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

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

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

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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

- 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.

P-16 CLARIFYING THE ROLE OF THE HOSPICE IN SUPPORT AND ASSESSMENT OF CARERS AND DEVELOPING BEST PRACTICE

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In 2015, five hospice representatives across Hertfordshire and Bedfordshire met as a 'meet and finish' group to review the service that hospices and palliative care providers give to carers.

The aims of the group were to identify:

- Gaps in provision
- Types of assessment tools used
- Key learning from other services
- The need for services to collectively to reach more people.

The types of hospice support for adult family carers within the Hospice UK (2013) document "Supporting family carers: report on the evidence of how to work with and support family carers to inform the work of the Commission into the Future of Hospice Care" were used as a basis of the discussion:

- Information, training and education – moving and handling, disease process, prognosis, specific care tasks, medication, dying
- Supportive activities – Drop in sessions, self-help groups, walking or activity groups, volunteer visiting, art-making groups
- Therapeutic activities – one-to-one counselling, therapeutic support groups, drama, music or art therapy, relaxations or mindfulness classes, complementary therapies and psychotherapy.

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.

P-17 THE POSITIVE IMPACT OF PROVIDING A CARER SUPPORT PROGRAMME TO INFORMAL CARERS WITHIN A HOSPICE ENVIRONMENT SETTING

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Background Following a dissertation that was undertaken, research showed the biggest increase of carers over the last decade was with carers providing more complex end-of-life care (Carers UK, 2012). This led to recognising that the needs of carers were not being completely met by the service.

A project group was formed and six sessions were planned focusing on safe care, financial issues, equipment, difficult conversations, coping with dying, illness and the family, stress and anxiety, nutrition, heart failure, respiratory issues, skin care, and medication/managing symptoms.

Aim We aim to provide sessions supporting carers in their role, giving professional and topical information to empower them. Enabling them to maintain their relative at home, (Hinton, 1994, cited in Mcllfatrick, 2007) whilst gaining each others support so recognising they are not alone. Complementary therapy taster sessions were available for each visit.

Methods Carers were identified in a number of ways. To encourage positive dynamics group size was kept between eight – 10 people. Sessions ran over six weeks, supported by two volunteers and the facilitators. These were generally employees so were cost neutral. Leaflets were sourced on a variety of topics relevant to carers.

Results The pilot programme was undertaken with very positive feedback from carers and staff involved. The sessions were scored on a scale of 0–10. Average scores ranged between 8.2–9.5. This allowed sharing of information, peer support and awareness of the different support services available to them.

Conclusion Following the pilot session, the second course was planned having made adjustments based on the feedback received from carers. Equally this session evaluated positively and we now run the course twice a year. The first carers' group still met informally and have attendees of future sessions join them.