

The Launch of the Macmillan Network Information and Support Service

As this launch involves an invited audience of palliative care, learning disability and cancer care professionals, delegates to the study day are asked to indicate whether they wish to attend this event. The Kathleen lecture will begin at around 4:15pm and the reception should end by 6:30pm

I would/would not like to attend the launch (Please delete)

Please send cheques made payable to 'NNPCPLD' to:

**Linda McEnhill, Co-ordinator
NNPCPLD, PO Box 522,
Cambridge CB1 0BL**

By 4th February 2006

Queries about the launch or study day can be directed to **01223 460 473** or

LindaMcEnhill@natnetpald.org.uk

Thanks are due to:

The **National Network** for **Palliative Care** of **People with Learning Disabilities** wishes to thank the **Langdon Down Centre Trust** for their kind gift of the venue for this event . For further information about the Langdon Down Centre or for travel details please visit their website on www.langdondowncentre.org.uk

For further information on the **Downs Syndrome Association** please see www.dsa-uk.com

The **National Network** also wishes to thank

- * **Macmillan Cancer Relief** (www.macmillan.org.uk) for their ongoing support and funding the establishment of the Information and Support Service
- * **Respond** (www.respond.org.uk) for hosting the Information and Support Service
- * **Mencap** (www.mencap.org.uk) for their particular support of this event and for providing photographs for the Information and Support Service Leaflets
- * All the speakers' organisations who have released them to make their contributions to this day and enabled them to develop our thinking on this important area of practice

Thank you!



Inaugural Kathleen Lecture
& Study Day

***'Not in a Vacuum:
Dementia
and Learning Disability
at the End of Life'***

Also : the launch of the
**Macmillan Network
Information and Support
Service**

**Wednesday
15th February 2006
9:45am to 3:45 pm**

Dementia & Learning Disability at the End of Life

Background: In February 2005 the NNPCPLD recognised the tireless contribution of its Carers' Representative, Peggy Fray, in advocating for people with learning disabilities who have complex health care needs. Peggy's commitment to this work comes from the experience of nursing her much loved sister, Kathleen Anne Richards, who had Downs syndrome and died of dementia; an experience which is poignantly captured in Peggy's book 'Caring for Kathleen' (BILD).

The Kathleen lecture therefore marks the contribution of both these remarkable women in enhancing our understanding. In future years this lecture will take place within the programme of one of the national study days hosted each year by the NNPCPLD.

All the speakers at this inaugural event have been invited by Peggy and indicate her appreciation of the main areas of concern. The focus of the day will be on the implications of dementia for the whole family

At the close of the day the formal launch of the Macmillan Network Information and Support Service will take place. This project is funded by Macmillan Cancer Relief to develop information on palliative care and learning disability. Delegates to the study day are invited to attend this event which will commence with the Kathleen lecture, delivered on this occasion by Peggy Fray.

Programme of events

Target audience: This is an action packed day aimed at formal and informal carers of people with learning disabilities. People with learning disabilities who wish to attend this event may consequently require support. Such delegates can therefore bring a supporter who will be eligible to attend without charge. Should a NNPCPLD supporter be required this should be indicated to the co-ordinator at the time of booking. Topics include:

- **Distress and dysphagia in people with Downs' syndrome and Alzheimer's disease:** Dr Claud Regnard, Palliative Care Consultant St.Oswald's Hospice & Dorothy Matthews, Macmillan Nurse for People with Learning Disabilities
- **The needs of siblings:** Karen Watchman, Director, Downs Syndrome Scotland
- **The place of friendship:** Dr David Thomson
- **Parents of dying people with learning disabilities:** Dr Stuart Todd, Senior Research Fellow, The Welsh Centre for Learning Disability, University of Cardiff
- **Disenfranchised grief:** Noelle Blackman, Assistant Director, Respond

In addition there will be facilitated group work sessions and opportunities for networking. There will also be opportunities to share good practice by displaying information materials related to practice or service development.

The Kathleen Study Day: Application Form

Title:

Surname:

First Name:

Job title:

Address for correspondence

Email Address:

Day time telephone Number:

Payment Details: Please circle relevant category

Non- member : £50

Member: £35

Membership Number:

Unwaged: without charge

***Please note that cancellations without notification or less than 48 hours in advance will be liable to pay the full delegate rate ***

Dietary requirements: Please indicate any special dietary requirements below: