

London Children's Palliative Care Network

LONDON CHILDREN'S PALLIATIVE CARE NETWORK ("LCPCN")

TERMS OF REFERENCE

1. Introduction

1.1 The provision of palliative care for children and young people across London requires an integrated, multi-agency approach.

1.2 The initial audit of existing services against standards, described by the Associations of Children's Palliative Care (ACT) and the National Service Framework for Children, Young People and Maternity Services - Palliative Care (DfES and DoH 2005) reflects a considerable distance to travel. The lack of a clear pathway and little coordinated or dedicated support was identified.

1.3 Following the independent review for Children's Palliative Care (DoH 2007) and the Aiming High for Disabled Children review (DfES and the Treasury 2007), it is clear that an integrated approach to providing services, both by existing providers and potential new services, is essential.

1.4 The outcomes and expectations from Every Child Matters and Every Disabled Child Matters need to help guide our principles.

1.5 A key point to this provision is that palliative care should not be seen in isolation, but as part of the wider developments identified in the Children and Young People's Plan, the Reviews and the forthcoming Children's Palliative Care Strategy (Feb 2008?).

1.6 A multi-agency working group will be established to develop an integrated multi-agency approach to the provision and delivery of palliative care for children and young people pan London, which recognises their different needs.

2. Constitution

2.1 A Pan-London multi-agency group will be established (to be known as the London Children's Palliative Care Network – LCPCN). This group will ensure that palliative care for children and young people and their families is delivered in a seamless and integrated way across the City of London (i.e. the area served by the Strategic Health Authority – NHS London).

3. Membership

3.1 The LCPCN should comprise of the following members:

- ☆ Parent representative
- ☆ Children's Community Nursing team representatives
- ☆ Commissioners of Children's Services for Primary Care Trusts and the Local Authorities
- ☆ Education representative
- ☆ Head of Service Improvement for Children and Young People (Primary Care Trusts)
- ☆ Paediatric Consultants with special interest in palliative care
- ☆ Children's Complex Needs representatives (Primary Care Trusts)
- ☆ Local Authority Children with Disabilities Team representatives
- ☆ Representation from local Children's Hospice services
- ☆ Representation from other voluntary organisations
- ☆ Cancer Network representative

3.2 The quorum of the group should be six members.

3.3 Other professionals may be invited to the group as appropriate.

4. Frequency of meetings

4.1 The LCPCN will meet quarterly to ensure development and implementation of the action plan and will be reviewed after one year.

4.2 Any working groups will meet at a frequency determined by the LCPCN to ensure their objectives are achieved

5. Remit and Functions

5.1 The remit and function of the group will be to:

- ☆ ensure that the responsibility of individual agencies are identified and met
- ☆ develop an integrated multi-agency care pathway for the provision and delivery of palliative care for children and young people
- ☆ ensure there is a shared accountability across agencies for the implementation of an integrated pathway for the provision of palliative care for children and young people across London
- ☆ receive information and feedback from families about the level of service they require to inform developments
- ☆ agree work streams and sub groups which will report to the Children and Young Peoples Partnership Board
- ☆ ensure that palliative care provision fits into the wider pan London agenda of the Children and Young Peoples Plan
- ☆ share progress and plans with other networks, Association of Children's Palliative Care (ACT), Association of Children's Hospices (ACH).

6. Reporting Procedure

6.1 The notes of each meeting will be formally recorded. Feedback and recommendations will be to the following groups:

- ☆ London Multi-Agency Planning Group
- ☆ Planning Group for Children who are Disabled
- ☆ Strategic Health Authority – NHS London
- ☆ Cancer Networks across London
- ☆ Directors of Commissioning for Primary Care Trusts
- ☆ Association of Children’s Palliative Care (ACT)
- ☆ Association of Children’s Hospices (ACH)
- ☆ Directors of Social Services and /or Directors of Children and Young People’s Services
- ☆ Managers of Children’s Trusts
- ☆ Managers of Children with Disabilities Teams

