



Llywodraeth Cynulliad Cymru  
Welsh Assembly Government

## **All Wales Palliative Care Standards** for Children and Young People's Specialised Healthcare Services



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# Foreword

It gives me great pleasure to introduce this series of documents which set out to address the specific needs of children and young people accessing specialised healthcare services in Wales and will form the foundation for the establishment of managed clinical networks to deliver these services.

The development of this document is thanks to an enormous amount of work by clinicians, service commissioners, service providers, healthcare professionals, voluntary organisations, parents and our children and young people and I would like to express my thanks to all those involved.

These documents will build on the important improvements already underway following the publication of the Children's National Service Framework in 2005 in delivering the best services for the children and young people of Wales. The Welsh Assembly Government continues to believe that the best investment we can make in the future is ensuring that high quality and equitable services are provided for our children and young people.



**Edwina Hart AM, MBE**  
**Minister for Health and Social Services**



# Children and Young People's Specialised Services

## Introduction

In 2002, the Specialised Health Service Commission for Wales undertook a review of specialised healthcare services for the children and young people of Wales, which identified that these services were being delivered in an ad hoc and fragmented way.<sup>1, 2</sup> Following this review, the Minister for Health and Social Services announced that Managed Clinical Networks (MCNs) would be developed to deliver specialised healthcare services for children and young people.<sup>3</sup>

The Children and Young People's Specialised Services Project (CYPSSP) was established by the Welsh Assembly Government (WAG) to take this work forward. The project's remit was to:

*Develop high quality, equitable and sustainable specialised children's health services across Wales based upon the best available evidence and with children and their carers at the centre of all planning and provision.*

This would be achieved by the following aims:

- To develop service specific standards for specialised healthcare services for the children and young people of Wales
- To enable equity of access through effective managed clinical network models for all children and young people in Wales requiring specialised services.

The agreed specialised services for the project are:

- Paediatric Critical Care (standards already published)
- Neonatal Services
- Paediatric Neurosciences
  - Neurosurgery
  - Neurology
  - Neurodisability
- Paediatric Oncology
- Paediatric Palliative Care
- Paediatric Specialist Anaesthetics and Surgery
  - Anaesthetics
  - General surgery
  - Trauma and Orthopaedics
  - Ear, Nose and Throat

- Ophthalmology
- Plastic Surgery
- Burns
- Maxillofacial
- Cleft Lip and Palate
- Nephrology
- Cardiology and Congenital Cardiac Services (and access to Cardiac Surgery)
- Endocrinology
- Gastroenterology, Hepatology and Nutrition
- Inherited Metabolic Disease
- Respiratory

## The Standards Documents

This document is one of a series of standards for specialised services for children and young people, which were issued for consultation between 2005 and 2008. The standards and key actions in this document are written from an all Wales perspective and therefore apply to all children and young people with this particular health need, wherever they live in Wales.<sup>4, 5, 6</sup>

There is also a Universal Standards document which contains key actions (KAs) that apply to all specialised services for children and young people. This document was initially consulted on in 2005; however it has continued to evolve, as further “universal” key actions have been identified during the development of the service specific standards. The Universal Standards should be read and used in conjunction with each of the service specific standards documents and can be accessed electronically on the CYPSSP website ([www.wales.nhs.uk/cypss](http://www.wales.nhs.uk/cypss)).

The CYPSSP standards should also be read and used in conjunction with the National Service Framework for Children, Young People and Maternity Services in Wales (Children’s NSF),<sup>7</sup> in particular Chapter 2, “Key actions universal to all children” which is relevant to all services and all children and young people.

The standards and key actions within the CYPSSP documents apply to all children and young people accessing the specific specialised service who are between the ages of 0-18 years of age. However, key actions that relate to transition apply to all young people who may require ongoing services beyond this age range. The age for transition to adult services must be flexible to ensure that all young people are treated by the most appropriate professional and in the most appropriate setting. This will depend on the young person’s mental, emotional and physical development.

## Purpose of standards

The standards and their key actions have been developed to provide a basis for service commissioners and providers to plan and deliver effective services.<sup>8,9</sup> They are to be used to benchmark current services and inform the development of future services to meet the specialised health needs of children and young people across Wales.<sup>10</sup>

## Developing the standards

An External Working Group (EWG) representative of key stakeholders has developed the standards for each service. Membership details can be found in Appendix 1 of the service specific standards documents.

The contribution made by EWG members is greatly appreciated. We are particularly grateful to the children, young people and parents who have been involved in the development of this work.<sup>11,12</sup>

The standards have been Quality Assured by a Project Steering Group comprised of strategic stakeholders, details of which are included as Appendix 2.

The standards have also been mapped against the Welsh Assembly Government's Healthcare Standards.<sup>13</sup> The Healthcare Standards for Wales set out the Welsh Assembly Government's common framework of healthcare standards to support the NHS and partner organisations in providing effective, timely and quality services across all healthcare settings. There are thirty-two Healthcare Standards covering four domains; The Patient Experience, Clinical Outcomes, Healthcare Governance and Public Health. These are designed to deliver the improved levels of care and treatment the people of Wales have a right to reasonably expect. The standards will be taken into account by those providing healthcare, regardless of the setting. Examples of how the healthcare standards relate to the CYPSSP standards are referenced at the end of each section.

The Healthcare Standards are used by Healthcare Inspectorate Wales as part of its process for assessing the quality, safety and effectiveness of healthcare providers and commissioners across Wales.

Since the CYPSSP commenced in 2003, three project managers have successfully managed and facilitated the development of the standards documents. We would like to extend our grateful thanks to all of the Project Managers, namely Eiri Jones, Sian Thomas and Mary Francis for their contribution to this work.

## Delivering the standards

Some of the key actions can be delivered within a year; however due to workforce and financial constraints others will take a number of years to achieve. Thus each key action has a timescale for delivery between one and ten years.

Every attempt has been made to ensure that the key actions are clear and measurable. However when terms that cannot be measured such as ‘timely’ and ‘appropriate’ have been used it will be for the specific MCN to agree on the acceptable definition of the term. This will allow each standard and key action to reflect the particular needs of each individual specialist service.

Whenever ‘children’ are referred to in this document it should be accepted that this also includes young people. Reference to “parents” includes mothers, fathers, carers and other adults with responsibility for caring for the children.

The standards within this document are based on the current configuration of the NHS. A recent consultation document ‘Proposal to Change the Structure of the NHS in Wales’<sup>14</sup> issued by the Welsh Assembly Government in April 2008, outlines a possible new structure for the NHS in Wales, which could impact on the key actions, specifically the responsible organisations for their delivery. Therefore, it should be understood that if the current responsibilities are transferred to another organisation, then they will then become responsible for delivery of the key actions. These Standards will continue to be enforceable subject to any changes to the structure of the NHS in Wales.

## Monitoring the standards

Standards will be monitored and audited annually as part of the MCN arrangements and will include audit of training, practice and compliance with pathways, protocols and agreed outcomes.

## Managed Clinical Networks (MCNs)

Children and young people accessing specialised services in Wales inevitably experience different patterns of care depending on the geography and population characteristics that impact on service provision in their locality. However it is crucial that although the pattern of care provided may differ, the standard of care provided does not. Developing MCNs is a way of ensuring that all Welsh children and young people receive equitable and high quality specialised services wherever they live in Wales.

MCNs can be defined as:

*“Linked groups of health professionals from primary, secondary and/or specialist care, working in a co-ordinated manner, unconstrained by existing organisational boundaries, to ensure equitable provision of high quality and clinically effective services.”<sup>15</sup>*

Through the formal establishment of MCNs, children and young people in Wales requiring specialised healthcare will access services in accordance with the following principle:

*Age appropriate, safe and effective (high quality) care delivered as locally as possible, rather than local care delivered as safely and effectively as possible.*<sup>16</sup>

An MCN is comprised of a number of disciplines working together in a co-ordinated, non-hierarchical manner, unconstrained by professional and organisational boundaries. As a result of this collaborative mechanism, MCNs aim to facilitate and promote equitable, quality services through the provision of seamless care.

Many disciplines already work in an informal professional network. However this is not the case across all professions and health sectors. MCNs provide a co-ordinated and managed structure, integral to which are agreed protocols and pathways of care, clinical audit, training and continuing professional development.

It should be acknowledged that a child or young person might need to access more than one of the CYPSSP speciality services. The MCN framework and structures for each speciality should ensure flexibility to work together to meet the needs of the child and the delivery of appropriate seamless care.

## Dental Care

Dental care is a service that has not been addressed separately. It is important to recognise that oral healthcare is a significant consideration for all children and young people and, because of their medical conditions, many of the children and young people requiring specialised healthcare services may:

- be at higher risk of oral disease and oral complications
- be at higher risk when treated for oral disease e.g. children with respiratory disorders requiring general anaesthetics and children who have had cardiac surgery
- have particular problems that make the management of their dental treatment difficult, e.g. there may be associated learning disabilities.

Prevention of oral and dental disease is therefore highly desirable for this group of children and thus preventative oral healthcare advice should be part of every child's overall care plan so that families and carers are well informed as to the specific risks for each child. Specific oral assessment and care should also be available where appropriate.

To facilitate this it is essential that the dental team is considered an integral part of the multidisciplinary approach advocated throughout this project and there should be a named dentist with specialised skills and knowledge in the oral healthcare of children e.g. a Specialist in Paediatric Dentistry linked to each large District General Hospital (DGH) to provide support and advice to the broader teams and ensure referral of children for appropriate healthcare.

## Palliative Care Services for Children in Wales

Palliative care can be defined as the care of a child or young person when their therapy is no longer curative. The care is physical, social, emotional and spiritual. The Palliative Care EWG members (Appendix 1) believe that all professionals working with children and young people should have an understanding of this field of practice and their role within it. When professionals are involved in delivering Palliative Care, they should be able to demonstrate expertise in this field of practice.

The palliative care needs of children and young people differ from adult services. In fact, children and young people can require palliative care for a number of conditions.<sup>17</sup> Many children can require palliative care for a significant period of time before it becomes an end of life stage. These standards are therefore aimed at children and young people who require palliative care irrespective of their diagnosis.

There is a significant interface with other specialised services, in particular:

- Oncology
- Neurosciences
- Nephrology
- Cardiology
- Neonatal
- Respiratory
- Inherited Metabolic Disease
- Endocrine

Standards documents from these services may therefore apply here.

The evidence base for this service remains under-developed, however, key documents have helped inform the development of these standards, including:

- National Institute of Clinical Excellence (NICE) Improving Outcomes in Children and Young People with Cancer<sup>16</sup>
- Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) and Royal College of Paediatrics and Child Health (RCPCH)<sup>17</sup>
- Palliative Care Services in Wales Review<sup>18</sup>
- A Strategic Direction for Palliative Care Services in Wales<sup>19</sup>
- Continuing Care Guidance<sup>20</sup>
- Palliative Care Handbook<sup>21</sup>
- Paediatric Palliative Care - Position Statement<sup>22</sup>

## **Current Service Model**

### **South and Mid Wales**

Palliative care services for children and young people varies greatly from Local Health Board (LHB) area to LHB area.<sup>18</sup> Very little local service is commissioned though there are some exemplars of good practice developed from within the current secondary care/ community child health services.

Ty Hafan children's hospice provides care to some of this population group. Hope House hospice also provides care for families in Mid Wales.

There is an All Wales Lead Clinician post based at Cardiff and Vale NHS Trust. This post is a half time academic post.

### **North Wales**

Whilst the South and Mid Wales lead clinician is defined as an All Wales service provider, some support is provided by a lead clinician at the Royal Liverpool Children's Hospital (RLCH). This service, however, is not currently commissioned.

CLIC (Cancer and Leukaemia in Children) nurses provide some level of local services, as do the Diana nurses. Both these services are under resourced for the demand placed upon them.

Ty Gobaith children's hospice provides care to some of the children of North Wales. As with the South Wales hospice, it is mainly funded through charitable donations.

## **Proposed Service Model (Appendix 4)**

Palliative Care services for the children of Wales need to be commissioned on an All Wales basis at both local and specialist level.<sup>19</sup>

The key requirements of an effective palliative care service as outlined in the NICE guidance<sup>16</sup> are as follows:

### **Core Elements of Palliative Care**<sup>16</sup>(Table 3, p 82)

- Timely and open communication and information
- Choices/Options in all aspects of care, including complementary therapies
- Death in the place of choice
- Co-ordination of services at home, where this is the chosen place of care
- Expert symptom management
- Access to 24 hour specialist advice and expertise
- Emotional and practical support for all family members
- Respite care, with medical and nursing input, when required.

### **South and Mid Wales**

Palliative care services are delivered locally through a community children's nursing service supported by a paediatrician with an interest in palliative care.

Specialist support is provided by the lead centre multi-disciplinary team (MDT) in Cardiff and Vale NHS Trust with recommendations for an All Wales paediatric palliative care nurse consultant post.

Access to hospice care is readily available when required.

### **North Wales**

Palliative care services are delivered locally through a community children's nursing service supported by a paediatrician with an interest in palliative care.

Specialist support is provided from the lead centre in RLCH with access to hospice care when required.

Both lead centres work in partnership to provide an All Wales service.

## Standard 1: Access to Palliative Care Services

**Rationale:** All children identified as needing to access palliative care have access to high quality, evidence based care provided by appropriately trained multi-professional teams in the most appropriate environment and with as little disruption as possible to the child, young person and family.

### Key Actions:

Key Action	Responsible organisation	Timescales
1.1 Access to palliative care is through the local child health services. <sup>7</sup> <small>KAs 2. 1,2.2</small>	LHBs Trusts	1-3 years
1.2 There are clearly defined referral pathways for local professionals to access advice from specialised palliative care services.	MCN	Less than 1 year
1.3 There are clearly defined referral pathways for children and their families to access local and specialised palliative care services.	MCN	Less than 1 year
1.4 Children and their families who wish to receive palliative/respice care in their own homes can do so. An infrastructure is in place to ensure that home services are clinically safe. <sup>7,20</sup>	LHBs Trusts Hospice	1-3 years
1.5 Access to a children's or age appropriate hospice service and or/other residential respice care, away from the child's own homes, is available for those children, young people and families who wish to use this service. <sup>7</sup>	Hospice LHBs HCW Trusts	1-3 years
1.6 Access to local generic symptom control and palliative care skills is available within 48 hours.	Trusts LHBs	Less than 1 year

1.7 Referral is made to specialist palliative care services if symptoms are not relieved after a maximum of 48 hours of intervention. <sup>19</sup>	LHBs Trusts	Less than 1 year
1.8 Telephone advice is available to children and/or their parents 24 hours a day.	Lead Centres	Less than 1 year
1.9 Telephone advice from specialised services is available for primary secondary care professionals 24 hours a day.	Lead Centres	Less than 1 year

Examples of some of the Healthcare Standards for Wales (HCS) that map across to the above standard are HCS 2, 3, 12 and 24.

## Standard 2: Staffing of Palliative Care Services

**Rationale:** Palliative care services are staffed with appropriately trained, multi-disciplinary professionals with access to other resources to ensure that children and young people have no delay in receiving palliative care services.

### Key Actions:

Key Action	Responsible organisation	Timescales
2.1 A fully established, community children's nursing service is in place in every Trust/LHB area. Each local team has the capacity and skills to be responsive to palliative care needs. <sup>7 KA1.1</sup>	LHBs Trusts	4-10 years
2.2 A named paediatrician in each Trust has responsibility for leading local palliative medicine. <sup>KA1.1</sup>	Trusts MCN	Less than 1 year
2.3 An identified professional is in place to co-ordinate the local palliative care team.	LHBs Trusts MCN	1-3 years
2.4 A child psychological assessment is available within 10 working days if required.	Lead Centres Trusts	1-3 years
2.5 A specialist core palliative care team exists for the children of Wales consisting of dedicated sessions. (Appendix 3)	Lead Centres	4-10 years
2.6 Established links are in place for the specialist service to access the relevant support services. (Appendix 3)	HCW LHBs Trusts	1-3 years

2.7 A counselling service is available for children young people and their families and staff both pre and post bereavement.	LHBs Trusts Hospices	1-3 years
2.8 A comprehensive counselling service is available for staff as part of the core palliative care service. <sup>23</sup>	Lead Centres LHBs Trusts Hospices	1-3 years

Examples of some of the Healthcare Standards for Wales (HCS) that map across to the above standard are HCS 2, 24 and 32.

## Standard 3: Facilities for Palliative Care Services (including equipment)

**Rationale:** Appropriate facilities are available to care for children who require palliative care and their families. This will include provision of care in their own home.

### Key Actions:

Key Action	Responsible organisation	Timescales
3.1 IT links are in place to support the all Wales palliative care network. <sup>23,24</sup>	WAG MCN Trusts	4-10 years
3.2 Data on Palliative Care activity is collected to a defined all Wales data set.	MCN	1-3 years
3.3 Further appropriate, needs based residential respite facilities are available away from the child/young person's home. <sup>KA 1.5</sup>	LHBs Trusts	1-3 years
3.4 Equipment is available locally to provide palliative care at home. Local arrangements are in place to ensure rapid access to this essential palliative care equipment. <sup>7</sup>	LHBs Trusts	4-10 years
3.5 All palliative care equipment is standardised and commissioned to meet all Wales quality standards. <sup>7,25</sup>	Lead Centres Trusts LHBs MCN	4-10 years
3.6 Needs led assessment and pooled funding is in place for all children and young people's palliative care equipment needs. <sup>7</sup>	Lead Centres LHBs Trusts	4-10 years

3.7 Access to symptom control medicines is readily available out of hours.	Lead Centres LHBs Trusts MCN	Less than 1 year
3.8 Access to children's BNF is available to all professionals involved in prescribing and/or administration of medicines. <sup>7 KA 2.27</sup>	Lead Centres LHBs Trusts	Less than 1 year

Examples of some of the Healthcare Standards for Wales (HCS) that map across to the above standard are HCS 2, 19 and 25.

## Standard 4: Care of the Child and Family

**Rationale:** The child and the family receive comprehensive, holistic and child and family centred care as close to home as possible and with ease of access to specialist centres when this care cannot be provided locally.

### Key Actions:

Key Action	Responsible organisation	Timescales
4.1 Suitable accommodation is available in facilities where palliative care is delivered away from home for parents and siblings to stay with the child. <sup>7,23</sup> KA 2.12	LHBs Trusts Hospice	4-10 years
4.2 Transitional arrangements are in place to plan for seamless transition to adult services. <sup>7,23</sup>	MCN Lead Centres Trusts Hospices	1-3 years
4.3 The views of children, young people and their families are actively sought in planning their care. This includes decisions about their treatment choices. <sup>7, 23</sup>	MCN Lead Centres Trusts Hospices	Less than 1 year
4.4 Holistic care is available for carers independently from the needs of their children. <sup>7, 23</sup>	Lead Centres LHBs Trusts	1-3 years
4.5 Where children, young people and their families wish to undertake elements of their own/their child's care, training is available locally to undertake this. <sup>7, 23</sup>	Lead Centres Trusts	Less than 1 year

Examples of some of the Healthcare Standards for Wales (HCS) that map across to the above standard are HCS 2, 4, 6 and 12.

## Standard 5: Communication

**Rationale:** Effective communication mechanisms are in place to ensure the smooth delivery of palliative care services to children and their families in a timely manner.

### Key Actions:

Key Action	Responsible organisation	Timescales
5.1 Clinical pathways and guidelines are in place for the care and management of children requiring palliative care.	Lead Centres Trusts MCN	Less than 1 year
5.2 Information tools are in place to inform children and their families about palliative care services for children. These are available in a variety of languages and communication methods e.g. leaflet, videos, tapes, web-based materials. <sup>7</sup>	MCN Trusts	1-3 years and ongoing review
5.3 An IT infrastructure is in place across the network to aid effective professional communication. <sup>24</sup> This includes links to specialist centres outside Wales with: <ul style="list-style-type: none"> <li>• secure email</li> <li>• video conferencing</li> <li>• teleconferencing.</li> </ul>	WAG HCW LHBs Trusts	1-3 years
5.4 Effective communication mechanisms are in place between all service providers of palliative care for children, young people and their families.	Trusts Hospices	Less than 1 year

5.5 Children, young people and their families have the opportunity to contribute to a patient satisfaction process as part of their annual review of care. <sup>7, 23</sup>	Trusts Hospices	Less than 1 year
5.6 Local mechanisms are in place to obtain off licence, unlicensed and difficult to access medicines if prescribed by a specialist. Funding for specialised medicines is available.	Trusts LHBs	1-3 years

Examples of some of the Healthcare Standards for Wales (HCS) that map across to the above standard are HCS 1, 2, 6, 12, 19 and 25.

## Standard 6: Education and Training

**Rationale:** All members of the multi-professional team are trained to the required standard to deliver a high quality service safely. Care will be delivered based on the best available evidence.

### Key Actions:

Key Action	Responsible organisation	Timescales
6.1 All professionals involved in the care of children and young people receive appropriate training in pain management. <sup>26,27,28</sup>	MCN LHBs Trusts Hospices	1-3 years
6.2 All professionals working closely with children and young people with palliative care needs have formal support and supervision included in their job plans. <sup>23</sup>	LHBs Trusts Hospice	1-3 years
6.3 All staff providing palliative care for children and their families have protected and funded study leave for their CPD. <sup>7,23</sup>	Trusts LHBs Hospice	Less than 1 year
6.4 Specialist education in children and young people's palliative care is available across the network as a continuous programme.	MCNs LA Lead Centres Trusts	1-3 years
6.5 Multi-professional research programmes are in place for palliative care.	MCN LHBs Trusts	1-3 years

Examples of some of the Healthcare Standards for Wales (HCS) that map across to the above standard are HCS 11, 13 and 22.

## Glossary

This glossary should be used in conjunction with the core definitions in the glossary of the Children's NSF<sup>7</sup>

Care Pathway/Clinical Pathway	Locally agreed, multi-discipline practices based on guidelines and evidence for a specific patient/client group.
Clinical Governance	A framework to maintain and improve standards of care bringing together quality assurance, audit, best-practice guidance and evidence-based research.
Off Licence/Unlicensed Drug	A drug, which has a marketing licence, but for use in a different age group, for a different health condition or by another route of administration.
Respite/Short Break	The provision of care (in a residential setting, the person's own home or elsewhere) to provide the child or young person, and/or the carers, parents and families with a break.
Palliative Care	The active holistic care of children and young people with life limiting conditions, including the management of pain and other distressing symptoms and the provision of psychological, social and spiritual support. It focuses on the enhancement of quality of life for the child and support of the family and provision of respite and care through death and bereavement.
Generic Palliative Care	Palliative care skills that might be expected from medical or nursing training in paediatrics or child health.

Semi-specialist Paediatric Palliative Care

Skills in holistic symptom management that may be expected from any speciality paediatrician or paediatric clinical nurse specialist with expertise in one particular condition or a narrow range of conditions. Examples include paediatric oncologists, clinical nurse specialists (CNS) in Cystic Fibrosis. Adult physicians with palliative medicine training would be a special category within this.

# Appendix 1

## External Working Group Members

Lynda Brook	Consultant Paediatric Palliative Care, Royal Liverpool Children's Hospital
Laura Clark	Senior Nurse Manager, Cardiff and Vale NHS Trust
Jane Dulson	Ty Hafan Hospice
Angela Gallagher	Paediatric Oncology Outreach Nurse, Cardiff and Vale NHS Trust
Dr Richard Hain	Consultant Paediatric Palliative Care, Cardiff and Vale NHS Trust/Senior Lecturer (Joint Chair)
Dr Meriel Jenney	Consultant Paediatric Oncologist, Cardiff and Vale NHS Trust
Kath Jones	Hope House Hospice/Ty Gobaith
Patricia O'Meara	Paediatric Palliative Care Nurse Specialist, Gwent Healthcare NHS Trust (Joint Chair)
Dr Gwyneth Owen	Consultant Paediatrician, Carmarthenshire NHS Trust
Rhian Pritchard	Community Nurse, Conwy and Denbighshire NHS Trust
Hillary Whitby	Parent
Dr Huw Jenkins	Director of Healthcare Services for Children and Young People, Welsh Assembly Government

We are grateful to the parents involved in the parent focus group held at Ty Hafan who helped with this work.

## Appendix 2

### Project Steering Group Members (as at time of consultation)

Rhian Davies (Observer)	Representing the Children Commissioner's Office
Dr Layla Al Jader	National Public Health Service
Alison Lagier	Local Health Board Chief Executives
Becky Healey	Welsh Nursing & Midwifery Committee
Angela Hillier	Welsh Therapies Advisory Committee
Jane Perrin	National Association of Chief Executives
Andrew Ferguson	Health Commission Wales
Andrea Mathews	Community Health Councils
Dr Michael Badminton	Welsh Scientific Advisory Committee
Sue Greening	Welsh Dental Committee
Dr Eddie Coyle	Welsh Centre for Health
Caroline Crimp	Association for the Welfare of Children in Hospital
Keith Bowen	Contact a Family
Irene Allen	Head of Children's Health and Wellbeing Branch, Welsh Assembly Government
Dr Huw Jenkins	Director of Healthcare Services for Children and Young People, Welsh Assembly Government

## Appendix 3

### Local Palliative Care MDT

- Community Children's Nursing Team
- Lead Paediatrician - named
- GP
- Play specialist

Access to:

- Lead Centre MDT
- Pain/symptom control service 24/7
- Children's Hospice
- Nutritional Support (dietetics)

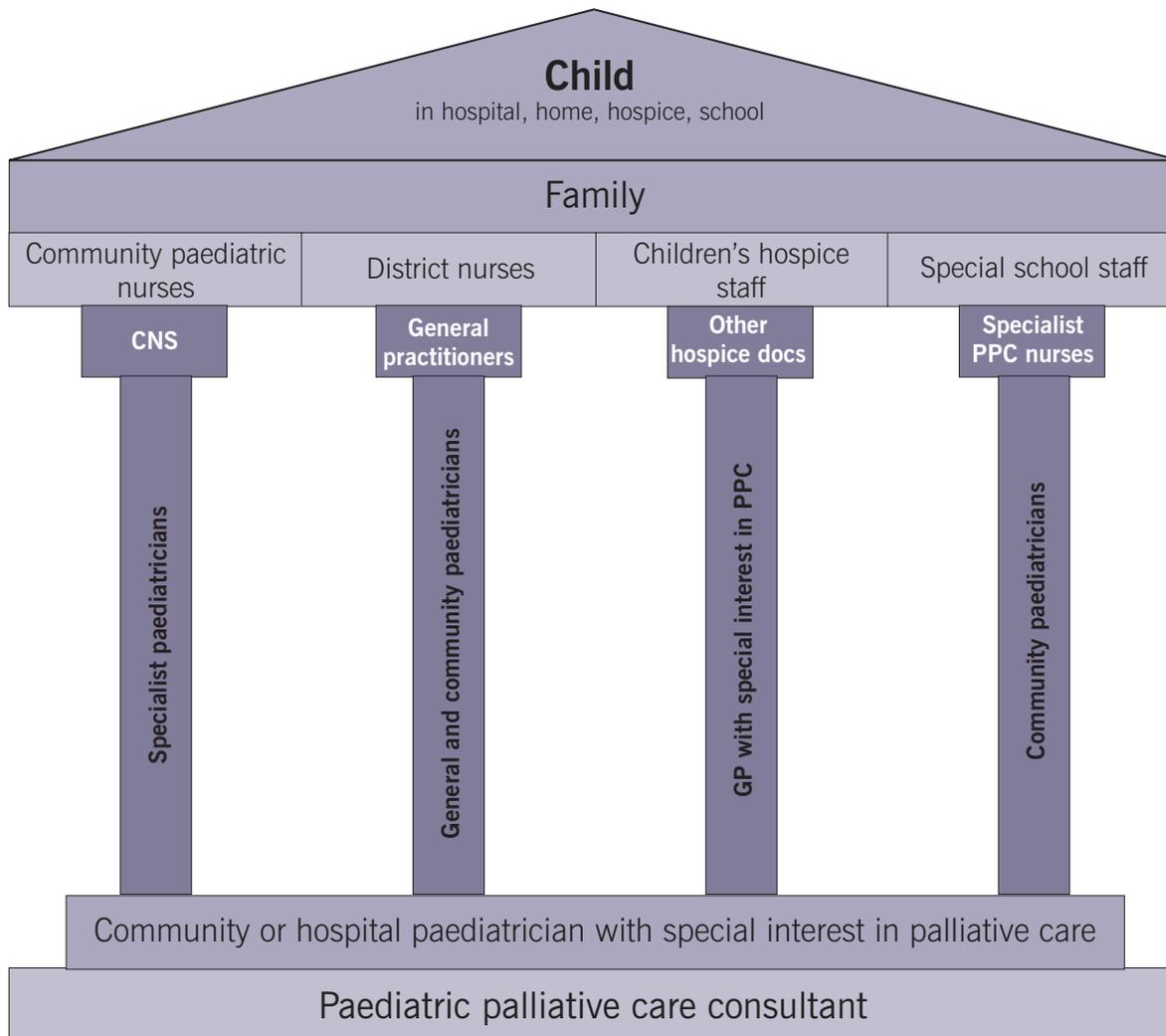
### Lead Centre Palliative Care MDT

- Lead Clinician
- Specialist Nurse
- Symptom control team
- Paediatric pharmacist
- Play therapist
- Trained specialist medical staff (FT)
- Trained specialist children's nursing staff with post registration training in Palliative care (FT)
- Psychologist
- Pharmacist
- Social worker
- Physiotherapist
- Occupational therapist

Access to:

- Children's Hospice
- Dietician
- Chaplain or other spiritual support
- Complementary therapies
- Education
- Dentist
- Counsellor

## Appendix 4<sup>22</sup>



Sections 76, 77 and 81 of the Government of Wales Act 2006 provide a basis for our equality work. The National Assembly for Wales is under statutory duties to aim to ensure that its business is conducted, and its functions exercised, with due regard to the principle that there should be equality of opportunity for all people. As the majority of the National Assembly's functions have been delegated to the First Minister and are carried out by the Welsh Assembly Government, in practical terms it is the Welsh Assembly Government which has principal responsibility for fulfilling these equality duties. This is further underpinned by UK Equality legislation, covering equality and human rights.

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