

# London Children's Palliative Care Network

Working together for better children's palliative care across London

Issue 1

June 2008

## Why the LCPCN?

The London Children's Palliative Care Network (LCPCN) was established in June 2007, following the Department of Health's independent review of Children's Palliative Care by Professor Sir Alan Craft and Sue Killen.

The aims of the LCPCN are to ensure a more integrated approach to children's palliative care, involving multi-disciplinary agencies from both the statutory and voluntary sectors, including social care, education and children's hospice services.

A copy of our Terms of Reference are available by emailing [dalton.leong@shootingstar.org.uk](mailto:dalton.leong@shootingstar.org.uk)

## Association of Children's Hospices (ACH)

The ACH has changed its name to **Children's Hospices UK** following some pro bono work by a marketing agency and extensive consultation with its members. The new website can be seen at [www.childhospice.org.uk](http://www.childhospice.org.uk)

## Contacts for Local Networks within LCPCN

South West : Cheryl Petty  
[cheryl.petty@sutton.gov.uk](mailto:cheryl.petty@sutton.gov.uk)

North West : Dalton Leong  
[dalton.leong@shootingstar.org.uk](mailto:dalton.leong@shootingstar.org.uk)

North East : Peter Ellis  
[PeterE@richardhouse.org.uk](mailto:PeterE@richardhouse.org.uk)

South East : Wendy Faulknall  
[wendy.faulknall@demelza.org.uk](mailto:wendy.faulknall@demelza.org.uk)

North Central: Bernadette O'Gorman  
[bernadette.o'gorman@islingtonpct.nhs.uk](mailto:bernadette.o'gorman@islingtonpct.nhs.uk)

The Comprehensive Spending Review stated that the DCSF was making £280m available to local authorities for short breaks alone and that the NHS settlement would "match" this. In their joint letter, the Ministers urge: "Now that these resources are confirmed, there should be, in every locality, a joint strategy and delivery plan involving Local Authorities, PCTs, relevant voluntary organisations and, where appropriate, the private sector, along with parents and representatives of parents."

## Cicely Saunders Institute

The Prime Minister has unveiled plans for the world's first institute of care for children and adults with life-limiting conditions. Gordon Brown said the Cicely Saunders Institute of Palliative Care would be the first international academic establishment in the world to focus on palliative care research and teaching. More than one million people are expected to benefit from the centre in the first year after it opens in autumn 2009. Brown said: "It will be the first to bring together research, education, information and clinical care under a single roof and is a true centre of excellence." The institute will be built next to King's College Hospital in South London

## New Association

Association for Young People's Health: launched in February intends to bring together professionals working with young people. The website is [www.youngpeopleshealth.org.uk](http://www.youngpeopleshealth.org.uk)

## Association for Children's Palliative Care (ACT)

The LCPCN newsletter can also be found on the ACT website shortly [www.act.org.uk](http://www.act.org.uk)

## New Book

*Why Money Matters - Family income, poverty and children's lives*  
A new book published by Save the Children on 26 February provides the most up to date evidence yet that families with disabled children are at considerably higher risk of living in poverty than other families. *Why Money Matters - Family income, poverty and children's lives* contains a specific chapter by Tania Burchart and Asghar Zaidi on poverty in families with disabled children. It highlights that although children in families affected by disability already face an increased risk of poverty, it is the extra costs associated with having a disabled child that leads to significant disadvantage.

## European court rules in favour of carers rights

Every Disabled Child Matters (EDCM) welcomes a decision made by the European Court of Justice that confirms treating employees less favourably because of their caring responsibilities for disabled relatives is unlawful. The decision follows the case of Sharon Coleman, a mother who claimed she was refused flexible working rights because she had a disabled child. Currently, parents with a disabled child under the age of eighteen have the right to request flexible working arrangements, which enables them to more easily balance paid work and care. Although the ruling in this case does not mean they have an automatic right to flexible working, it does mean carers, including parents of disabled children, have the right to protection against discrimination or harassment on the grounds that they are a carer.

LCPCN

# London Children's Palliative Care Network

Working together for better children's palliative care across London

## London Children's Hospices Alliance (LCHA)

The London Children's Hospices Alliance (LCHA) was established in May 2007, following endorsement of the three respective boards of trustees of Shooting Star House, Haven House and Richard House agreeing to such a joint venture. Our main purpose is to drive forward the national strategy for children's palliative care (Better Care: Better Lives), which aims to ensure that all children with a life limiting or life threatening condition have equitable access to a high quality and sustainable palliative care service. The three hospices recognised that our joint effort to achieve consistency and economies of scale would lead to further benefits for our children and their families.

The LCHA is about to start a three month (initially) programme of work, facilitated by the Grubb Institute, to assist us in developing a joint strategy. The initial partnership that has been formed through the LCHA requires tangible outcomes, and we want to better understand how this can be achieved.

We are concerned that there are children and their families in London who do not access a children's hospice or palliative care service, and we want to know why, so that we can begin to respond to the various needs as they are expressed. We are keen to understand this so our work with the Grubb Institute will aim to focus on needs analysis that helps to answer these questions.

For further information on the LCHA, please contact any one of the Chief Executives; Dalton Leong (Shooting Star House); Jeremy Todd (Haven House); Peter Ellis (Richard House)

## Better Care, Better Lives

Better Care, Better Lives is the recently launched direction-setting document for the future of palliative care services for children and young people. The document sets out 8 service development goals for service commissioners and providers to work towards. The success of the strategy requires an integrated approach and action from key delivery partners across the statutory and voluntary sectors. ACT, the Association for Children's Palliative Care have suggested 4 priority actions for members to consider:

- Attend the local launch of Better Care, Better Lives
- Take opportunities to play an active part in local CPC networks
- Contact your PCT now to remind them of their new responsibilities with regard to the strategy
- Share examples of good practice to facilitate the development of support materials

## Funding for CPC Services

As part of the Better Care, Better Lives launch, Ivan Lewis, Minister for Care Services announced £20m funding for hospice services, he stated that a significant investment had been made in CPC services through PCT allocations, but did not quantify this amount. You may be aware that Health Minister Ivan Lewis and Education Minister Lord Adonis wrote to PCT Chief Executives and Local Authority Chief Executives and Directors of Children's Services on 19 December 2007 to stress that major new growth funding had been included in PCT baseline allocations specifically to:

- (a) Enable PCTs to work with local authorities to significantly increase the range and number of short breaks for children with disabilities and complex health needs; and
- (b) Support PCTs in responding to the forthcoming children's palliative care strategy, focusing on building a sustainable service of palliative care networks and support for community nursing teams.