Abstracts

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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 Atwood. St Peter’s Hospice, Bristol, UK

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

Context CNs 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.

<table>
<thead>
<tr>
<th>Impact on care</th>
<th>Use of service</th>
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<tbody>
<tr>
<td>Trust enabled respite</td>
<td>‘I could leave the house without worrying’</td>
</tr>
<tr>
<td>Caring approach facilitated emotional support</td>
<td>‘My husband was in good hands’</td>
</tr>
<tr>
<td>Planned respite allowed personal support</td>
<td>‘Time to do essential things, that was important to us’</td>
</tr>
<tr>
<td>Practical advice enabled ability to care</td>
<td>‘I could make plans around visits’</td>
</tr>
<tr>
<td>Good company reduced loneliness</td>
<td>‘someone to talk to and laugh with’</td>
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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 Oxenby, 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

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- Helping people to move safely
- Protecting vulnerable skin and preventing pressure sores
• Nutritional needs and eating on a budget
• Fatigue management
• Developing coping skills.

Having a carer specific group allows the sharing of practical ideas and personal experience, as well as hospice staff being able to promote good practice, providing a forum for carers to engage with hospice services earlier for them and their families.

The three-week course is run every third month; each session lasting 90 minutes, enabling delivery to five cohorts per year. Between 2015 and 2016 the course was delivered to 70 carers.

Feedback gained following sessions suggested that the support and advice delivered was specific to their needs and delivered at the correct time to enhance confidence in their caring role when supporting their loved ones at the end of their lives. The course has been commissioned for a further 12 months by the Local Authority.

We have developed the scope of the Share and Care service to include a more informal drop-in service for carers supported by local carer support agencies known as “Carers’ Retreat”, supporting 85 carers in the last 12 months.

Carers play a vital role in managing issues for patients with life-limiting illnesses and the group provides practical support with this. Additionally it allows earlier access to more traditional hospice services whilst challenging stigma around the role of hospice care.

The focus group ascertained that hospices are confidently providing therapeutic activities, however, they were less confident that hospices provide sufficient information, training and education and supportive activities for carers.

Outcome The group agreed to produce a minimum standard for specialist palliative care providers/hospices in meeting carers’ needs.

Minimum standard for supporting carers by specialist palliative care providers/hospices
• Signpost those early in the trajectory to partner organisations
• Young carers
• Carer Support Needs Assessment Tool
• Moving and handling, the care towards the end of life and Caring in Confidence courses
• Leaflets and website
• Financial or benefit advice
• Supportive activities
• Therapeutic activities.