

"Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around."

- Leo Buscaglia



Julie Kembrey -facilitator

I am the bereaved mother to Francesca and Josephine who died in their teens. I cared for my daughters, both of whom died from sanfilippo, for 18 years. During that time I developed a range of nursing skills. This led me to understand the importance of a co-ordinated approach, parent and healthcare team working together, and the need for effective communication in order to provide the best care to those children with life limited conditions. I am a trustee of Jessie May. Founder and parent lead of Jessie May Purple Group giving peer support to bereaved parents and carers. I have spoken at both national and international MPS society conferences.



Josie Pavey -facilitator

I am mum to Billy-Rose who lived for 6 wonderful months having been diagnosed ante-natally with a condition called hydranencephaly. I have been a social health care training consultant for 12 years and now use my personal and professional experience to provide training workshops for palliative care teams and baby loss support services to a vast array of professionals working in this field. I have spoken at fundraising events for Children's Hospice South West and recently helped develop and approve the new guidelines for neo-natal palliative care at Bath RUH. I am also a trustee for a disabled children's youth club and advocate for disabled people's rights and improved quality of life.

TOGETHER WE MATTER

WORKSHOPS



Love and Loss - a Parent's Perspective

Following the publication of the book *'Lives Worth Living'** we are offering half day interactive workshops looking at the issues raised in the stories and the reality of caring for children with a life limited condition.

**Lives Worth Living is available directly from us upon request.*



AIMS OF THE SESSION

To ease the journey that professionals and families make together at key challenging times identified in the book.

This workshop will be of interest and value to practicing or training professionals with an interest in, or already working with profoundly disabled/life limited children.

People who may be interested include:

- Medical staff and consultants
- Hospital nurses
- Community teams
- Teachers
- Care Assistants
- Students
- Charitable Organisations
- Children's community teams
- Children's palliative care steering groups
- Paediatricians
- G.P's
- Midwives
- Children's hospices
- Fundraisers
- Schools, churches & community groups



Francesca and Josephine



Billy-Rose

WHAT TO EXPECT

An interactive workshop that can be tailored to your individual needs.

Including:

- Examples from the family's stories.
- Presentation and exploration of key concerns.
- Opportunities for interactive contributions and group work.

What workshop participants have said:

"Very powerful workshop, lots of food for thought to improve my own practise when dealing with bereaved families" -Children's Hospice South West

"Really valuable for hospital professionals and trainee doctors" -Children's Palliative Care Network South West

"Moving and Insightful" -Student Nurse

AREAS COVERED

- Diagnosis-the day life changes and how this affects all concerned.
- Home coming
- - Adapting to the 'new now' by the family, friends and siblings, including those with the same condition and those without a condition.
 - Involvement of services and professional support teams.
- Hospital experiences
- Transition from child to adult services
- Quality of living and dying
 - Palliative Care
 - Respite care provided by the Children's Hospice/Children's hospice at home.
 - End of Life
- Supporting Bereaved Families

For more information and to book please contact Julie and Josie on:

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and visit our website

www.togetherwematter.co.uk