- The majority of the sample were referred to specialist palliative care teams in their last week(s) of life
- Access to formal supports and care packages varied throughout the country.

**Future plans** A report will be made available online with the findings of this audit. This includes recommendations for people with dementia, for family members, for staff and for service planners. Information will also be shared with all of the specialist palliative care teams.

# P-138 LOSS AND GRIEF IN DEMENTIA

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**Background** A range of losses occur throughout a person's journey with dementia. Losses occur for the person and for their families as the disease progresses. Grief as a result of these losses is under-recognised and under-reported by people with dementia and their families.

Aim To develop a guidance document and factsheet to support healthcare staff to recognise, acknowledge and respond to loss and grief in dementia.

Methods An Expert Advisory Group (EAG) was convened. The group followed the NCEC approach to developing clinical guidance which included literature reviews, consensus building and consultation with key stakeholders.

**Results** The guidance document and factsheets are available to support healthcare staff in working with loss and grief in dementia. The document has four key considerations for staff to use as good practice when working with loss and grief in dementia. These are followed by four guidance areas which are responding to loss and grief, supporting the person with dementia experiencing loss and grief, supporting families with loss and grief and supporting yourself as a healthcare staff member. Resources will be listed for each of these areas.

**Conclusion** Recognising loss and grief as part of the experience of having dementia is a core part of good dementia care. Provision of supports to people and their families at transition points is essential.

Future plans This guidance document is one in a suite of seven guidance documents developed relating to different aspects of dementia palliative care. A dissemination plan has been developed to ensure findings and guidance are implemented and evaluated.

### P-139 CREATING A DEMENTIA FRIENDLY HOSPICE & COMMUNITY CORPORATE PARTNERS

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10.1136/bmjspcare-2016-001245.162

In 2015 the Douglas Macmillan Hospice launched a project to become dementia friendly as we are supporting more patients with a primary or secondary diagnosis of dementia. Staff undertook the Dementia Friends Champion training and to date we have over 300 dementia friends, staff and volunteers, throughout the hospice and retail outlets.

A cross-hospice working party is evaluating and adapting the hospice environment ensuring it is accessible to those who are

living with dementia. This has led to further discussions and adaptations for all those who have a disability.

Our in-patient facilities and community teams have implemented a Pain Scale Tool to ensure those living with dementia, who are unable to communicate verbally, have their pain effectively managed.

The hospice is engaged with local and national forums to share best practice and to shape and support the local community in becoming dementia friendly.

**Creating dementia friendly community corporate partners:** In January 2016 we launched the opportunity for our corporate partners to engage with the hospice in an entirely new way. As a way of the hospice giving something back for their support we offered to deliver Dementia Friends training to local companies and their staff. We have sessions booked to create Dementia Friends in our community with Hanley Economic Building Society and other hospice corporate partners.

**Case study: Stoke City Football Club** Stoke City Football Club have supported the hospice for a number of years, they received the highest Corporate Award the hospice offers and became a Platinum Corporate Partner for contributions made throughout 2015. Since we launched the scheme to our corporate partners over 80 members of staff at the football club have become Dementia Friends. The club is now aiming to become one of the first Dementia friendly football clubs with the support of the Douglas Macmillan Hospice.

#### P-140 'LOCAL PEOPLE HELPING LOCAL PEOPLE': A TEENAGER'S CONTRIBUTION TO DEMENTIA FRIENDLY SWAY

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**Background** In the UK there are around 800,000 people with dementia. Dementia friendly communities are places where more people understand dementia and people are supported to live well. Sway is a small village in the New Forest (population 3548). One of Sway Parish Council's strategic objectives is to help ageing people live well. As a carer and as part of her Duke of Edinburgh Bronze Award this abstract describes a 15-year-old's activity in supporting the parish council's strategic objective.

#### Aims

- To support people with dementia and their carers: 'Local People Helping Local People'
- To connect and collaborate with other local groups: 'Helping People Live Well'.

#### Method

- Dementia Friends sessions to parish council, girl guide groups, churches, interest groups, care homes and agencies as well as businesses (e.g. hairdresser, gardeners, and postmen)
- Role-modelling dementia friendly attitudes and behaviour *(e.g. there is more to a person than dementia)* in village activities, Saturday job in local coffee shop and monthly dementia friendly coffee and chat group
- Information animations to raise awareness
- Providing a teenager's perspective to local volunteer action group.

**Results** As part of Hampshire's Dementia Friendly Communities initiative and Sway parish council's objectives; business in Sway are becoming officially Dementia Friendly through attendance at Dementia Friends sessions and always having a dementia friendly helper on duty. There is partnership working between the parish council, other local charities, volunteer groups and the dementia action group.

**Conclusion** Dementia is a progressive terminal disease which benefits from a palliative care approach at all stages. Palliative care does not only have to be provided by health services or by adults. It can also be delivered by neighbours and community partners of all ages. Harnessing the experiences and passion of a community including teenagers (with school or vocational curriculums to meet) has the potential to support Dementia Friendly Communities where people live and die well with dementia.

### P-141 HOSPICE PHILOSOPHY IN DEMENTIA CARE: TAILORING INDIVIDUALISED TRAINING

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In June 2015 a partnership was formed in a health economy in the West Midlands between a hospice, CCG, council and a housing, health and social care organisation with the aim being to improve dementia and end-of-life care in care homes for a 12month pilot. The hospice and housing provider each provided a dementia support worker (DSW) with the focus of their roles being to help support, educate and signpost care homes within the borough to improve quality of life for people living with dementia.

The uniqueness of this pilot project has been the joint leadership and management between the two providers commissioned. Both have combined their knowledge and expertise to provide a seamless service to people living with dementia in care homes.

Within the initial 12 month pilot the DSWs have managed to make vast improvements. Within the first 12 months they have supported 33 out of 56 care homes providing individualised, bespoke support, training and advice to each home. They have also enabled 11 care homes to be part of the Activity Coordinator Forum, created by the DSW service; 8 care homes are now implementing elements of the Namaste Care Programme; three care homes have implemented Advance Care Plans as a result of the service and seven care homes have implemented the use of Pain Scales as a result of the service.

In addition to this there have been awards presented by the mayoress to celebrate four homes' engagement with the dementia support workers and also they have arranged for a dementia steering group to be formed that covers all professions and settings in the borough to ensure dementia patients get the same level of care, regardless of setting. It has been so successful it has been commissioned for a further 12 months with the focus being on improving dementia and end of life in the community.

# P-142 BREATHE BETTER – FEEL GOOD, DO MORE

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Breathe Better, a palliative chronic lung disease program run over five sessions within the hospice support and therapy centre, was devised as a collaborative initiative between the hospice team, the acute trust, community services and CCG, providing information and practical support signposting patients to hospice services and reducing avoidable hospital admissions. Allowing patients to access hospice services and improve symptom management in end stage disease, changes patients' perceptions and helps to improve quality of life and self-management.

Patients are referred to the course via healthcare professionals, have a Medical Research Council Dyspnoea Score of 4 or 5, and are invited to attend with carers.

Over the five sessions goal setting is a common theme and continually revisited reinforcing positive achievements and support when required. Sessions include; Medication management, Relaxation and anxiety, Care planning and Fatigue management. Exercises are also completed during each session in a controlled and safe environment.

From feedback, patients feel more confident in self-management and ability to perform their daily activities. There has been a significant increase in patients accessing hospice services and recorded future care planning. Patients are achieving their goals and carers report seeing positive differences. Timely input and support is also being given to patients as their condition deteriorates. Importantly, hospital admissions for the six months post Breathe Better are less than half than the six months pre- Breathe Better, at a time when arguably more admissions would be expected.

The programme demonstrates that hospices are perfectly placed to address unmet palliative needs for patients with end stage lung disease. We have the skills, expertise and environment to begin to address end-of-life issues with patients and carers and this project demonstrate the huge benefits hospice care can offer this patient group.

# P-143 CLAN CLUB... CANCER, LEADING A NORMAL LIFE

Myfanwy Howells. St Lukes' Hospice, Corringham, UK

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The St Lukes' Hospice Information Service provides information and support for individuals affected by cancer/life limiting illness at any stage of their journey. The Clan Club is a support group for children/young people aged 16–19 years with a cancer diagnosis ranging from diagnosis into survivorship and beyond. It also offers support to siblings and parents of children aged under six. There is no support group identified in Essex for this group of people.

The group provides the youngsters with the opportunity to meet peers, get support from trained facilitators and more importantly have fun. There are indoor and outdoor activities available and the youngsters are encouraged to partake as they are able. In the summer months there is greater emphasis on being more physically active with the winter months being more suitable to board/electronic games and creative activities. From a Macmillan grant other activities are funded e.g. bowling.

The adults have access to support for themselves. The sharing of information, hints and tips as well as managing the mire of tertiary care whilst ultimately getting the 'best' for their child are key themes of discussion.

All the individuals that attend the group have the opportunity to be referred to hospice services. This can include counselling