

One Day Annual Conference

## **WHO CARES?**

**Palliative Care for people with learning disabilities:  
A focus on carers and family carers**

Chair:

**Dr. Noelle Blackman**

Keynote Speaker:

**Baroness Sheila Hollins**



Jean Willson and her daughter Victoria Willson

**16th November 2015, 9.30am-4.30pm  
at St Joseph's Hospice, Mare Street, Hackney, London, E8 4SA**



St Joseph's  
Hospice



PCPLD Network  
Palliative Care for People with Learning Disabilities

**We are delighted to gather national researchers, skilled specialists and carers from a variety of backgrounds to share with us their professional and personal insight, into the complexities and challenges of caring for someone who has learning disabilities and palliative care needs.** In sharing their experiences, knowledge and expertise within this wonderful setting at St Josephs Hospice we aim to highlight and promote best practice.

Additionally the conference will commemorate the life and work of Peggy Fray who sadly died in April 2014. Peggy was a longstanding carer representative on our Steering Group. A lifelong advocate for people with learning disabilities – Peggy supported her sister, Kathleen, who had Down's syndrome and latterly dementia. Her book, *'Caring for Kathleen'* has been an inspiration for many of us in this field of care.



Peggy Fray: Carer and Campaigner  
1923 - 2014

When people with learning disabilities are on the palliative care journey carers are crucial, yet their needs are often overlooked. Furthermore failing to involve carers can lead to poorer outcomes for individuals.

This day will provide an opportunity for you to explore various complex issues in relation to carer involvement and support in the area of learning disabilities and palliative care and challenge and support you to address these with- in your day to day practice.

### **Who should attend?**

Clinicians from primary and secondary health care settings, palliative care services and learning disability services, commissioners and service managers, family and carers.



## Programme

- 9.00** Registration
- 9.30** **Welcome and chair opening remarks** - Noelle Blackman. CEO Respond
- 9.40** **“Supporting Victoria at the end of life”**  
**Jean Willson OBE** *Family carer and Victoria’s team: Centre 404 Housing Service and Islington ELiPSe and Camden Palliative Care Team, Winners of the Linda McEnhill Award 2014.*
- 10.25** **“Supporting families of people with PMLD through loss and bereavement”**  
**Brenda Garrard.** *PAMIS Bereavement & Loss Project Team, Dundee. Winners of the Linda McEnhill Award 2014*
- 11.15** **Coffee break**
- 11.45** Announcing the winners of the 2015 Linda McEnhill Award
- 12.00** **Soap box session**  
*led by Allison O’Donnell /Jason Davidson/ Patricia Charlesworth .*  
A series of 2 minute talks from a wide range of people
- 1.00 LUNCH BREAK AND POSTER VIEWING**
- 1.45** **“People with learning disabilities at the end of life: The challenges for carers”**  
**Baroness Sheila Hollins- Key Note Speaker**  
*Professor of Psychiatry of Disability and member of House of Lords, London*
- 2.15** **A new model to improve carer involvement in inpatient settings**  
**Irene Tuffrey Wijne** - *Associate Professor, Kingston University & St George’s University of London*
- 2.45** **When Worlds Collide: Family and service interactions in the last months of life of people with learning disabilities’**  
**Dr. Stuart Todd, Dr Rhian Worth and Ms Julia Shearn,** University of South Wales.
- 3.15** **A tribute to Peggy Fray** - **Linda McEnhill** *Head of Supportive Care, St Joseph’s Hospice, London*
- 3.45** **Discussion and chair closing remarks**
- 4.00** **End**  
*(4.15pm until 4.45pm Annual General Meeting - members of PCPLD Network only)*

## BOOKING FORM

Name:

Job title:

Organisation/company name:

Tel:

Email:

### **PAYMENT**

I enclose a cheque for £100 (payable to "PCPLD Network")

please send an invoice to: **(write clearly)**

Name:

Email:

Telephone:

Purchase Order number (if available:)

Please indicate any special requirements (e.g. vegetarian diet; disabled access)

Please scan the completed form and email to: [annegarley@gmail.com](mailto:annegarley@gmail.com)

or print out and return to: Anne Garley,

66 Castle Street, Portchester, Fareham, Hampshire PO16 9PX

**PLEASE NOTE Deadline** for registration: 09/11/2015. Places cannot be guaranteed unless payment is received by this date.

Cancellations: 80% refund before 09/11/2015; no refunds after this date. Bookings may be transferred to someone else at no extra cost.

Final confirmation details will be sent to delegates on 10/11/2015.

### **Delegate fee:**

**£100 per person**

including lunch and refreshments

### **Information and registration:**

Anne Garley

Email [annegarley@gmail.com](mailto:annegarley@gmail.com)

Phone **07808 402565**

### **Invitation for poster abstracts**

Poster abstracts are invited on any aspect of palliative care of people with learning disabilities. Email your abstract (maximum 300 words) to Anne Garley (see above) by 05/10/2015.

Notification of outcome: 12/10/2015

Presenting authors must register for the conference as a paying delegate.