

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

Project Report

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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.

People with dementia

Dementia has been the leading cause of death in England and Wales since 2015, the same year the Marie Curie report *Living and dying with dementia in Wales*¹ was released. This report identified many barriers to accessing end of life care for people with dementia, including the lack of recognition of dementia as a terminal condition, advance care planning not being done early enough, and failure to refer people with dementia to palliative care services. In 2012, the NHS Wales Informatics Service found that only 3.8% of people who died in Wales with dementia as the underlying cause of death had been formally identified as having a palliative care need or receiving palliative care services. The report also recognised inconsistent care standards when people with dementia do access palliative care.

People with learning disabilities

In 2013 the *Confidential inquiry into premature deaths of people with learning disabilities* found that men with learning disabilities died on average 13 years sooner than the average UK male population, and for women this difference rises to 20 years. Despite 57% of deaths included in the inquiry being 'expected', only 20% of these received support from specialist palliative care services². Initial consultations with people with learning disabilities, their families, and professionals in Cardiff and the Vale found limited knowledge and understanding of palliative care services and people felt that this lack of awareness limited their access to services.

People with different or no religious beliefs

From 2013-2015 Marie Curie ran a project to improve access to palliative care services for minority ethnic communities. Although this project was not focused on religious groups, there were participants from Hindu, Muslim, and Jewish backgrounds and cultural sensitivities around death and dying linked to faith emerged. The project found that the two biggest barriers to accessing services were lack of awareness of services and anxieties around whether religious or cultural needs could be met. In addition, a growing number of people in the UK now identify as non-religious, with this being the second most common religious identity in Cardiff and the Vale reported in the 2011 Census, by 32% of people. For people who are non-religious there can be barriers around not receiving appropriate spiritual care, if the only services available are provided from a religious perspective.

In this context the Including Diverse Communities in End of Life Care project set out to find out more about the needs of these groups of people and the barriers faced in accessing palliative care and to make it easier for them to access our services. This report summarises the findings,

¹ Marie Curie and the Alzheimer's Society. 2015. *Living and dying with dementia in Wales: barriers to care*.

² Heslop, P et al. 2013. *Confidential inquiry into premature deaths of people with learning disabilities (CIPOLD)*. Bristol: University of Bristol.

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 a period of 18 months, 368 people shared their views through focus groups, online surveys, telephone, email, and face-to-face conversations. Participants came from a wide range of backgrounds including those with lived experience of dementia, learning disabilities, and different beliefs as well as carers, social care professionals, healthcare professionals, and researchers. Faith and belief backgrounds of participants included Christian, Muslim, Buddhist, Hindu, Jewish, humanist, and non-religious. Though scope was primarily focused in Cardiff and the Vale, some exceptions were made to include groups within South Wales whose own structure did not function in this way and who were keen to participate. All quotes throughout the report come from people who were consulted.

All participants had heard of Marie Curie prior to consultations and many shared positive experienced and impressions of Marie Curie's services, which fell into two thematic areas: family and carer support and person-centred care.

Family and carer support

Participants highly praised their experiences of Marie Curie including family and carers in a patient's support and keeping them involved and informed.

Many people said they valued the expertise that Marie Curie brings: *"You are there, you have seen a lot of situations, you know how to handle them with compassion and that I think is something that is so important, especially with families."*

Person-centred care

There were many comments about the calm atmosphere and sense of reassurance within the hospice, and participants had very positive perceptions and experiences of Marie Curie's support in all settings. One participant said, *"There is often an enhancement of life"* for patients cared for in the hospice. Many people talked about nurses' positive communication skills and ability to provide emotional support, and how the staff *"make it alright to ask questions and helping people to live with an end of life diagnosis."* This linked in with stories shared of work staff had done *"supporting patient's choice"* through advanced care planning.

What stops people from using our services?

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 before outlining the barriers specific to individual groups.

“So it isn’t just cancer?”



Frequency of participant responses to question, "What kind of illnesses do you think Marie Curie help people with?"

Participants' understanding of who could access our services was often limited and many people thought we only supported people with cancer. Those who did name other conditions were often uncertain as to whether we did support people with those conditions. Significantly, most people affected by dementia who contributed to our consultations were unaware that people with dementia could receive palliative care services and uncertain about when and how this could happen.

People had limited knowledge of the specific services available from Marie Curie unless they had personal experience with us. Inpatient services were mentioned slightly more frequently than nursing and support services at home. People had less awareness of community services, day therapies, and information and support services. In focus groups people would mention that Marie Curie "provide advice or support" but few knew how this could be accessed or that our Information & Support materials are available to the public.

Social care professionals shared this lack of knowledge and understanding of palliative care services. One support worker for people with learning disabilities said, "A pound for a penny the support worker wouldn't have that [knowledge] so it needs to be clear." Comments like this were common from professionals and raise concerns about how people with learning disabilities and dementia can be expected to access services as social care services are often their point of entry into accessing support.

What is palliative care?

A limited understanding of palliative care and different terminology used was also cited as a factor in reducing people's access to services. People discussed not understanding diagnoses and treatment options and that many people 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." They

told us that people may be confused about their prognosis and may feel that accepting palliative care services is “*admitting that this is the end.*” The importance of educating families was also discussed, as family influence can impact people’s decisions on accessing services:

“Somebody can be very ill and accept that they are ill but their family go into denial and because they know it upsets the family...they don’t talk about it.”

Many people, especially those with learning disabilities, felt that a better idea of what to expect when accessing services would support them to feel more comfortable doing so.

Concerns about whether interpretation services were available, perceptions of a lack of diversity amongst staff, and a fear of being placed on mixed-gender wards were concerns raised specifically by minority religious groups.

Assisted dying

“I’d like to end my life when I choose, not be cared for until my body says no. When my mind says enough, it’s enough.”

-Person living with dementia

As an organisation providing care, Marie Curie is focused on helping terminally ill people and their families live as well as possible and on the continued growth and development of palliative care services. While we support the existing rights of competent patients to refuse consent to medical treatments and recommend that patients actively plan for their future care, we are not seeking a change in the law to permit euthanasia or physician assisted suicide³. Despite this, participants across all groups seemed unclear as to what connection, if any, existed between assisted dying and palliative care services.

In one focus group, participants with dementia unanimously agreed that their beliefs related to assisted dying would make them reluctant to access end of life care services. All said they wanted to have some level of autonomy and felt this might be possible with a home death, but worried that this would be taken away from them if healthcare services were involved. The group was uncertain as whether assisted dying would occur in a palliative care setting and the legal status of assisted dying in the UK had to be clarified. A project participant with a learning disability asked for clarification of whether assisted dying was a part of palliative care provision.

Multiple non-religious respondents to the online survey mentioned assisted dying as something related to palliative and end of life care. One person whose mother had died in a Marie Curie hospice said, “*My personal experience [of end of life care] involves my mother believing...she would be helped to end her life. She actually said, ‘you lied, you said I wouldn’t suffer’.*”

Such examples highlight widespread misunderstanding of what pain management and end of life care mean. 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.

³ <https://www.mariecurie.org.uk/who/plans-reports-policies/ethical-statements/care-research>

Barriers for people with dementia

No pathway to access palliative care

“What about the people that don’t have anyone to fight for them?”

-Carer

Many participants discussed having to “fight the system” to get support for themselves or the person they cared for. People feel that primary care services, dementia services and palliative care services aren’t well-linked and healthcare professionals don’t discuss palliative care services early enough or often enough. People with dementia and their carers feel they must navigate their own care pathways where systems fail them, and worry that this leaves many people without access to services.

“Respite care doesn’t happen until you are in a crisis, perhaps end of life won’t happen until you’re in a crisis.”

-Nurse, younger onset dementia service

Carers and professionals also discussed the fact that dementia services are often crisis-driven rather than focused on early intervention and this may be the same with referrals to palliative care. Services which are provided at the point of diagnosis often focus on the short-term needs. An example is the Alzheimer’s Society’s Dementia Liaison service. Staff told us they may only see a person once or twice following diagnosis to signpost to other services, and it would rarely be appropriate for the dementia support workers to discuss palliative care or advance care planning if this has not been previously discussed by a healthcare professional.

We know that the end of life trajectory for people with dementia can be a much more prolonged and uncertain decline than for acute illnesses such as cancer. This, combined with the inequality of dementia services across different localities means that many people with dementia are missing out on services which could benefit them due to lack of a direct pathway to accessing palliative care.

Dementia not recognised as terminal

“It’s the GP saying, ‘Palliative care, shush now, why do you need that?’”

-Carer

People with dementia talked about how healthcare professionals had never talked with them about the terminal nature of the condition or about advanced care planning. Carers shared stories of being told palliative care wasn’t appropriate for loved ones with end stage dementia. People said they often feel unsupported by healthcare services and rely more on personal support networks and social care or community services. Yet carers and social care staff cannot make referrals to specialist palliative care services and are rarely trained specifically around providing end of life support. This makes the additional support that specialist palliative care services could provide even more vital, but participants felt that they did not trust that their GPs would make a palliative care referral when appropriate.

Limited service provision

Dementia is now the leading cause of death in England and Wales, but we know that few people with dementia die in hospices⁴. Participants expressed concern about limited availability of end of life care services and that consequently it can be even harder for people with dementia to access services, as patients with acute terminal diagnoses may be prioritised. One nurse working in a

⁴ Marie Curie and the Alzheimer’s Society. 2015. Living and dying with dementia in Wales: barriers to care.

dementia service in Cardiff said they had experiences of “*applying for patients and not being able to get it [the Hospice at Home service]*”. This service is only available to patients who meet fast track Continuing Health Care criteria, and people with dementia can often get caught up in disputes as to whether social services or health are responsible for funding their end of life care, causing delays in access to services.

Barriers for people with learning disabilities

Paternalistic culture of care

“Please don’t hide things from people with learning disabilities; you’d be surprised how much they understand.”

-Person living with a learning disability

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. But professionals supporting people with learning disabilities said that there can be paternalism both professionals and loved ones supporting people with learning disabilities. They shared examples of people with learning disabilities not being told a family member or friend had died or not being permitted to attend funerals as it was assumed this would upset the person too much. We also heard how families and professionals may not tell a person with a learning disability that they are dying as they feel they are “protecting” the person. Some professionals thought that this reaction could come from staff not feeling confident or comfortable discussing death with the person. However, this can make it challenging for appropriate support to be provided and prevents the person from being able to make choices about their care.

Communication

“It’s just people with a learning disability are aware of you, but they may be frightened to come over to Marie Curie. If they have been explained to them, what services and what support you give them, they may come over.”

-Person living with a learning disability

People with learning disabilities can have communication needs that impact how they understand information when it is given to them. Communication about health and palliative care needs should be tailored to the level of understanding that the individual has. People also told us they appreciate information in a wide range of formats, as different people communicate differently. These include Easy Read and audio or visual formats. When information is not accessible this can lead to misunderstandings and fear which may lead the person to refuse support. Failure to meet their communication needs can also prevent the person from having choice and control in their care.

Non-healthcare professionals not listened to

“We had one student who was feeling more and more unwell. The support staff [social worker] were dismissive of our concerns. Not long after, she died. We were the only agency picking up that there may be a problem.”

-Learning disabilities support worker

It is widely known that it can be difficult to recognise the end of life phase of an illness in people with learning disabilities, who are more likely to have unidentified health needs and complex comorbidities⁵. This story is one of many that we heard from third-sector support providers about recognising a person’s decline and being unable to access further support for that person as their concerns were dismissed. Social care professionals can serve as gatekeepers to accessing other services for people with learning disabilities, and can be in a powerful position to advocate on the person’s behalf. But if these individuals’ concerns are not taken seriously by healthcare professionals, this can be a barrier to people accessing palliative care services.

⁵ Care Quality Commission. 2016. *A different ending: addressing inequalities in end of life care*.

Barriers for people from religious and non-religious backgrounds

Limited spiritual and cultural awareness amongst staff

At a focus group with the Church in Wales, chaplains and clergy talked about patients not receiving appropriate spiritual care when clinical staff don't discuss religion or spirituality with the patient. They emphasised the importance of understanding a patient's spiritual needs through appropriate assessment and conversation. While this may not be a barrier to initially accessing services, it can be a barrier to ensuring that all patients have the appropriate support to meet all their needs while they are being supported. Members of the Jewish community also emphasised the importance of staff asking the right questions:

“People will have all shades of practice. Some people who are Jewish will eat anything and have no compunction whatsoever; others will be very strict...you need to ask every individual what aspects of their religion they actually practice or would like you to make an effort for.”

50% of religious people who completed the survey said that 'healthcare staff not understanding specific needs of culture and religion' would be a barrier to accessing services and 33% said 'concerns about staff understanding dietary requirements' would also be a barrier. This was reflected in feedback from members of the Hindu, Muslim, Jewish, and Buddhist communities, many of whom asked about staff's awareness of different religious and cultural needs and about how dietary needs could be accommodated. They also talked about the importance of maintaining community links and being able to socialise with people who share their beliefs. For some people this might mean staying at home, and they felt this choice should be made clear. But they also told us they recognise that this is not always possible and that it can put significant burden on families and carers. They said that better understandings of community services or of how they or their family member's needs would be met in a hospice setting would make them more likely to access these services. They also said they would like to know what spiritual care is available as for some people it is important to receive this from someone who shares and understands their beliefs.

Language barriers

“It may be that the only people to grasp the information are the younger generation and if they are interpreting for family members, they may not cope with the information.”

33% of those with a religious belief who completed our survey felt that language differences could prevent people from accessing our services. In written and group consultations, Muslim and Hindu participants expressed similar concerns. From their awareness and experiences, interpretation services such as the language line can have limited availability and are not always used. This can often shift the burden of responsibility onto family members, adding pressure at an already vulnerable time.

Lack of non-religious spiritual care

Hospice care and chaplaincy services have long been rooted in the Christian tradition, as both developed at a time when Christianity was the majority religion in the UK. As the country has grown more diverse there has also been a trend in growing numbers of people identifying as non-religious. 25% of the total population of Great Britain identified as non-religious on the 2011 census. There is an increasing need to consider how we can meet the spiritual and pastoral support needs of people who are non-religious within palliative care settings.

Many non-religious participants felt that concerns around how we provide spiritual care for the non-religious would be a barrier to their access to care. People said they fear *“religious evangelism and attempts to convert during times of extreme emotional stress”* or simply a lack of any provision of support for non-religious people based on an assumption that they would not need spiritual

support. Participants also shared how vulnerable one can feel in healthcare settings when this need is not understood, as reflected by this account of an experience in hospital:

“I had to hide under the blanket when the vicar came round...I didn’t have the strength to tell him ‘I am an atheist’.”

Such examples highlight that many people who are non-religious are wary of the influence that Christian chaplaincy has in a healthcare setting, and their concerns over how they will be treated and whether they would be able to access support from someone who shares their beliefs and worldviews can prevent people from accessing services.

Recommendations

We asked participants for feedback on what we could do to make our services easier to use. We analysed this feedback alongside the barriers to identify the key themes and to make recommendations as to how we can improve access. Some of these recommendations are already being taken forward within Marie Curie, but some reflect wider challenges and wider responsibilities and will require the support of commissioners and partner agencies.

Despite the differences between the groups and the different challenges faced, the project identified ten key recommendations which would help to reduce many of the challenges faced by all three groups. These recommendations fall within three thematic areas which are interconnected and support each other: community engagement, building inclusive services, and increasing flexibility of services.



Community Engagement

In the context of this report community engagement encompasses a wide variety of approaches to develop and sustain relationships between Marie Curie and the communities that we work in, with the goal of improving mutual understanding to:

- ensure our service design and delivery is appropriate to meet local needs,
- improve joint working between Marie Curie and other services and professionals to improve the quality of care for all, and
- improve public understanding of who we are and what we do.

Both within Marie Curie and nationally, there is a drive to ensure that more people with a terminal illness have access to the support they need year on year. People's understanding of who we are and what we do is vital to achieving this goal and in addition, to increasing fundraising and voluntary support of our services which will need to continue to grow for us to continue to meet this need. The importance of community engagement to increase access was highlighted as a recommendation in a recent report on inequalities in access to palliative care in Wales⁶.

Three major recommendations within this theme of community engagement emerged from the ways people told us that we could improve access to our services:

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.

We need an active presence within communities to educate people about who we are and what we do. This should include promotion of lesser-known services including community services, and our information and support services. Information should be tailored to suit the communities we are working with, accounting for any specific needs which may pose barriers to different individuals or communities engaging with these events, such as geographical location or language barriers. Participants saw it as Marie Curie's responsibility to be raising awareness not only of our services but about death and dying more generally, to encourage more people to talk openly about it, and felt this should be happening in a wide range of settings. This form of engagement can also serve to initiate a two-way dialogue and opportunities to build lasting relationships with communities and allow them a more active role in influencing service development.

People suggested a variety of community settings this work should be happening in, including:

- Community centres and day centres
- Libraries
- Schools
- Faith communities
- Other community groups such as Women's Institutes, Rotary clubs, lunch clubs—anywhere there are existing networks and communities.

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.

There is continual movement away from printed information and towards digital information, as more people are getting online and involved in social media. While participants felt that we should continue to grow our online presence, they also feel it is important that digital information does not replace written information and other forms of information sharing and

⁶ The Cross-Party Group on Hospices and Palliative Care. 2018. *Inequalities in access to hospice and palliative care.*

advertising. For people who are not online, availability of written information is vital and having leaflets available in settings such as community centres, places of worship, chemists and GP surgeries is more accessible to some than having to search for the information online.

People with learning disabilities highlighted the need for information in accessible formats such as Easy Read. They also told us that non-written formats could be a valuable way to lessen anxiety people may have prior to initially accessing services. One frequent suggestion was videos, such as virtual tours of the hospice, using accessible language to explain our services. Participants felt it was important that any information and resources being developed to meet specific needs involve people with those needs to ensure these resources are developed in a truly inclusive way.

Key messages that people felt needed to be included in our information included:

- That there is no charge to access services
- That we support patients of all faiths and none, and how we support patients' spiritual and cultural needs to be met
- Understanding the links between Marie Curie and other local hospice services or healthcare services such as district nursing
- How to be referred to Marie Curie services.

3. As recognised national experts in palliative and end of life care, Marie Curie should work to educate both professionals and the public about palliative and end of life care.

We know that a lack of understanding of palliative care can be a barrier to access, and that earlier involvement with the advance care planning process can ease some of the pressure on patients and families to have these conversations when end of life is imminent. We should be using our expertise to support people to think and talk more about death and to improve their understanding of palliative care. Commissioners of health and social care services nationally should also be drawing on our expertise and experience to inform the development of services.

Social care professionals involved in consultation were very interested in opportunities to receive training from Marie Curie around supporting people to discuss advance care planning and at end of life. With increasing numbers of people dying in care homes and supported living settings, non-specialist social care staff are increasingly being expected to provide care at end of life and would benefit from Marie Curie's support in building their understanding and confidence in this area. There is also a need for greater recognition among healthcare professionals of how specialist palliative care services can support patients with dementia and the impact this could have on improving the end of life experience for patients and carers (both professional and unpaid). Linking up with health and social care professionals in this way could be mutually beneficial as we recognise that these individuals hold expertise in other areas of development for Marie Curie, such as supporting people with dementia and learning disabilities, and educational systems could be built around a system of knowledge exchange.

Professional and public education about palliative care also needs to clarify people's understanding of what palliative care is and what it isn't—this could be an opportunity to examine public misconceptions of assisted dying being linked to palliative care and ensuring we communicate more clearly about the status quo in this area.

Building Inclusive Services

Marie Curie needs to ensure that services can provide high-quality care tailored to a range of individual needs and that staff are confident to understand and support a diverse range of needs. The following recommendations in this area arose from the project's consultations.

- 4. Palliative care services should actively focus on connecting with belief-based communities and exploring new ways of providing spiritual care, to facilitate spiritual care being provided to patients of all faiths and none and enable choice in how this care is provided.**

The hiring of a spiritual care coordinator to replace the traditional chaplain role with the Cardiff and the Vale Hospice reflects the hospice's recognition that one person and one approach cannot meet everyone's spiritual needs. This role was developed to facilitate greater diversity in spiritual support that is available through coordinating links with belief-based communities. It is important for people to be able to have choice in the support they can access and most people, regardless of their religion or belief, would prefer to receive spiritual care from someone who shares their worldview.

Palliative care providers should also consider the needs of community-based patients, who will not have access to the same levels of support as patients in the hospice. In this setting the ability to refer on to other community members and support providers would be a valuable way to ensure that patients have access to the equivalent support that they would be able to receive as an inpatient.

- 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.**

Both this project and previous projects have worked to improve staff understanding of different cultural and religious needs, including training around recognising and understanding these needs and sharing of resources about different faith and cultural traditions. Such resources should be recognised as a starting point for staff to gain an understanding of various elements of different cultures and religions but are always shared with the caveat that it is more important to ask patients what their beliefs mean to them and how they practice them.

In an increasingly diverse society people may feel under pressure to "understand" everyone and fear negative consequences if they get something wrong. Staff need to be supported to be comfortable with uncertainty and to recognise people they are supporting as the experts on their own beliefs and wishes. The ability to listen to a person and learn from them, about them, will be more valuable to that person's care than generalist knowledge about different cultures and religions.

- 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.**

With dementia continually on the rise we will continue to see an increase in the number of people with dementia accessing our services. This should be prioritised as an area of staff education, specifically around understanding the cognitive and emotional impact it has on a person and how this may affect their behaviours and communication. This is one of the areas that poses the greatest challenge in health and social care settings and getting this right can be the difference between a good and bad experience of care, for both the person and their support networks. Recognition of this need is growing nationally. A new dementia training

framework⁷ was released in Wales in 2017 and the Welsh Government released a five-year Dementia Action Plan⁸ in 2018 which calls on all health boards to commit to training their staff to meet these new training standards. Carers told us it would be very important for them to know that the staff providing care to their loved ones were suitably trained to support them.

While there are similarities in the needs of people with dementia and people with learning disabilities and how their cognition, capacity, and communication can be affected, it is important to recognise the conditions as different and ensure staff have access to training in both areas to be able to provide informed, high-quality care.

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.

The physical environment can have a powerful impact on people with dementia since dementia affects people's perceptions and senses. Many of the recommendations for Dementia Friendly environments regarding décor, colour, lighting, and signage also make environments more accessible for people with sensory loss, literacy issues, or other forms of cognitive impairment so investing in environmental improvements is investing in improved accessibility for a wide range of people.

More Flexible Services

The Palliative Care Cymru Implementation Board annual report for 2017 named earlier identification of palliative care patients as an area of focus, specifically for those with complex conditions. With people living longer and increasing numbers of people now dying from chronic, long-term conditions, one of the challenges for palliative care services is adapting a care system that has historically supported people dying with short-term, acute conditions. If Marie Curie wants to continue providing support to more people with a terminal illness year on year, we need to look at making our services more flexible for those whose terminal illness does not fit this traditional model of care.

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 referrals from key social care professionals to enable easier and faster access to care when it's needed.

We heard from many people about healthcare professionals not referring to palliative care services appropriately. A group of care home managers told us that when Marie Curie's support for people with dementia in their homes improves the experience for both the resident and staff, but that GPs do not always make the referral even when they recognise a patient is dying. People in care and supported living settings may be overlooked due to assumptions that their needs are being met. If professionals in these settings could make a referral this could improve rates of access to services at the right time by enabling a more direct line of contact.

We also heard from some religious groups that there could be stigma and discomfort associated with attending the hospice, so clinics based in community settings as a point of initial access might reduce some of these barriers.

⁷ Care Council for Wales, NHS Wales, Public Health Wales, and the Welsh Government. 2017. *Good Work: A Dementia Learning and Development Framework for Wales*.

⁸ Welsh Government. 2018. *Dementia Action Plan for Wales: 2018-2022*.

9. Marie Curie should work with health and social care partners 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.

People affected by dementia will need support and care over a much longer time, and it can be hard to identify when someone with dementia is in the final year of life. People affected by dementia told us that they would like to be able to receive support sooner, even if it is low-level support such as having a case manager to contact in a crisis, so that they and their carers would know the support was there when they needed it. This could be linked up with GP surgeries identification of patients with terminal conditions. Other services people suggested were support or activity groups for people with dementia and their carers within hospices, open to all regardless of whether the person were accessing other palliative care services. People across all three groups appreciated opportunities to visit the hospice as they felt it helped them reduce fear and they would be more comfortable if they ever needed the service, so running groups and clinics out of the hospice could be valuable in this regard. Service models looking at earlier interventions could also work well for linking up with social care settings to ensure people can be cared for in their place of choice.

At a time when health and social care services are under increasing strain, palliative care services have a role to play in delivering more prudent healthcare. Longer-term flexible services could allow us to support more patients, more efficiently, and ensure that when patients' needs increase they are already known to the right teams to receive the right care.

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.

The Palliative Care Cymru report also identified "people being well-prepared for the end of their life" as an area of focus, and this included increasing the number of people comfortable about talking about their own deaths and planning for them. This report has discussed improving this awareness as a public health responsibility for Marie Curie, but beyond education, participants told us that they value Marie Curie's expertise and would like to see a service that would support them through the process of advance care planning, prior to a terminal diagnosis and without accessing any other services.

For people with dementia specifically, it is important for advance care planning to happen early, while they still have the capacity to engage with it. Without targeted support to do this, it may not be considered until the person is accessing end of life care services, at which point they may be less able to engage. Having completed an advance care plan will help ensure the patient's wishes are known, which can reduce strain on both informal and professional carers.

Changes made and planned within Cardiff & the Vale

Becoming a Dementia Friendly hospice

In 2017 the Marie Curie Hospice Cardiff and the Vale pledged to work towards becoming a Dementia Friendly Hospice, in line with Alzheimer's Society's Dementia Friendly Communities initiative. A group of people with dementia and their carers visited the hospice to provide feedback on how the hospice's physical environment could be improved to be made more accessible for people with dementia, and their feedback helped shape our Dementia Friendly Plan.

To date the hospice has made the following changes:

- Improved bilingual (Welsh/English) and pictorial signage in the hospice to identify key rooms such as toilets and lounges
- Installation of "calendar clocks" which clearly show the date and time and are colour-contrasted for easy identification, to support patient orientation when on the wards
- Development of a dementia resource kit for each ward which contains various items to support patients with dementia, including items to support sensory stimulation and reminiscence.

The project is also supporting ongoing refurbishment in the hospice to ensure that the needs of people with dementia are considered regarding décor, such as in choice of flooring, paint colours, and lighting. New directories will also be purchased to support with wayfinding. Many of these changes will improve the accessibility of the hospice more widely, such as the pictorial signage which can also be helpful for people with learning disabilities or people whose first language is not Welsh or English.

In addition to this work the project has worked towards improving awareness of dementia across all staff. At the time of this report the project has created 82 Dementia Friends within Marie Curie in Wales, primarily hospice staff and volunteers but also some from community services. The hospice has committed to delivering Dementia Friends sessions as part of every new staff members' induction going forward using internal Dementia Champions.

Dementia training

Within the context of Marie Curie in Cardiff and the Vale providing care to increasing numbers of people with dementia over the last few years, the project identified the need for specific training around supporting patients with dementia. Currently Marie Curie staff can complete an online learning package developed by the Social Care Institute for Excellence and the Alzheimer's Society which provides a general introduction to dementia and the experience of living with dementia. It is not part of mandatory training for Marie Curie's clinical staff so completion rates vary.

Marie Curie staff in the hospice and across the Wales nursing services completed a survey to assess their confidence around supporting people with dementia, and to identify specific challenges they felt they faced in supporting people with dementia. We worked with a local dementia trainer to develop a bespoke dementia training package for Marie Curie, informed by the staff surveys and with a specific focus on supporting patients with dementia in a palliative care setting. This training package was initially delivered to all hospice nurses and healthcare assistants by the trainer, and subsequently key staff in both the hospice and our community services across Wales will be attending a train-the-trainer session so that they are able to support the delivery of this across our services going forward.

Comparison of pre- and post-training surveys shows evidence of the training's impact. Prior to the training 30% of staff said they felt "not at all confident" to support patients with dementia, while following the training all staff say they feel "fairly" or "very confident". Write-in feedback also

reflected that staff felt significantly more confident in understanding how dementia can affect people and how this will improve their practice in supporting patients with dementia. Importantly, many staff felt it shifted their perception in recognising that dementia is a terminal condition, highlighting why it is important that we can support these patients well in a palliative care setting.

Informational videos with Cardiff People First

In response to feedback from people with learning disabilities about the importance of having information available about our services in different formats, we are working with Cardiff People First, a local learning disabilities self-advocacy group, to create two informational videos about Marie Curie's services. One will talk about being cared for by Marie Curie and one will share information for people with loved ones being cared for by Marie Curie. They will focus on introducing people to our services in accessible language and will include a video tour of the hospice, to help give people more information before they visit or access our services and to reduce people's fear. Members of Cardiff People First have supported us to write the script and will be acting in these videos.

We are looking forward to having these videos available for use with people both with and without learning disabilities, as regardless of this many people can be afraid and uncertain about accessing palliative care services and we hope these videos will be a tool to help lessen some of these anxieties.

Development of spiritual care service

The project has supported the redesign of the hospice's spiritual care services with the aim of ensuring diverse and inclusive spiritual care is available to people of all faiths and none within the hospice. We worked with members of belief-based communities to support the development of the spiritual care coordinator role, a new post within Marie Curie. This role replaces a traditional chaplain role and is designed to ensure we can provide diverse and inclusive spiritual and religious care for patients and visitors at the hospice. The spiritual care coordinator serves 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. Where appropriate the spiritual care coordinator herself provides spiritual care and pastoral support. 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.

Using equality data to support person-centred care

Early in the project, we recognised that staff felt uncomfortable about talking to patients about their religious, spiritual, and cultural needs. Patients' religion and ethnicity was not being collected consistently, which meant that there were not always clear opportunities for patients to discuss spiritual or cultural needs relevant to their care. In addition, it limited our ability to use equality data in planning services or identifying inequalities in access.

The project manager worked with staff to identify the challenges in collecting this information. We identified that staff discomfort often stemmed from lack of knowledge or training on recognising and meeting these needs. Gaps were also identified in the processes for collecting and recording this data across our systems, meaning that dependent on points of access to a service this information could be recording on four separate assessments or not at all, and that across different assessments the information was being captured in different ways.

In December 2017, a new digital patient records system was implemented in the Cardiff and the Vale hospice, and presented the opportunity to improve collection and recording of equalities information. The project team worked to ensure that religion and ethnicity were included in the

mandatory information collected on the new patient assessments, aligning with the categories used in the census to ensure comparable data. The project manager and spiritual care coordinator delivered training to all inpatient staff, focused on how to collect this data sensitively and how to use these questions to further explore patients' spiritual and cultural needs. This training also helped raise staff awareness of the organisation's responsibilities to collect this data from a statutory perspective.

This work has significantly reduced the gaps in our data and means that all patients are being given the opportunity to discuss their religious and cultural needs. Since implementing this change the hospice has recorded religion and ethnicity for more than 80% of inpatients, with the remaining 20% being those who chose not to or were unable to answer. Prior to this change the number of patients each month for whom this data was collected rarely exceeded 40%.

We are the first of Marie Curie's nine hospices to implement mandatory collection of equality data and the remaining hospices are now looking to follow our lead. We are working with staff to use this data going forward to monitor, develop, and improve services. We are working to support similar improvements within our community services and the organisation is looking to use this model to improve collection of data regarding the other protected characteristics in the future.

Community engagement and education

Throughout the project, people told us how important it was for Marie Curie to work to improve people's understanding of, and access to, palliative care services. Delivering community engagement and education opportunities across all three groups has been a key focus of this project, done in partnership with Marie Curie's nursing and allied health teams to draw on their expertise and experience in delivering palliative care. This work has included:

- Delivering a workshop at the Learning Disabilities Wales conference on talking about death and advance care planning with people with learning disabilities.
- Speaking to local authority and third-sector social care providers to improve their understanding of our services and enable better signposting.
- Information stalls in public libraries, older peoples' cafes, and health fairs.
- Meeting with local community groups to talk about our services.
- Supporting bereavement volunteers to understand the needs of people with learning disabilities and feel more confident supporting them.

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. For example, we've noticed improved communication between the local dementia support team and our Marie Curie Helper service, which has helped ensure referrals are more timely and appropriate.

Education sessions have also been impactful and received significant positive feedback. The project manager and spiritual care coordinator delivered an education day jointly with the Church in Wales for their clergy across South Wales, to support them to have better conversations about death, dying and bereavement in their pastoral work. 76% of attendees said they learned something new about Marie Curie's work, including that we support people with any terminal illness, and 72% said they felt better equipped to have conversations about death and dying. Many appreciated the opportunity to reflect on their own views and experiences of death and grief, and how this has an impact on the work they do.

The spiritual care coordinator has been working to establish relationships with a wide range of community leaders, with the project's support. Following the Church in Wales education day, she was invited to become a member of Penarth's Cytûn, a forum which brings together representatives from all denominations of churches to support better communication between religious leaders. This event's impact is just one example of our community engagement work highlighting 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 influence 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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Buddhist Council of Wales
Cardiff 50+ Forum
Cardiff People First
Cardiff Parents' Federation
Church in Wales, Diocese of Llandaff
Dementia Engagement and Empowerment Project (DEEP)
Dimensions
Diverse Cymru
Humanists UK
Interfaith Council for Wales
Learning Disability Wales
The Mentor Ring
Mirus
NHS Centre for Equality and Human Rights
South Wales Jewish Representatives Council
Velindre NHS Trust
Vision 21

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