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P-13 THE PURPLE GROUP – DEVELOPMENT OF A PARENT-LED BEREAVEMENT GROUP – THE JESSIE MAY EXPERIENCE

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Jessie May is a children’s hospice at home charity which was founded in 1994 by the parents of Jessica May following her death aged 4½ months. Whilst working with the families, Jessie May nurses recognised a need for bereavement support and began to offer parents telephone calls, support visits and send cards to acknowledge the children’s birthday and death anniversaries.

In 2010, a recently bereaved Parent Representative for the Clinical Governance Group observed that, as parents ‘need to grieve for themselves’, there was a gap in the Jessie May bereavement service and initiated discussions around the potential for a parents’ support group. Following this discussion, the parent representative worked with the bereavement lead to set up the Purple Group and trialled an initial four meetings. The core purpose was to enable bereaved parents to come together within a peer group to discuss the loss of their children and feelings around that loss, gaining support through shared experiences and would describe it as ‘therapeutic’ rather than a ‘therapy group’. No one would be pressured to speak, but parents would have the opportunity to share their stories and experiences.

So far there have been 26 meetings over six years. There is empathy within the group and parents listen to each other, giving respect and encouragement. Each meeting has no agenda or topic so parents can talk about anything they choose, although recurring themes focus around anniversaries, Christmas and expectations from others for parents to ‘move on’.

Meetings are arranged a year in advance to enable parents to plan ahead to attend as many meetings as they wish. Jessie May continues to seek informal feedback from parents and by conducting formal questionnaires to ensure they are providing a service that is useful and needed by all of the parents on the Jessie May bereavement caseload.

Carers

P-14 HCA FOR CARER SUPPORT AT HOME PILOT

Elizabeth Attwood. St Peter’s Hospice, Bristol, UK

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‘It has been wonderful for me as a carer’.

Context CNSs identified carers as the highest priority area for service development.

Importance Carers are expanding and are at higher risk of ill health compared to non-carers. Poor health can have a detrimental effect on the health and well-being of the person for whom they are caring (Carers UK, 2014).

Aim To provide a programme of support at home to enable carers as caregivers and to allow access to personal support for themselves.

Intervention A programme of visits by a health care assistant to patients and carers on CNS caseload. 43 carers received an average of five visits lasting three hours, totalling 210 visits and 562 hours July 2015 and March 2016.

Approaches included:

- Carer Support Needs Assessment (Ewing and Grande, 2013)
- Respite care
- Emotional support
- ‘Gentle Touch’
- Information giving
- Role modelling

Evaluation 10/43 carers returned the questionnaire (ONS, 2013). All the carers responded positively that the service has made a difference to them as carers.

8/10 gained a lot of benefit and the remainder gained some benefit.

A planned programme of visits and continuity of care led to trust in the health care assistant which enabled the carer to benefit from the service.

Impact on care	
Trust enabled respite	<i>‘I could leave the house without worrying’ ‘my husband was in good hands’</i>
Caring approach facilitated emotional support	<i>‘anxieties were dealt with’ ‘helped put things into perspective’</i>
Planned respite allowed personal support	<i>‘time to do essential things, that was important to us’; ‘a break from a stressful period’; ‘I could make plans around visits’.</i>
Practical advice enabled ability to care	<i>‘dealt with queries’; ‘guided my care of my husband’</i>
Good company reduced loneliness	<i>‘someone to talk to and laugh with’</i>

All carers felt that the negotiated day, time and duration of visits were convenient. Two would have liked more visits.

Future practice The importance of planning visits and continuity of care for carers to feel prepared to care and supported will be taken forward in a new respite service.

P-15 SHARE AND CARE – SUPPORTING CARERS TO CARE FOR PEOPLE WITH LIFE-LIMITING ILLNESSES

Catherine Thompson, Jackie Holmes, Stephen Oxberry, Michael Crowther. Kirkwood Hospice, Huddersfield, UK

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Share and Care is an innovative project developed within the hospice setting run in collaboration with a carers charity and the local authority to improve support, knowledge and education for carers of individuals with life-limiting illnesses. The course was designed to deliver specialist support to carers, an area for development identified within the hospice User Forum.

Share and Care provides sessions on a variety of topics including:

- Helping people to move safely
- Protecting vulnerable skin and preventing pressure sores