Delivering End of Life Care and Bereavement Care for People with Learning Disabilities
Where we then, Where we are now

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The beginning

- 1997: ROC – Bereavement Service for People with Learning Disabilities Closure of long stay hospitals, return of people to hospital when ill-sick ward closing – providing palliative care? Trying their best but not PC
- Survey of 5 local hospices – how many pld were patients in past 5 yrs?
- 1998 – back to oncology 'where have all the people with Learning Disabilities gone?' Groundhog Day
- Preparation for Pavilion Conference – pockets of excellence (Prudhoe (John Murdy), Ashgreen Hospice (Mari Kewin))
- Let's set up a Network
- First meeting of Network at Northgate but not our first meeting at Northgate!! – Beware being seen as an 'expert'!

Why a Network?

- To overcome individual practitioner isolation
- To link and replicate good practice (feast or famine)
- To collate and record instances of poor practice
- To more effectively influence practice and policy in both palliative care and learning disability services

The Mission Statement

- ***We believe that people with Learning Disabilities have the right to access and receive high quality palliative care, to facilitate this right the National Network for the Palliative Care of People with Learning Disabilities will:***
- ***Promote collaboration between all service providers and carers who work for the benefit of people with learning disabilities who have specialist palliative care needs.***
- ***Promote 'best practice' in the palliative care of people with learning disabilities by the dissemination of information regarding resources, research, skills and training.***
- ***Contribute to the establishment of guidelines and standards for the palliative care of people with learning disabilities in consultation, where possible, with people with learning disabilities.***

Early days: developing a ‘national’ network

- By 2000, 100+ members, listed in the Hospice Directory – enquiries from as far away as Australia and Canada (and a laptop!)
- Contact with National Hospice Council and Dr Illora Findlay to send rep
- Contact with David Congdon, Mencap, Beverley Dawkins who **is a new National Officer for the organisation**
- Fiona Cathcart – new rep for Scotland
- Northgate (fax) developing outreach PC for People with LD, teaching
- Wordless book on palliative care being developed
- Breast and testicular screening work presented –debate – decision taken that we needed a ‘*reworking of traditional definitions of palliative care to incorporate the specific needs of people with learning disabilities* ‘

2001 – beginning to reach out

- Annual network conference displayed the posters from EAPC (Palermo)- 7 in total
- John Northfield - Experiences of Cancer services for PLD: feedback from the Cancer Services Scoping Study- first proper study looking at differential incidence of cancer in people with learning disabilities and access within access issues for people with LD in hospices
- Case Examples of Consent issues relating to the palliative care of people with learning disabilities- facilitated by Colin Beacock, Nurse Advisor on Learning Disabilities, Royal College of Nursing. ’Lively’ debate on the issues of subjective ‘quality of life assessments’ in formulating ‘do not resuscitate’ decisions
- 8 area groups in existence by now
- Northgate had now become a Beacon site for pcpld- CLiP articles (DisDAT)- Richard West ‘Pallor?’
- Bereavement research group set up – Sue Read (not then Dr Sue Read!!!)
- Articles beginning to appear and Noelle Blackman (not then Dr Noelle Blackman) book on Bereavement and PLD published
- St George’s lottery funded improving access project begun – led by Irene Tuffrey (not then Dr…!)
- Valuing People’ – Gold Group – hearing the voice of People with Learning Disabiliti4es

John’s lived experience

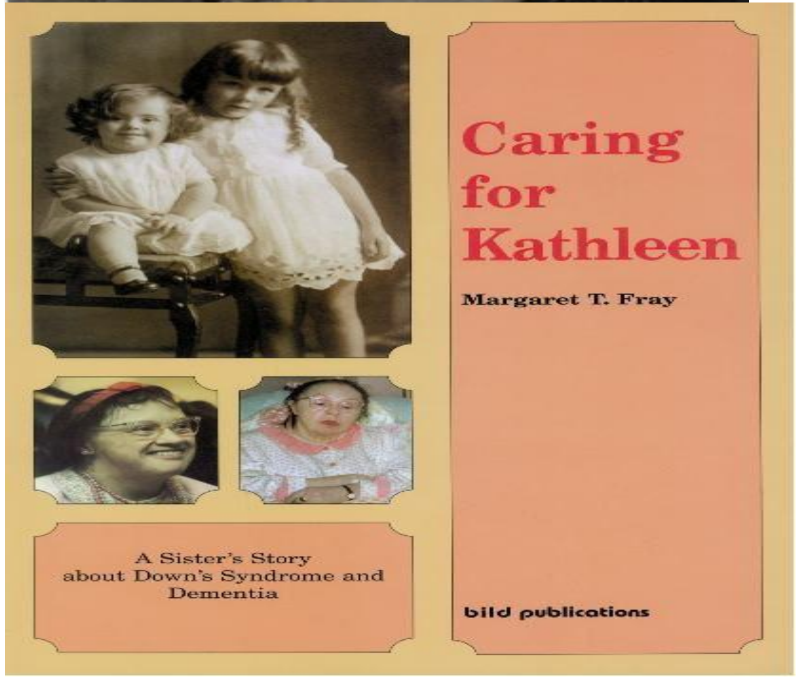
2002-2004

- Beginning to think about how to communicate with people with learning disabilities about serious , dying and bereavement
- Article in J.Intellectual Disability
- 2003 Treat me right, Mencap
- Hambro Macmillan Associate Fellowship
- Set the scene for information service

2005-2006

- Respond Elders Project (funded by Lloyds Bank) set up to support older families to plan for the future – support in thinking about their own death and to plan for the bereavement of their adult children- resulted in working more with services
- Caring for people with LD who are dying (Todd & Blackman) 2005
- 15th Feb 2006, Langdon Down Centre, Teddington, Launch of the MNISS and Kathleen Study Day
- RSM study day
- CRUSE national study day
- Glasgow LD Partnership
- Sue Read's book(s)
- Affinity Group for IASSID (2002)

One of our heroines: Peggy Fray



Caring for Kathleen

Margaret T. Fray

A Sister's Story
about Down's Syndrome and
Dementia

bild publications

2007-2013

Preventable deaths

- Connor Sparrowhawk, Stephanie Bichliffe, Thomas Rawnsley, Richard Handley, Danny Tozer, Oliver McGowan to name but a few
- The importance of social media
- LeDER review
- STOMP

Where are we now?

- Vital work on Dementia, EoLC and People with Learning Disabilities- but much more to be done –Hope for Home
- Bereavement is still very underdeveloped and access is still very poor + Spiritual care
- Research has a louder/clearer voice
- Practice based projects are more strategic e.g. Building Bridges Project
- Influence on policy is greater
- Buy in from a wider range of organisations e.g.
  Delivering High Quality End of Life care for people with a Learning Disability NHS England, in partnership with the Palliative Care for People with Learning Disabilities (PCPLD) Network, has today published Delivering high quality end of life care for people with a learning disability. Resources and tips for commissioners, service providers and health and social care staff.

The PCPLD 2018 – well done

The aim is the same

- Throughout the country members are developing small networks where they can pull their expertise. Where gaps in training are identified then they are trying to meet those by days such as these and it is clear that the newly formed PCG's would benefit greatly from these.
- CONCLUSION: In summary therefore,
- There is no doubt that there is a big task to be achieved to make palliative care accessible and appropriate to the needs of PLD but the solution it is clear lies in (ACETATE) **Partnership.**
- Without you there is no network- Thank you for all the you do to make the end of life and bereavement care of people with learning disabilities as excellent as they deserve it to be