

P-18 **NEUROLOGICAL CARER WELL BEING PROGRAMME: A NEW INITIATIVE TO SUPPORT CARERS OF PEOPLE LIVING WITH PALLIATIVE NEUROLOGICAL CONDITIONS**

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Background The day hospice has observed a growing demand for services in relation to patients suffering neurological conditions, in particular the need to support their carers. Caring for someone with a progressive neurological condition can have a significant impact on their life both psychologically, emotionally and practically and a hospice setting is an ideal place to provide this support.

Aims

- To provide a specific carers well-being programme for carers of people with a palliative neurological condition.
- The aim of the programme is to develop carers' resilience through learning more about living with someone with this condition, enhancing their coping strategies and developing new ones, learning new practical skills, sharing experiences and gaining support from others in similar circumstances.
- To increase partnership working with MND specialist nurse and Parkinson's disease specialist nurse.

Method The hospice has gained funding from the Board of Trustees to extend the number of carers' groups.

In view of this, we have liaised with specialist nurses representing patients with Motor neurone disease and Parkinson's disease to discuss offering carer support.

A planning meeting is in the process of being established involving multi-disciplinary professionals from the hospice and specialist nurses to discuss and plan the well-being programme carers.

A pilot group is planned to start in July 2016.

Results The Pilot will be evaluated through a carer questionnaire and feedback from the specialist teams.

The results will be collated and presented to the Audit Group for approval of an agreed action plan.

If this pilot is successful, the group may be offered twice yearly.

Conclusion Living with a neurological condition can have a major effect both emotionally and psychologically on carers. This programme is an excellent opportunity to ensure they are supported both emotionally and psychologically improving quality of life for both carers and their loved ones.

P-19 **CARERS CUPPA – A SUCCESS STORY**

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Background In our locality, a carers' course was undertaken by an agency for years to support them to care effectively. Topics covered were; practicalities of caring; financial support; looking after yourself; the ongoing journey; and nutrition. Our hospice was approached by the care agency to work in partnership offering the same course.

Aims

- To support more carers of patients with a life-limiting illness or disability

- Provide opportunities for carers to meet socially and support each other facilitated by volunteers
- To work in partnership with external agencies, to reach out to diverse and hard-to-reach groups
- To reach carers, pre- and post- bereavement to enhance continuity of care for carers.

Approach Informal weekly carers meetings (Carers Cuppa) were established at different times and places indicated by previous evaluations. Sessions ran for two hours with volunteers and the care agency co-facilitating. Feedback was obtained from the attendees.

Outcomes Some carers developed friendship extending out of the group setting. Carers supported one another, sharing information, ideas, problems and other supportive services. There was opportunity to speak to nursing staff and somewhere private to go if things got too much. Over the year, numbers attended increased to over 200.

We also noticed a need for a group for bereaved carers, due to the number of carers experiencing the death of their cared-for person. Providing a Bereavement Cuppa allowed for smooth transition from the Carers Cuppa to the bereavement group.

Conclusion The feedback has been highly positive, identifying what the group means to carers. By utilising volunteers we have provided support at a small financial cost, but with huge benefit to carers. Due to the increased demand, we have further plans to increase the number of sessions

P-20 **DEVELOPMENT OF A HOSPICE CARERS' STRATEGY**

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Background Approximately 500,000 carers support relatives and loved ones at the end of life. Around 90% of those with incurable illness spend the majority of the last year of life at home, often with limited support; the prevalence of anxiety and burden for carers increases in the last year of life (Ramirez *et al.*, 1998).

Aims and objectives To raise the profile of carers' needs; to develop effective carer/staff partnerships; to respect carer experience and expertise; to enable and support carers to remain carers for as long as they wish; to develop services independently and with local partners; to develop a strategy based on service user and staff experience to take forward in meeting the needs of carers in the future.

Design Formation of a hospice steering group; workshops with current and bereaved carers; workshops with clinical and non-clinical hospice staff; thematic coding analysis; presentation and consultation of findings with participants. Development of task and finish groups to take forward recommendations made.

Findings key themes identified include the external image of hospices as places to die; variable knowledge of hospice services in the acute sector, particularly amongst medical staff; transition challenges from cure to palliation; carers' needs not always acknowledged; the physical and emotional impact of being a carer; the end of life heralds a challenging phase for carers.

Conclusion Carer needs in end-of-life care are not formally assessed and carers can experience physical and emotional problems without intervention. We are working to raise awareness of the hospice role and services available, which include local publicity campaigns, carer assessments and a number of carer-tailored support strategies including practical sessions and advice on emotional and physical wellbeing for carers, and the introduction of a