



PCPLD Network
Palliative Care for People with Learning Disabilities

NEWS



www.pcpld.org

New NICE guidance

End of life care for infants, children and young people with life-limiting conditions: planning and management

This [guideline](#) covers the planning and management of end of life and palliative care for infants, children and young people (aged 0–17 years) with life-limiting conditions. It aims to involve children, young people and their families in decisions about their care, and improve the support that is available to them throughout their lives.

New CQC report

A new CQC Report says that NHS investigations of deaths are inadequate. People with learning disabilities are especially at risk; the level of acceptance and sense of inevitability when they die early is too common. Read the full report [HERE](#).

WINNERS OF THE LINDA MCENHILL AWARD 2016

The 2016 award was won by Sarah Jane Price's team. Sarah Jane was 21 years old when she died in 2015. Her foster mother, Louise Ellis, nominated the whole team for the award.

It was clear to the judges that Sarah Jane's care during her final months had been outstanding. This clearly depended on having a wonderful and loving family, but this alone is never enough. It also depends on that family receiving a huge amount of support and reassurance; on skillful management of physical, emotional, spiritual and social problems; and on planning ahead. The professionals involved in Sarah Jane's care learned from her situation. They developed new ways of working, which will benefit people with learning disabilities in the future. We are delighted, therefore, to be able to highlight Sarah Jane's care as an example of best practice. Sarah Jane's full story can be found [HERE](#).



Louise Ellis receives the award and speaks about her foster daughter Sarah Jane

MEMBERS VOTE FOR CHARITABLE STATUS

At our AGM in November, members voted unanimously for the PCPLD Network to become a Charitable Incorporated Organisation (CIO), and for the new proposed constitution to be adopted. There was also a unanimous vote for the first three trustees to be Jason Davidson, Irene Tuffrey-Wijne and Annie Stewart. We have just sent our application to the Charity Commission and are expecting a response around February 2017. Full minutes of the AGM can be found [HERE](#).

The PCPLD Network would like to wish all our members a very Happy Christmas and best wishes for the New Year



SUCCESSFUL 2016 CONFERENCE

Our annual conference was held in Huddersfield on 4th November 2016, in a spectacular football ground setting. It was a hugely inspiring day, with excellent and stimulating talks. Many thanks to all the speakers. Some of the slides can be found on our Slideshare page [here](#).



Irene, Jason and Annie sign the newly adopted constitution



Some of the conference delegates



The Steering Group will continue to support the running of the PCPLD Network