

**PCPLD Network**

Palliative Care for People with Learning Disabilities

NEWSwww.pcpld.org

A low priority?

A report examining local health planning and needs assessments in relation to dying people and finds that 34 per cent of health and wellbeing boards do not take into account end of life care needs. The report calls for greater collaboration in order to better cater for local palliative and terminal care needs.

Read the full report from Hospice UK [here](#).

Better care in my hands

This report describes how well people are involved in their own care and what good involvement looks like. It is based on newly analysed evidence from our national reports and inspection findings, as well as national patient surveys and a literature review. It identifies what enables people and their families to work in partnership with health and social care staff and illustrates this with good practice examples from our inspection findings.

Read the full report from the Care Quality Commission [here](#).

BRAND NEW 'BOOKS BEYOND WORDS' APP

A new and unique picture story App is launched to support people with learning disabilities

Books Beyond Words has gone mobile and created a new app, which holds over 400 short picture stories and 1800+ pictures from across their entire back catalogue. This includes several picture books relevant to cancer (incl screening), loss, bereavement, death and dying, such as: When Dad Died, When Mum Died, When Somebody Dies, Getting On With Cancer, Looking After Your Breasts, Am I Going To Die?

The app has been designed to work on your tablet or smartphone, and is powered by both iOS and Android. The app is available to download for free with limited content from the App Store and Google Play, and for £29.99 per year you can unlock the full version with access to our entire library of pictures. They also offer an expanded organisation subscription, complete with a bookshelf feature, for small and larger organisations, saving up to 50% on each user. Email orders@booksbeyondwords.co.uk for more information go [here](#).



CARE QUALITY COMMISSION

'A different ending': addressing inequalities in end of life care

This review of end of life care found that people from certain groups in society, including people with learning disabilities, sometimes experience poorer quality care because providers do not always understand or fully consider their needs. In light of this, the report argues that some commissioners and providers might not be fulfilling their duties under the Equality Act 2010 as all public bodies have a legal duty to consider the needs of a range of equality groups when carrying out their day-to-day work. The review identified examples of good practice, but found that action is needed to make sure everyone has the same access to high quality, personalised care at the end of their lives, regardless of their diagnosis, age, ethnic background, sexual orientation, gender identity, disability or social circumstances.

You can read the full report [here](#).

The Unkindest cuts: the painful reality of disability

EVENING SEMINAR FROM THE IPD,
CHAired BY VALERIE SINASON

The Institute of Psychotherapy and Disability is hosting an evening seminar to discuss the impact of disability cuts and whether PIP are working. There will be a presentation by Valerie Sinason who will then chair a free association discussion. The event is free to members of the IPD, £20 otherwise.

WHEN: 1st July 2016, 18.30 - 20.15

WHERE: The Freud Museum, 20 Maresfield Gardens, NW3 5SX

Please get in touch with Alice at admin@instpd.org.uk to reserve your place

Some concerns about the mental health of disabled babies and their mothers. Are we helping or hindering?

This article by Peter Limerick of the TAC expresses concern that the mental health needs of disabled babies and their families are not being addressed soon enough. You can read the article in full here: [Click link](#)

STUDY DAY THIS THURSDAY!

A CPPD study day on Palliative Care for People with Learning Disabilities will be held on Thursday, 23/6/2016 at London South Bank University Southwark campus.

We will be looking at enabling and supporting positive experiences of death and dying from a whole person perspective. The day is aimed at health and social care professionals of any background and will feature opportunities for sharing knowledge and experiences across agencies and professions.

To book onto the course, please go to the website [here](#). For more information, contact Renée Francis at francir6@lsbu.ac.uk