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## EVALUATING THE USE OF THE CARERS SUPPORT NEEDS ASSESSMENT TOOL (CSNAT): A PILOT STUDY

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Aim and objective To assess feasibility, acceptability and benefits of using the Carers Support Needs Assessment Tool (CSNAT) in a Day Therapy Unit (DTU) in a hospice setting.

Background The CSNAT is an evidence-based copyright tool designed by Dr G. Ewing and Prof. G. Grande which was introduced to the social work team on a study day organised by Hospice UK. It is designed to assess carers' needs in supporting a family member/friend at home towards the end-of-life. It uses a person-centred approach; providing carers with the opportunity to take control in considering, expressing and prioritising needultimately enabling the development of a shared action plan to support carers. It was identified that this tool dovetailed well with the current practice in undertaking an assessment in the DTU whilst giving the opportunity to undertake a more holistic assessment.

Method A six-month pilot commenced September 2015 in the DTU. A total of 36 carers were assessed using the CSNAT, adhering to the 14 support domains. There was representation of carers across Barking and Dagenham (B&D), Havering, Brentwood and Redbridge boroughs.

Results Overview of the findings showed 100% of B&D carers, 88% of Havering carers, 86% of Brentwood carers and 63% of Redbridge carers had needs. Concerns from carers were raised regarding illness progression, future symptoms and where to seek help if circumstances changed. Carers were able to prioritise need and demonstrate how they were managing them.

Conclusion This pilot study showed that the CSNAT is feasible and acceptable by carers with identified benefits, including carers knew they had been assessed; it promoted carers' autonomy and choice and enabled the development of action plans to provide support and timely signposting.

Implication CSNAT is being used routinely in the DTU and consideration will be made to use it within the inpatient unit and community services.

### Communities

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DEVELOPING AND IMPLEMENTING A COMMUNITY-BASED PROSTATE CANCER AWARENESS CAMPAIGN FOR HARD-TO-REACH MEN

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Introduction Black men in the UK have substantially greater risk of developing prostate cancer (PCa) compared with white men (PCUK, 2013). This initiative aims to raise awareness of these risks and signpost this group of men to appropriate services that are available. We aim to explain this risk in a clear way that men can relate to and understand their risk.

Method This proactive project will build upon and develop initiatives with key members of the Black and African Caribbean (AC) community through the Benjamin's Brothers project at John Taylor Hospice, a concept set up with the local community, including religious and community leaders, carers and prostate cancer survivors, with clinical support from primary and secondary care.

Results Recruitment of 'health activists' to support and enable men and their families to live longer with PCa in the community closer to their homes offers many benefits, including:

- Improved access to advice and support to equip men and their families with the knowledge, understanding and support to self-manage their health
- Provide men and their families with a point of contact within the community who can signpost them to the appropriate services, act as a liaison between the multifaceted multidisciplinary team across primary and secondary care setting
- By providing support and education to the GPs who monitor these men in the community setting, to enable men to have access to advice and support
- Offer a new way of working and enhances the way information and support is disseminated through these communities.

**Discussion** The aim of the post is to:

- Offer advice and support to men of AC Heritage
- Enable those with PCa to lead as full a life as possible, taking the whole family context into account.

This gold standard ambition for people, designed with health economics in mind envisages a change to the PCa survivorship landscape.

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#### ORAL HISTORY PROJECT – ST RICHARD'S HOSPICE, 30 YEARS OF MEMORIES

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In 2014 at the 30th anniversary celebrations for St Richard's Hospice there was an overwhelming feeling from those present that the memories and experiences of those involved in the foundation of the hospice should be recorded for prosperity before it is too late. The project 'St Richard's Hospice Voices' has collected digital recordings, photos and documents charting the creation of the hospice from kitchen table to the present building and services offered to date. The project has been funded by the Heritage Lottery (HLF) as it is considered this project is 'of immeasurable heritage value' and the HLF were pleased to support the capturing of evidence for 'moments in history when palliative care changed dramatically with the emergence of the hospice movement in the UK'. Lord Howard supported the application stating 'the hospice movement has grown significantly over a 50 year period and we are fortunate to have many of their original founders still available, however, this scenario is a changing one and it is becoming increasingly important to capture their memories and thoughts as a record for in perpetuity'.

The full interview recordings are to be archived at the Worcestershire Record Office at the Hive (part of the national archive) providing researchers of the future a snapshot of the changing face of palliative care between 1984 and 2015. All the recordings and photographs are on the hospice website.

We have thoroughly enjoyed working on this project and would love to share the results and more about how we secured funding for this project through the HLF.

We have an audio post with a snapshot of some of the recordings. The display is portable as we intend to move it around our community over the coming months.

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# SIMPLE ACTS OF KINDNESS: RESPECTFUL BURIALS FOR NEEDY MUSLIMS WITHIN A HOLISTIC END OF LIFE SERVICE

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Background Although the specific end-of-life needs of Black and Asian people have been discussed in some detail, relatively few Muslim communities have been involved in developing end-of-life services. Important religious imperatives for Muslims include not only having a funeral as soon as possible, but also avoiding cremation. Although it is customary for Muslim communities to spontaneously help with burial costs for the needy, there is increasing funeral poverty across the UK. Since burials are even more expensive than cremations, there are significant practical and financial pressures on dying Muslims and their families. Muslim community members in East London have therefore developed a Muslim Burial Fund.

Aims To ensure that needy Muslims are helped with the practicalities and financial costs of a respectful Muslim burial, as part of a holistic end of life service.

Methods The Muslim Burial Fund has responded to the specific requirements of needy dying or deceased individuals. Services offered have included: hospital and home visits; help with statutory declarations; help with Social Fund applications; helping fund, organise and attend funerals and burials; funeral prayers; and supporting family and friends. If necessary, a Rapid Response Team carries out 24/7 visits when a person is nearing death.

**Results** So far, 18 Muslims have been given free and personalised burial support. The initial focus has been on the neediest: those with no next of kin; those who have no Muslim family; and Muslims found dead by the police.

With increased experience and knowledge, the aim is to sustainably expand the service.

Conclusions The Burial Fund provides a simple act of kindness. By breaking the community taboo around discussing death, the service also promotes engagement with a local Muslim befriending and advocacy service for those nearing end-of-life.

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#### **VOLUNTEERS: RESOURCES OR PEOPLE?**

Sally Muylders. St Joseph's Hospice, London, UK

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The hospice movement has been built on the efforts of volunteers and their contributions continue to be essential for the survival of the movement today. The impact of the work volunteers undertake is often quantified in terms of benefit to the hospice in financial terms or in additional services provided to patients, but the impact on the volunteer themselves and on the wider community is often overlooked. This is an essential component of a community development or compassionate communities approach. This presentation will assume a new perspective and

argue that a volunteer-focused perspective is essential in developing a community development approach in a hospice, but that this often sits at odds with a predominant patient-focused view.

Compassionate Neighbours is a community development project run through a large hospice which aims to start a social movement to transform the experiences of those affected by death, dying and loss. A key component of this is the training of community members to become 'compassionate neighbours' and visit people locally in need. The project manager is responsible for recruiting, selecting, training and supervising the compassionate neighbours and managing their position within the hospice. The manager does not see them just as a resource for the hospice to use but rather sees their personal development, their relationship with the hospice and their understanding of its work as key outcomes in their own right.

This presentation will use a case study approach to explore this situation in more detail, making use of evidence from the project evaluation to explore issues of risk, autonomy and the difficulties of starting community development projects where the outcomes are difficult to specify in advance. The outcomes of this approach including a buddying system, community champions and the acceptance of the project in the wider community will be presented.

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#### WELCOME TO THE MILL, ST CATHERINE'S PARK

Lynn Kelly. St Catherine's Hospice, Preston, UK

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Background The Mill, St Catherine's Park is to help address the feelings of apprehension and abandonment many patients feel about 'entering' palliative care or when they are discharged. Prior to The Mill opening, 96% of hospice patients, staff and volunteers surveyed felt that an informal and welcoming drop-in centre could help to overcome this. In November 2014 The Mill, St Catherine's Park opened – a community hub with a welcoming cafe on the ground floor and therapy rooms on the first floor.

#### Aims

- To promote independence through specialised information, advice, counselling, therapies and peer support in a relaxing, therapeutic environment
- To provide continuity of care to reduce apprehension and isolation
- To engage with the local community and change public perception of hospice care.

#### Method

- Use of volunteer 'advisors' to provide help, support and information to people to encourage independence and choice.
- New patient education programmes to encourage independence and choice
- A new drop-in coffee morning for patients to overcome loneliness, anxiety and feelings of abandonment.
- A timetable of gentle exercise activities such as a tai chi and yoga.

#### Results

 Creation of an informal, non-clinical environment for patients and families – 'it was so good to have somewhere in the grounds to go for some rest and relaxation; thank you so much for the haven you offered at this time'