Marie Curie Response

Connected communities – Tackling loneliness and social isolation – January 2019

Introduction

1. Marie Curie provides care and support for people living with a terminal illness and their families and carers. Last year we provided care to over 40,000 terminally ill patients in the community and our hospices. We are the largest provider of hospice beds outside the National Health Service. We also provide nationwide support through our information and support service including our national helpline.
2. Marie Curie's vision is for a better life for people and their families living with a terminal illness. Our mission is to help people living with a terminal illness, their families and carers, make the most of the time they have together by delivering expert care, emotional support, research and guidance.

3. We welcome the Welsh Government's moves to identify and tackle both loneliness and social isolation, however, we are concerned that it does not fully consider issues and actions relating to those living with a terminal illness or those who have been bereaved.

Definitions

4. Often loneliness is thought of in simple terms, The Oxford English Dictionary defines loneliness as "feeling of being unhappy because you have no friends or people to talk to." Whilst the definition is often boiled down to one basic definition, the causes and consequences of loneliness are often side-lined or simply ignored.

5. We are concerned that the government's proposed definition will not capture it's complex nature, and feel it needs expanding upon, for example the lack of reference to reference bereavement, which can be a significant factor in both loneliness and social isolation and can be immensely felt by some people.

The draft strategy

6. The draft strategy, quite rightly, focuses on supporting people, empowering communities, building meaningful relationships and on working together to tackle social isolation and loneliness. It sets out aims to help young people to get the best start in life and draws on the public health agenda to reduce stigma, tackle poverty and address inequality, while promoting health and wellbeing – all of which we are naturally supportive of, but we emphasise that bereavement needs to be referenced as a cause of loneliness and whilst stereotypically this will impact on older people (especially those who are widowed after a long marriage/relationship) young people may also find themselves being lonely following the death of a parent or friend, especially if that death triggers changes in lifestyle or relationships with others.

7. We would recommend that the final strategy reflects this complexity and recognises a growing population of people that are experiencing social isolation and loneliness. This is particularly the case when the causes of social isolation and loneliness may be unavoidable, such as in the case of when someone is living with a terminal illness and the effects this can have on family, carers and loved ones. 32,000 people die in Wales each year. The number of people due to die each year is set to increase to 35,000 by 2037. As the population ages and grows, more and more people are dying from complex multiple conditions. This inevitably means that the potential for greater number of people experiencing loneliness and social isolation will grow.

8. The draft strategy also draws on work around the public health agenda to help tackle social isolation and loneliness. Too often people do not talk about dying, death and bereavement. This lack of open and honest, albeit often difficult, conversations can mean that many people miss out on the support that they need towards the end of life.

People Marie Curie support and help

9. No-one should have to live or die isolated and alone. Sadly though, that happens far too often. At Marie Curie, we see the widespread effects of loneliness and isolation, the different forms it can take and the fear it can bring. In the increasing age of multiple and complex conditions, social isolation and loneliness coupled with a chronic life-limiting or terminal illness can become debilitating.

10. Across parts of Wales Marie Curie runs our well established “Helper Service” which supports people who have a terminal illness by offering befriending and companionship. It also allows them the opportunity to leave their home, with the support of the Helper, and get out into their community, helping them to connect with those around them, bump into familiar faces and offer a sense of independence. We know of people who only leave their house with our Helper volunteer. If someone has a carer this service also enables them to have some respite for a few hours, allowing them to have time for themselves or time with friends. It is very important that loneliness and isolation experienced as a result of becoming a full-time carer is recognised and addressed. This is a free service which is 100% funded though charitable donations to Marie Curie.

11. Marie Curie also runs a freephone advice line which can act as a signposting service, but also acts as a safe space for patients and carers to discuss their worries and concerns with trained staff.

12. Isolation and loneliness can be at its worst for those living with a terminal illness; at initial diagnosis, as their health declines or when approaching the end of life. A terminal diagnosis is, by its very nature, a life changing experience and with it can come responses that cause people to distance themselves from their family and social networks. It can also affect informal carers, including family members and loved ones, as their caring responsibilities grow and following bereavement. Not only that, formal health and social care providers can also experience loneliness and isolation, and when their caring role ends, many people feel lost due to the all-encompassing role of caring full time for a terminally ill friend or relative. It is vitally important that any Welsh Government strategy focuses on supporting all of these people.

13. Being diagnosed with a terminal illness can in itself be very isolating. Realisation and acceptance of a terminal illness will inevitably have a significant psychological impact, affecting someone’s self-identity and the roles they fulfil in their personal, social and

working lives. It can often be characterised by feelings of helplessness and a lack of control with people experiencing difficulties understanding and expressing their emotions. This can lead not only to social withdrawal and the erosion of social networks, but also towards existential loneliness and feeling lost due to the all-encompassing role of caring full time[1].

14. As a person's physical health declines these challenges can continue, particularly as they may be forced to give up work, volunteering roles, sports and recreational hobbies. Our staff tell us that one of the issues they most commonly see in the people is a loss of identity. Many people when they are living with a terminal illness, are isolated within their own thoughts or within their own close family group. They often can't be what they have been before their diagnosis. This can lead to further withdrawal with people often feeling like a burden on others including those close to them.

15. Across both Wales and the UK, the number of single person households has increased and is forecast to continue increasing[2]. StatsWales reported that in 2017 that 31.9% of Welsh properties housed one person. That is around 429,000 properties with only one resident, (compared to 474,000 with two). Although it should be noted that people who live alone, may not be lonely.

16. In a survey of Marie Curie's community nursing staff in Scotland social isolation and loneliness were found to be most chronic in people who live alone. Even with a care package in place, staff found people could be on their own for up to 22 hours a day if they live alone. The only social interactions they have is with their paid carers, already stretched with workloads. Scottish geography naturally exacerbated this, but large areas of Wales share many similarities with rural Scotland, where naturally problems of social isolation and loneliness can be far more acute, especially if people are dependent on their own transport or if there is not an adequate public transport system in place.

17. Terminally ill people will also often need complex symptom and pain management, which will differ according to their specific circumstances and conditions. Sometimes these symptoms can have a considerable impact on their feelings and emotions and the social connections and relationships they have. They may be symptoms that cause them embarrassment or they may be personal care needs which cause them to put distance between themselves and those that have been close to them prior to their illness.

18. For example, people with Motor Neurone Disease (MND) may experience difficulties talking, swallowing and eating which can cause social embarrassment. Increased fatigue may also mean they are unable to leave the house. This can cause issues with self-image and self-esteem. This is often also the case for Dementia and other neurologically disabling illnesses, where physical and mental deterioration can often lead to social isolation, depression, and feelings of becoming a burden on their loved ones, especially if there are no community support networks. This can all mean people withdrawing from friends, family groups and social networks.

19. Caring for a loved one with a terminal illness can also have its challenges, both physically and emotionally. Research has shown that becoming a carer increases the risk of loneliness[3]. Informal carers can become lonely, especially as their life partner is no longer able to communicate effectively, do the activities or go to the places they used to enjoy.

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[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2866502/

[2] Various StatsWales and ONS Data estimates and forecasts as well as the 2001 and 2011 censuses.

[3] http://www.msstrength.com/multiple-sclerosis-and-isolation/

Social networks surrounding the carer can breakdown as they feel guilty about leaving their loved one or fear of what might happen if they are away from the home for too long.

20. Carers and family members are at increased risk of becoming depressed and experiencing social isolation as well as physical illness and injury related to the demands providing care. Carers may lose touch with family and friends while providing care. Many people have no time to themselves and suffer from physical, mental and emotional exhaustion

21. Research, undertaken by the London School of Economics (LSE), commissioned by Marie Curie, shows that having a live-in carer is the single most important factor in enabling a person to be cared for at home. If someone is single or lives alone, they are less likely to get the same access to care and support. Similarly, if someone lives in a remote and rural setting they are less likely to get the same access to care and support services at the end of life as those living in urban areas. Rural Wales accounts for roughly three fifths of the land mass of Wales.

22. Caring for a loved one with a terminal illness can also be both physically and emotionally challenging. Research has shown that carers and family members are at increased risk for depression, social isolation and loneliness as their caring responsibilities increase, and as they struggle to cope with the decline and death of a loved one. However, many people can be isolated or live great distances from their families. The care staff, especially in care and nursing homes, can often become close to the people they are caring for. This can have an impact on staff when that person dies and it is important that staff are supported.

23. Spiritual care can often be seen as a low priority in end of life care and support, yet for many people it is a vital component of their quality of life and what 'matters to them'. In order to deliver this care, staff (and others who are supporting a person, including families) need to be able understand the person's motivations and aspirations. More training and support is needed for staff, alongside the time to help deliver those needs.

24. Carers often go unidentified by statutory service providers, such as GPs and social workers and schools. This means they often do not get the support they need to help the carry out their role. Issues of loneliness and isolation being experienced by a carer will then also go unidentified and unaddressed. This could lead to these issues being exacerbated in the carer with further impacts for not just their health and wellbeing, but their ability to provide care to the person they are caring for.

25. Following the death of a loved one, services, such as community nurses, also start to be withdrawn after the person they're caring for has died[4]. The sudden removal of these services can leave bereaved people feeling extremely isolated and alone. At this time, people often don't have any support, when they are expected to re-establish their lives. And often people are not signposted to relevant bereavements groups/services. Carers benefits are also withdrawn following death of the cared-for person and people can be expected to return to work, if they are of working age. Money does not compensate for bereavement, it doesn't help to regain that life, but it can help the transition process and facilitate building confidence and connections. This is particularly relevant for people living in poverty, in areas of economic deprivation

[4] Holdsworth LM (2015) *Bereaved carers' accounts of the end of life and the role of care providers in a 'good death': A qualitative study.* Palliative Medicine 29 (9): 834-41

The workforce

26. We are concerned that the draft strategy does not consider the health and social care workforce, whether in statutory, independent or third sector services. These are often the only people that lonely and social isolated people encounter during their daily lives. There needs to be skilled staff that can support families and carers in appropriate, local, environments. This health and social care workforce plays an important and vital role in communities, providing housing support, home care and care home services. Many of these staff will be required to support people living with a terminal illness in their own homes or in care homes.

27. However, the lack of investment in the workforce can mean high turnover and relatively inexperienced, low-paid staff supporting the most vulnerable people, particularly those who are terminally ill and approaching the end of life. These people can make a significant difference to the lives of people in the community and offer an emotional lifeline to people who are lonely and experiencing social isolation. However, they also need to be supported and there needs to be recognition of this in the strategy.

28. Nine out of ten paid carers report facing limited time for care visits, with many carers reporting they worked longer than their contracted hours to allow them to support people properly.

29. We would expect the final strategy to recognise the vital role that the workforce provides and ensure frameworks are in place to support staff working with vulnerable people who may be lonely and socially isolated.

What is needed in Wales

30. Any strategy aimed at tackling loneliness and social isolation must be person centred We need to recognise what people want and need. Often people just want normality, they want to do the activities they have always enjoyed with the people they enjoyed doing them with. They want to feel safe and supported. A befriending service may be important and helpful, but people don't want just a befriending service, they want a friend. It's a very real and important distinction.

31. It is becoming increasingly evident though that people need more support and help to make connections. It is important that they need the right people for them at the right time. That means that there needs to be multiple services and a mix of different types of people delivering it.

32. Currently in Wales, many aspects of the health system are still unconnected including health and social care. However, even if it were working perfectly, health and social care integration alone wouldn't be able to solve the problem, it requires a societal response and a culture change.

Compassionate Communities

33. Marie Curie in Wales introduced the concept of Wales becoming a Compassionate Country and we are very supportive of the Welsh Government's recently stated aim to make Wales a 'Compassionate Country' and welcome the progress made to date and funding which has been identified.

34. The aim behind compassionate communities and workplaces is to develop a greater understanding of the role community plays where end of life is concerned. Core to the concept is building social networks which are supportive of people at the end of their lives and people who are bereaved. We think there should be direct recognition of this initiative in the strategy and the important role it can play in helping to address the loneliness and social isolation that people in Wales experience at particularly vulnerable times of their lives.

35. The 'No One Should Die Alone Foundation' in America is an initiative which is an excellent example of the links between kindness in communities and end of life care, which provides compassionate presence to individuals who have no family or close friends to sit with them at the end of life.[5] A similar programme could become a cornerstone of any compassionate community or country.

Recommendations

36. There needs to be a greater recognition of issues relating to isolation, loneliness and spiritual needs in delivering of care to people living with a terminal illness and approaching the end of life.

37. A Wales wide VOICES survey of the bereaved (similar to that undertaken by ONS on behalf of the NHS in England), could help quantify some of the unmet need regarding loneliness and social isolation at the end of life.

38. Training and support for staff is needed to help them identify and deliver spiritual support needs for people, and to deal with bereavement and grief following the death of people in their care.

39. There needs to be more research into experiences of single people who have no partner or carers living at home.

40. There should be more support for carers and families, during their loved one's illness and following death.

41. There needs to be provision for fair and consistent access to specialist palliative care, recognising that specialist palliative care practitioners have specific skills in supporting individual needs.

42. There needs to be a specific focus on the greater impact loneliness and social isolation has on people at the end of their lives, as well as a focus on the potential to experience loneliness on becoming a carer or when bereaved.

[5] https://nosdaf.com/

43. Bereavement and the impact of loneliness needs to be further supported through provision of specialist palliative care. Primary Care services should receive the resources they need to enable them to proactively contact recently bereaved partners of patients, offering them advice and signposting.

44. The Compassionate Communities model needs to engage the whole community and recognise the important role of community groups in tackling social isolation.

45. Greater promotion of bereavement services is needed, by everyone in the sector/community.

46. It is also our view that greater emphases needs to be placed on the role of online communication in terms of tackling social isolation and loneliness, recognising that this will only be a small part of an integrated response.

Further information:

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