

Gofal a chefnogaeth
drwy salwch terfynol
Care and support
through terminal illness



Improving access to palliative care for people with dementia, learning disabilities and people with different or no religious beliefs

A Big Lottery funded project in Cardiff and the Vale of Glamorgan

Summary report

August 2018



ARIENNIR GAN Y LOTERI
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Background

In January 2016 Marie Curie launched the Big Lottery-funded Including Diverse Communities in End of Life Care project. The goals of this three-year project were to explore the needs of three groups of people living with a terminal illness in Cardiff and the Vale, and to work to reduce barriers to access to our services. The groups included in this project were identified based on current research around gaps and challenges in palliative care provision, and through consultations with members of these groups in Cardiff and the Vale. These groups were:

- People with dementia
- People with learning disabilities
- People with different or no religious beliefs.

This report summarises the findings, recommendations, and actions of the project. To date the project has implemented a range of changes which are shared here, along with wider recommendations for what needs to be done to improve access.

Over 18 months the project consulted with 368 people across the three groups to identify the barriers to access. Participants included those with lived experience of dementia, learning disabilities, and different belief backgrounds, as well as carers, social care professionals, healthcare professionals, and researchers, within Cardiff and the Vale. Faith and belief backgrounds of participants included Christian, Muslim, Buddhist, Hindu, Jewish, humanist, and non-religious. All participants had heard of Marie Curie prior to consultations and many shared positive experiences and impressions of Marie Curie's services, in two key areas:

- **The support Marie Curie gives to families and carers.** People appreciate the emotional support provided and keeping loved ones involved and informed in a patient's care.
- **Person-centred care.** Many people talked about nurses' compassion, communication skills and how the staff support patients' choices through advance care planning.

Barriers

The three groups the project worked with have a wide range of needs and face a wide range of challenges and barriers to accessing healthcare services, including palliative and end of life care. Some barriers were identified across all three groups and this report will begin with those wider-ranging barriers identified before outlining the barriers identified for each individual group.

- **People's understanding of who could access our services was often limited.** Many people assume that we only support people with cancer, and most participants did not know that people with dementia could access palliative care.
- **A limited understanding of palliative care** was recognised as a factor in reducing people's access to services. Many people told us they still perceive hospices as a place people go to die, instead of going in to have their symptoms controlled and support to live the rest of their life.
- **Social care professionals shared this lack of knowledge and understanding about palliative care and our services.** As social care services are often the point of entry for people with learning disabilities or dementia to get different types of support, this raises concerns about how they can be expected to access services that they need through social care professionals.

- **Misconceptions about assisted dying could impact access to care.** Assisted dying is currently illegal in the UK and Marie Curie is not seeking to change the law in this area. However, people's understanding of the differences between assisted dying and end of life care, as well as their personal views and wishes regarding assisted dying, may prevent them from accessing our services or mean that they feel let down if our services don't meet their expectations.

Barriers for people with dementia

- **Lack of a formal pathway to palliative care for people with dementia** can make it harder to access these services. In addition, carers and people with dementia told us they often feel they have to fight to access the support they need, as the range of health and care services they access aren't well-linked.
- **Dementia isn't always recognised as a terminal condition**, despite being both progressive and incurable. As a result, many people with dementia told us that medical professionals don't talk about advance care planning or palliative care with them.
- **Limited availability of palliative care services makes it harder for people with dementia to access services.** Due to less recognition of the benefits palliative and end of life care can have for people affected by dementia, people felt that people with dementia were seen as less of a priority when palliative care services are limited. We also heard that disputes between health and social services regarding funding can delay access to palliative care services.

Barriers for people with learning disabilities

- **Carers and professionals may try to "protect" a person with a learning disability from talking about death.** Professionals told us that this can mean a person with a learning disability is not told that they are dying and they don't have the chance to make choices about their end of life care. This can make it difficult to provide this care. People with a learning disability have a right to know about their own health and be listened to and involved in decision-making about their health and care.
- **Communication needs not being met** can reduce a person's access to services if they are not given information in a format that supports them to understand what is available. People with learning disabilities told us a lack of appropriate information can lead to fear and make them refuse a service.
- **Non-healthcare professionals not being listened to** can mean that people with learning disabilities miss out on palliative care services. We know that social care professionals can be a key point of contact for people with learning disabilities and their role in identifying changes in a person's health should not be underestimated.

Barriers for people from religious and non-religious backgrounds

- **People from different religious backgrounds expressed concerns about palliative care staff's ability to meet their spiritual and cultural needs.** They emphasised the importance of ensuring that staff ask people what their spiritual and cultural needs are and of informing patients how these needs can be met. They said it would be important to be able to receive spiritual support from someone who shares and understands their beliefs.

- **Language barriers** can limit people's access to healthcare services or lead to lower quality of care. People told us that interpretation services such as the language line are not always used by healthcare professionals and that if services rely on family instead of interpretation services, this can put more pressure on families at an already vulnerable time.
- **Lack of non-religious pastoral support** can prevent people who are non-religious from accessing services. Some non-religious participants told us that they would fear evangelism or discrimination at a vulnerable time in their lives, and that it is important to them to be able to access support from someone who shares their beliefs and worldview.

Recommendations

The following recommendations were developed by analysing the feedback we received and identifying key themes and areas for improvement. These recommendations fall within three thematic areas: community engagement, building inclusive services, and increasing flexibility of services.

Community engagement

1. Awareness raising activities need to be part of Marie Curie's core services and delivered at the local level, making a long-term commitment to engaging with the communities we serve.
2. Information in a variety of accessible formats should be widely available in community, health and care settings. It should include key information and messages which counteract common misconceptions that can serve as barriers to accessing services.
3. As recognised national experts in palliative and end of life care, Marie Curie should work to educate both professionals and the public around palliative and end of life care.

Building Inclusive Services

4. Palliative care services should actively focus on connecting with belief-based communities and exploring new ways of providing spiritual care, to facilitate pastoral care being provided to patients of all faiths and none and enable choice in how this care is provided.
5. Palliative care staff should be supported to develop understandings of different spiritual and cultural beliefs and practices and to have open conversations with people about what their beliefs mean to them and how these beliefs can be supported.
6. Palliative care staff should be supported to understand how dementia and learning disabilities impact on a person and their care experience and consider this in care planning and delivery.
7. Hospices should consider the accessibility of the environment to different groups and ensure that any future refurbishments take into consideration accessibility needs for all.

More Flexible Services

8. Social care and palliative care services should work more closely to ensure better identification of patients with palliative care needs. This may include taking direct referrals from key social care professionals to enable easier and faster access to care when it's needed.
9. Marie Curie should work with service planning bodies across health and social care to explore service models which would enable earlier interventions, particularly for people with dementia, to ensure people can be supported well for longer in their place of choice.
10. Marie Curie should consider delivery of advance care planning services not linked to receiving any other services, to encourage more people to prepare for future end of life needs.

Changes made and planned within Cardiff & the Vale

- **Marie Curie Hospice, Cardiff and the Vale is working to become a Dementia Friendly hospice.** Since making our pledge in 2017 we have worked with a group of people with dementia and their carers to identify areas for improvement to make the hospice more accessible. In line with our Dementia Friendly plan we have installed bilingual (Welsh/English) pictorial signage to identify key rooms such as toilets and lounges, and the project is supporting ongoing refurbishment in the hospice to ensure that any changes made take into account the needs of people with dementia. The project has made 82 Dementia Friends within Marie Curie in Wales and there are now Dementia Champions in the hospice committed to delivering Dementia Friends to all new staff.
- **A new dementia training course has been developed for Marie Curie staff.** We have worked with a local dementia trainer to develop this and ensure that it meets the specific needs of our staff providing care to people with dementia at the end of life. The training has increased staffs' confidence in supporting patients with dementia, and key staff across our services in Wales will become trainers so that this course can continue to be delivered to new staff in the future.
- **We are working with people with learning disabilities to develop informational videos about Marie Curie's services.** One video will talk about what it's like to be cared for by Marie Curie and one will share information for people with loved ones being cared for by Marie Curie. Cardiff People First, a local learning disabilities self-advocacy groups, are working with us to develop and produce the videos. These videos will be available on our website to support people to understand more about our services.
- **The project has supported the development of the hospice's new spiritual care service.** The spiritual care coordinator leads this new service and acts as a liaison between the hospice and different religious and spiritual communities across Cardiff and the Vale to enable patients in the hospice to be supported. Since coming into post the spiritual care coordinator has developed a new and inclusive spiritual care service and through this work has supported staff to better understand and meet the spiritual needs of patients. She is currently working to recruit a diverse team of spiritual care volunteers, including people from different faith backgrounds and non-religious backgrounds.
- **We have supported our services to improve the collection of patients' religion and ethnicity data and supported staff to ensure religious and cultural needs are considered in delivering person-centred care.** Staff did not feel confident talking to patients about their religious, spiritual, and cultural needs, so they were not always asking about them. There were also gaps in the processes for collecting this data. With the introduction of a new digital patient records system, collecting information on patients' religion and ethnicity became mandatory and the project manager and spiritual care coordinator trained staff on how to ask these questions and how to talk to patients about their spiritual and cultural needs. The hospice is now collecting this information for more than 80% of all patients, with the remaining portion being those who choose not to or are unable to answer. We now know that all patients are being given a chance to discuss these needs. Other Marie Curie hospices are looking to replicate our success and we are looking at how we can use this process to improve collection of data on other protected characteristics.
- **The project has focused on delivering community engagement and education opportunities across all three groups.** People told us how important it was for Marie Curie to work to improve people's understanding of, and access to, palliative care services. The project manager has worked with our nursing and allied health teams to deliver education and awareness raising events to a range of audiences, including health and

social care professionals, community leaders, and the general public in settings such as community centres or places of worship. The project has reached over 2000 people directly through face-to-face events. Although talking about palliative care and death can be difficult, we found that these events are well-received once the initial barrier of the topic is broken. People value the opportunity to learn about new services and ask questions. Key messages can be delivered, including that Marie Curie supports people with any terminal illness and that we have a wide range of services in the community in addition to our hospice care. By being present in the community, our project manager has been able to signpost people and organisations to Marie Curie's services or to other local services. Education sessions with community leaders or professionals have also received positive feedback on the impact they have on people's understandings of Marie Curie's services, and supporting people to feel better equipped to support others affected by terminal illness. This work has highlighted the role that education and involvement in the community can help more people to access our services and promote our work as a charity.

Conclusion

This project has improved our understanding of the barriers faced in accessing palliative care services for people with dementia, learning disabilities, and people with different or no religious beliefs. It has allowed us to work directly with these groups to ensure their voices are considered as we plan, develop and deliver our services and their feedback has enabled us to make changes to both increase access to and to improve the inclusivity and accessibility of our services. These outcomes and recommendations will continue to support Marie Curie beyond the project, in line with our current strategic objectives to reach more people affected by terminal illness and to improve the way terminally ill people are cared for in the UK. We also hope that the information shared in this report can be of value to other service providers, both within palliative care and the wider health and care sector, in supporting equitable access to palliative care services for all people.

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Dementia Engagement and Empowerment Project (DEEP)
Dimensions
Diverse Cymru
Humanists UK
Interfaith Council for Wales
Learning Disability Wales
The Mentor Ring
Mirus
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Vision 21

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We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

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