

Delivering high quality end of life care to people with learning disabilities

Learning Disabilities Health Support Team

What is the group's experiences so far?

Nationally

- **2013 - Confidential Inquiry into premature deaths (CIPOLD) reviewed 247 deaths of people with LD**
 - found to be less likely than comparator group of people without LD to have access to specialist palliative care services
 - found to receive less opioid analgesia
 - Deaths unplanned for, uncoordinated and poorly managed.

- **Palliative Care for people with LD network - chaired by Irene Tuffrey Wijne**



PCPLD Network

Palliative Care for People with Learning Disabilities

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In Bradford

- In 2007 Palliative care team asked for some support from LD nursing team following number of referrals for people with learning disabilities
- Set up a steering group made up of LD professionals from community team & Palliative Care team - later stages included district nursing
- Regular meetings to set up pathway and share skills/knowledge – held a conference at Marie Curie 2009
- Steering group closed in 2018 as everything working well and close links in place

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Local deaths feedback



Bradford District Care
NHS Foundation Trust

- Palliative v end of life – some people with LD can be palliative for years!
- Mortality reviews in last 18 months - at least 6 people with learning disabilities died with end of life support
- District nurses take the lead – using GSF
- Learning disabilities team & palliative care team provide additional support

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What do we do to support person, carers and other professionals

- **We support in addition to what should always happen for everyone ie district nursing and GSF. We might close our input if everyone else is up and running - sometimes too many people are involved at the same time. Needs to be right support ,at the right time by the right people .**
- **If we know the person well we may introduce to the other services and support people until they are confident and then pull out – depends very much on the individual**
- We ensure people get on pathway in first place eg if being discharged from hospital which may be with a new diagnosis or they may have degenerative condition that has now progressed
- Communication – people understanding they are dying or impact of illness? (**Change books**)
- Capacity and decision making
- Easy read resources
- Reasonable adjustments – symptom management, pain assessment & relief
- Multiple co morbidities – managing these
- Complex family relationships and social situations
- Sorting out funding
- Impact on other people in houses
- Preferred priorities - advanced care planning, funeral plans etc
- Ensure staff teams feeling confident to deal with things

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Easy read info

- Planning end of life
- Strong pain killers
- What happens if my heart stops
- Books beyond Words
- Change Cancer series
- Pain assessments

End of Life Pathway