Time-consuming feeding Often vomits, leading to large amounts of washing Often constipated, difficult to manage constipation.	5	<i>Supervision</i> Frequent supervision needed due to epileptic seizures	3	<i>Family's perceived needs</i> No statutory support but both parents are at home as carers. Stress related to managing feeding and washing. Two school age siblings	5 2 2	<i>Overall stability</i> Potentially unstable, prone to chest infections	4	<i>Extra points allocated</i> Not attending school due to health problems	5	Total	26
<i>Factors taken into account</i>	<i>Score</i>														
<i>Nursing care needs</i> Time-consuming feeding Often vomits, leading to large amounts of washing Often constipated, difficult to manage constipation.	5														
<i>Supervision</i> Frequent supervision needed due to epileptic seizures	3														
<i>Family's perceived needs</i> No statutory support but both parents are at home as carers. Stress related to managing feeding and washing. Two school age siblings	5 2 2														
<i>Overall stability</i> Potentially unstable, prone to chest infections	4														
<i>Extra points allocated</i> Not attending school due to health problems	5														
Total	26														
<i>Visits allocated to family</i> One visit of up to three hours a fortnight.															

The team at The Jessie May Trust has had experience over several years of allocating respite care following an assessment of the families needs. This experience was used to review the scores and work out the frequency, timing and duration of respite visits which had to date been regarded by families as meeting their needs.

Further details can be obtained from Liz Lewington, Care Team Manager, JMT and Ruth Butcher Care Team Leader JMT

Appendix 8

Useful Additional Resources

ACT (2003) Guide to the Assessment of Children with Life-limiting Conditions and their Families

ACT (2004) Integrated Multi-agency Care Pathways for Children with Life-threatening and Life-limiting Conditions

ACT (2009) A Guide to the Development of Children's Palliative Care Service (3rd Edition)

ACT (2009) Making life-limited children and young people count: A Framework and Guide for Local Implementation

ACT (2011) Children's palliative care handbook for GPs

Department of Health (Jan 2011), PCT cluster implementation guidance

Department of Health (2011), NHS at Home: Community Children's Nursing Services

HM Treasury / Department for Education and Skills (2007), Aiming High for Disabled Children

United Nations (1989), A Child's Right to Care.

Welsh Assembly Government (2010), Setting the Direction

Selected Websites

NB: with current changes to government agencies, many websites are undergoing change. Some are having their contents frozen, but retained, and some are having the content removed and archived over time. The list below is accurate at the time of writing.

ACT	www.act.org.uk
Children's Hospices UK	www.childhospice.org.uk
Commissioning Support Programme	www.commissioningsupport.org.uk
Department for Education	www.education.gov.uk
Department of Health	www.dh.gov.uk
National Transition Support Team	www.transitionssupportprogramme.org.uk http://resources.transitioninfonynetwork.org.uk
Royal College of Paediatrics and Child Health	www.rcpch.ac.uk
Together for Disabled Children	www.togetherfdc.org