

END OF LIFE CARE

CASE STUDY

Marie Curie Hospice, Cardiff and the Vale

Increasing the number of people from a Black, Asian and Minority Ethnic (BAME) background accessing palliative care services

Background

An increase in the number of patients from Black, Asian and Minority Ethnic communities, who represent 15% of Cardiff's population, accessing palliative care services has been achieved through a project focussed on building links and networks with those communities, consultation and implementing changes suggested by them. Building on knowledge and relationships developed, it's had a significantly positive impact on people and their families living with a terminal illness beyond the hospice, wider community organisations and employers.

In September 2012, Marie Curie employed a keyworker at its Cardiff and the Vale hospice to work with people in local Black, Asian and Minority Ethnic communities to improve awareness of palliative care and to increase access.

The three year project, which is Big Lottery funded, highlights the importance of working with people in communities to improve awareness of palliative care, and ensure equal access to services and the wide impact of a focused approach.

Approach

- The aim of the keyworker role is to build relationships with individuals in local Black, Asian and Minority Ethnic communities, to understand and address barriers that may prevent individuals accessing palliative care services
- 130 community members were consulted
- The keyworker identified barriers experienced by individuals in these communities in accessing palliative care, need for community engagement to increase awareness and highlighted steps needed to improve access to services
- As part of the project evaluation, the Marie Curie Palliative Care Research Centre, based at Cardiff University, interviewed community members and hospice staff at the start and end of the project to understand the difference made. The keyworker was interviewed at regular intervals.
- Initial Research Centre findings included:
 - "Despite the fact some participants had worked in Cardiff for many years (including in healthcare), most had never been to the hospice and most had never heard of the hospice or knew that it cares for patients with other terminal illnesses, and not just cancer"

- “GPs are held in high regard. GPs play a very important role in providing information. There is a need to ensure that GPs understand Marie Curie’s services and refer patients from Black, Asian and Minority Ethnic backgrounds”
- “People from BAME backgrounds volunteer all the time in their day-to-day lives but do not see it, or name it, as volunteering. People are keen to help fundraise and volunteer and not just be seen as service users”
- Positive stories of patient experiences when accessing services were widely published through a variety of communication channels including the [BBC](#) and [local press](#).

Some changes from listening to the community and their impact

Sample changes include:

- An improved quiet room and washing facilities for prayer or quiet contemplation, furnished with religious items for different faiths for use by staff, patients and families
- Consideration of patients who may feel isolated when in the inpatient unit. To reduce isolation, the purchase of iPads and CD players for patients to use, for example to listen to prayers, books and make contact with relatives
- Review of policies and processes, for example large number of visitors, information for staff around diet, religion, the cultural calendar and defining common words in bedside information for patients
- Case scenarios highlighting issues from the perspective of patients and families when accessing services and a professional’s perspective were created, based in part on real stories to help learning for professionals
- The hospice saw a significant increase in the number of patients who had been under represented accessing the service since September 2012. 120 people from Black, Asian and Minority Ethnic communities were supported in both the inpatient unit and/or community services in the first two and a half years (September 2012 to March 2015). In the last quarter (April – June 2015) an additional 25 people have been supported.

Partnership working with stakeholders includes:

- Input into the Older People's Commissioner's Residential Care Review
- Advisory input into the planned series of Velindre's books for children whose family member had been diagnosed with cancer, which will be representative of the wide range of families and people across the community – [find out more](#)
- Member of the 2015 Cardiff Health Fair Planning Committee
- Cardiff University – training for interpreters
- Work nationally with EDF Energy's Black Asian and Minority Ethnic staff networks to increase awareness [find out more](#)
- Link person to disseminate information to community contacts

Due to the knowledge and relationships that have been built up, signposting support has benefited people in the community and stakeholders outside the hospice. Examples of signposting to organisations include:

- Support for a patient who needed immigration advice for their family to come to the UK
- Support for another patient to receive counselling in another language
- Support for a young patient experiencing isolation and for whom English was a second language
- Support for a student from abroad who was diagnosed with cancer and needed social and financial support.

Sustainability and spread

- A resource pack for staff with a directory of community based services that support people from Black, Asian and Minority Ethnic communities was developed. It is based on some staff questions when supporting patients from these communities. These include:
 - Writing an Islamic Will
 - Whole family support for a patient's family
 - Support to access a paid carer who meets patients' religious and cultural needs
 - Registering a death out of hours
- Volunteer community champions will continue to share/promote the message of Marie Curie within Black, Asian and Minority Ethnic communities
- A DVD was created to showcase the hospice and its services in six community languages with English subtitles to help share information about Marie Curie in local communities
- Written literature is now available in community languages
- A report published around barriers to access has been widely disseminated.
- Increasing Black, Asian and Minority Ethnic care needs on key stakeholders' agendas (for example on Cardiff and Vale's University Health Board's Local end of life delivery plan)
- Dissemination of lessons learnt and sharing good practice at national conferences and events including the Marie Curie Palliative Care Conference in March 2015 [find out more](#).

Weblinks and resources

[Marie Curie Palliative Care Research Centre, Cardiff](#)

[Improving access to palliative care services for people from Black, Asian and Minority Ethnic backgrounds in South East Cardiff](#)

[Support for ethnic minorities](#)

[Breaking down barriers: evaluating a Marie Curie Hospice project aimed at improving access to palliative care by ethnic minority groups – article](#)

[Marie Curie and Cardiff and Vale College work together to break barriers – web story](#)

To find out more about the support available from NHS Improving Quality for End of Life Care visit: www.nhs.uk/endoflifecare

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