Gender and end of life care

A Marie Curie policy paper exploring gender differences in end of life experience in Wales

Contents

Defining sex and gender[1]

A person's sex (male or female) is assigned to them at birth according to their primary sex characteristics (genitalia). Meanwhile, gender identity is often culturally determined and generally expressed in terms of masculinity and femininity. Someone's gender identity can align with their assigned sex at birth (cis men and cis women), but can also differ from their assigned sex at birth. Trans/transgender is used as an umbrella term for people whose gender does not align with their assigned sex, and a number of more individualised terms exist in the transgender community depending on a person's preferences, including but not limited to, trans man, trans woman, non-binary, gender fluid. They may or may not choose to transition socially – for example by changing their name and pronouns, and/or physically – by undergoing medical treatments such as hormone replacement therapy.

The following policy paper primarily aims to explore the impact of gender on end of life experience, rather than assigned sex at birth. However, existing data and research often uses sex and gender as interchangeable concepts, with no clear definitions. This paper strives to be an inclusive document and has made a concerted effort to distinguish between sex and gender where needed; clear definitions of how 'men' and 'women' are used have been included throughout.

We are aware that there are a myriad of inequalities in end of life care that will specifically impact the transgender and gender diverse community, and exploration of this will require more extensive and specialist research and consultation. Marie Curie looks forward to developing its research in this area.

Foreword from Sam Skelton

One of my most poignant memories as a child was learning that everybody dies. I had run to my father with the excitement of a five-year-old ready to play and found him on the phone in tears. He told me my grandmother had passed away peacefully at home. This precipitated a flurry of questions, and I realised that yes, my mother, my father, my sister, and I too would die someday. My dad was gracious in his explanation. I was devastated. I asked who would look after me if Mum was dead? Who would help me to die if she wasn't there? He didn't immediately reply, too caught up in the emotions of the recently bereaved, but when he finally did, he mentioned the concept of 'a good death'.

I didn't understand what he meant then, but years later, as I approach my own death, I do. If everybody dies then what becomes important, what should be the focus, is the quality of life you have at the very end, the care and support available, the place of death, and agency to be able to make choices. This is what I want. This is the 'good death' my father was talking about.

At the end of 2022, I was contacted by Marie Curie after making a comment on one of their social media campaign posts. I am a woman in her 50s, married with three grown children and dying from stage four cancer. I wrote that the challenges as a woman at the end of her life are endless: I have lost my ability to work and maintain financial independence, I feel a burden on my husband as he supports me both emotionally and financially, I worry for my grown children struggling in the cost of living crisis with a new baby, job security and housing, while also facing the inevitability of losing a parent. I feel diminished as a woman who had previously prided herself as strong and independent.

I am writing from my own personal experience and position, and I have witnessed women so often being the hub of family activity and care. I see it in all the oncology clinics I have attended over the past eight years. Women are present supporting their male partners, but also more frequently supporting other women. The nursing and support staff are mainly women and despite the decision makers and consultants being predominantly men (something that also needs addressing), it is the women who reassure and check that my needs are met.

As a woman, I cannot help but apply a gender lens to my lived experience and I have been delighted to contribute to Marie Curie's gender and end of life care research. By gathering information, looking at lived experience, and considering equality, we can identify areas where gender specific support is overdue and essential for the wellbeing of all palliative care patients and the improvement of services.

This research is the start of how we ensure that all those dying have good quality of life for their remaining time, no matter their gender, and helps all my family feel reassured by the targeted care and support available. It helps me not to worry that my illness makes me a burden on my loved ones, and most importantly it gives other dying women the chance for the 'good death' that my father spoke about so many years ago.

Sam Skelton
Member of research steering group

Introduction

Gender inequity continues to be prevalent in our health and social care systems across the UK, but awareness of how gender impacts a person's health and wellbeing is increasing[2]. Progress has been made in recent years with a commitment to a dedicated women's health plan in three of four UK nations, with the Welsh Government most recently publishing a Women and Girl's Health Quality Statement in June 2022[3]. Despite these positive steps forward however, one area of health appears to be repeatedly omitted – palliative and end of life care (PEOLC).

Everyone will be affected by dying, death and bereavement, and deserves the best possible end of life experience, reflecting what is most important to them. But international evidence and recent Marie Curie research suggests that someone's final months, weeks, and days are no exception to gender inequity. This policy paper shines a spotlight on how gender impacts a person's end of life care experience, including how and when they are accessing services, their preferences, and who is caring for them. Consequences can be felt by both the person at the end of their life and their loved ones and carers. It is clear that more research and awareness is needed to explore the gender differences within palliative and end of life care in Wales and this paper is a first step in that direction.

With the current social and political climate presenting opportunities to eliminate gender-based inequities in health and social care in Wales, we must ensure that the actions being taken adopt a life-course approach, and not just in name only. If we are to see everyone achieving the best possible end of life experience in Wales, the Welsh Government, NHS Wales, and other decision-makers need to actively consider gender as part of an intersectional approach to eliminating health inequities, not only within palliative and end of life care, but the health and social care system as a whole.

Key findings

- There are no evident or conclusive gender inequities in the delivery of palliative and end of life care within Marie Curie services across Wales, but the research has raised many questions that require addressing Wales-wide.
- Marie Curie data suggests that men are more likely to prefer to die at home than women, although home still remains the preferred place of death for all.
- According to current Marie Cure data, it appears that women in the community may be less likely to achieve their preferred place of death than men, but more research is needed to explore this substantively.
- There are different perceptions regarding how gender impacts if, when and how end of life care is sought, accessed, and accepted. Many believed that men tend to be less proactive and likely to access care and support, as a patient and while in a caring role, leading to consequences for both men and women.
- The pressures of unpaid caring tend to fall disproportionately on women. When men are in a caring role, they were thought to be less likely to seek and/or accept support.
- Clinical staff hold some anxiety and concern over initiating conversations and collecting personal patient data, in particular with regards to gender identity and pronouns.
- Age, socio-economic status, and rurality were all considered to intersect with gender and lead to differences in access and experience of end of life care and support.

Key recommendations for Wales

- Palliative and end of life care must be included in the 10 Year Women and Girl's Health Plan.
- A dedicated section of the Wales women's health research budget should be ringfenced to further understand gender differences in palliative and end of life care experience, including for transgender and gender diverse communities.
- Improved data collection on sex and gender identity within palliative and end of life care services. This must include comprehensive training for any patient-facing roles and data collectors.
- The National Programme Board for End of Life Care must commit to adopting a gender lens as part of an inclusive, intersectional, and whole-system approach to eliminating health inequities.
- Services should be equipped and supported to deliver person-centred palliative and end of life care to everyone in Wales, no matter their gender.
- A new National Survey for Bereaved People in Wales should be carried out. Alongside this, advance and future care planning conversations and accompanying digital tools should be used to direct more people to Carers Needs Assessments.

Setting the scene

The existing evidence and data used in this section refers to sex and not gender. As a result, **the use of 'men' refers to cis men and the use of 'women' refers to cis women.**

To our knowledge, there has been no specific attempt to investigate gender differences in palliative and end of life care in a Welsh context. However, with international evidence beginning to explore gender inequities at end of life, many studies have suggested that there appears to be a disproportionate impact on women.

It is important to consider that the gender disparities discussed are largely a result of ingrained biases, unconscious or otherwise, and structural societal issues dating back through history. To contextualise this policy paper, the inequities highlighted in existing research should be acknowledged.

Evidence shows that women often report more severe daily feelings of pain, nausea, and fatigue[4,5,6], but may also have to report greater symptom distress than men for their pain to be acknowledged[7]. While some research shows that women with a terminal illness tend to be more open, accepting of palliative support, and engaged with their end of life journey[8,9], other studies show that some women are less likely than men to state a preference for end of life care treatments such as chemotherapy, cardiopulmonary resuscitation, and artificial feeding[10,11]. Past social norms have dictated a society where women are deemed natural caregivers, and many women report feeling like it is their duty to provide care for others[12]; however, women also tend to be more likely to express fears around feeling like a burden if they themselves need the reciprocal level of care from their family and loved ones[13]. In fact, some studies report more women receiving care and support from healthcare professionals and specialists rather than unpaid carers[14].

Women have a longer life expectancy than men but are more likely to live with a greater number of 'years with a disability', ie live with more years of restricted activity as a result of a long-lasting physical or mental health condition. Women who were aged 65-69 between 2018-2020 in Wales, could expect to live 11.5 years with a disability, in contrast to 9.8 years for men[15]. In comparison to other cohorts of the population, women aged under 65 years from more deprived areas of Wales are also more likely to need out-of-hours emergency visits to A&E in their last year of life[16].

Demand for palliative care services is expected to increase in the future. The number of people dying each year in Wales is set to increase from 33,000 before the pandemic, to 41,000 in 2040[17]. The vast majority of these individuals will need some level of palliative and end of life care (PEOLC) and the biggest proportion of those in need will likely be those aged over 85, with the leading cause of death projected to be dementia[18]. Of all women's deaths in 2021, where they would benefit from palliative care, 23% were from dementia. For men's deaths in the same time period, of those who would benefit from PEOLC, dementia made up 11%[19].

With an ageing population, increasing comorbidities, and more demand on palliative and end of life care services, it is clear that more research on gender and end of life care is vital in order to understand how we can deliver truly person-centred care and ensure our services are as inclusive as possible. This policy paper is one step in this direction and should be used by future researchers and decision-makers as a roadmap to ensure more people can have the best possible end of life experience.

Marie Curie research

In February 2022, Marie Curie awarded a research grant to a small project team consisting of internal policy and research colleagues, and a researcher from UCL. The research was led by the project team and guided by a steering group involving people with lived experience, healthcare professionals, and experts working in the health and gender equality policy space. The project consisted of a quantitative analysis of service-level data from across the UK, four focus groups conducted with Marie Curie staff in Wales and Scotland, and an internal focus group to understand how data is collected. A roundtable with healthcare professionals external to Marie Curie was also carried out in Wales to contextualise the findings of the research and consider next steps.

Wales quantitative findings

Quantitative data was collected from Marie Curie services across the UK, including the Marie Curie Hospice, Cardiff and the Vale, and community nursing services operating across Wales. The data request covered 2019-2022 and consisted of a number of variables: sex, gender, age, ethnicity, sexuality, religion, primary diagnosis, reason for referral, length of stay, and preferred and actual place of death.

It is important to highlight that there were some gaps in the data received, partly due to Marie Curie's ongoing project to transfer data to a new collection and storage system. This has inhibited the ability to draw conclusive findings from the quantitative analysis. The below findings are suggestive and should be explored more substantively in future.

While recording the sex of a patient is mandatory upon referral to Marie Curie services, recording the patient's gender is not. Some Marie Curie systems provide the option of collecting and recording both the sex and gender of a patient, but this varies across different services and regions. There were some gaps in data in Wales in relation to gender and so the following quantitative analysis has been carried out according to differences in sex; **the use of 'men' and 'women' in the following section refer to cis men and cis women.**

Demographics

- Overall, there appeared to be an even split between men (51%) and women (48%) supported across hospice and community services.
- The majority of patients across all services were white British (82%) and although there were big gaps in data in terms of sexuality, of the data received, the majority were heterosexual.
- The mean age of patients across all services was 77.3 years old, with patients supported in the community generally older than those supported in the hospice.

Place of death according to community vs hospice care

Figure 1 shows the differences between men and women in hospice and community settings with regards to place of death. There were some cases where the sex of a patient was unknown, likely due to complex processes of transferring anonymous data; these patients have been excluded from figure 1.

Figure 1:

	Cis women		Cis men	
	Hospice	**Community**	**Hospice**	**Community**
Total	937 (34)	1,852 (66)	1,030 (35)	1,944 (65)
Preferred place of death				
Home	342 (36)	1,619 (87)	435 (42)	1,779 (92)
Care/nursing home	51 (5)	18 (1)	39 (4)	14 (1)
Hospice	316 (34)	43 (2)	327 (32)	26 (1)
Hospital	7 (1)	6 (0)	1 (0)	4 (0)
Other	18 (2)	3 (0)	26 (3)	3 (0)
Unknown/missing	203 (21)	163 (9)	202 (20)	118 (6)
Place of death				
Home	306 (33)	1,398 (75)	353 (34)	1,536 (79)
Care/nursing home	42 (4)	51 (3)	32 (3	15 (1)
Hospice	405 (43)	22 (1)	423 (41)	19 (1)
Hospital	91 (10)	26 (1)	119 (12)	15 (1)
Other	0 (0)	0 (0)	0 (0)	2 (0)
Unknown/missing	93 (10)	355 (19	103 (10)	357 (18)
Died in preferred place of death?				
Yes	566 (60)	1,296 (70)	616 (60)	1,448 (75)
No	117 (12)	85 (5)	146 (14)	63 (3)
Unknown/missing	254 (27)	471 (25)	268 (26)	433 (22)

It must be considered that there are challenges when using a big data set in isolation to explore differences in people's preferred and actual place of death, with an abundance of complexities and nuances unaccounted for. However, figure 1 suggests that in both hospice and community settings, we see more men noting home as their preferred place of death in comparison to women.

Of those supported in the community, figure 1 also shows that actual place of death aligned with preferred place of death for more men than women; although there was more missing data for women than men, figure 1 shows a slightly higher number of women dying in nursing homes, care homes, and hospitals when this was not their stated preference. This difference between men and women was not observed in the hospice.

International evidence suggests that women often associate dying at home with being a burden on their loved ones[20]. Additionally, research has shown that those who have previously been carers (of which the majority are women), are less likely to want to die at home due to a greater understanding of the reality of caring pressures [21]. With figure 1 in mind, it is important that we seek to fully understand whether uninterrogated gender biases are influencing women's preferences around place of death, and likely their outcomes. We need to have more research into whether women in Wales are able to, and being supported to, die where they choose. Alongside this, we need to be considering what resources and care packages must be available in the community to allow more women to die at home if this is their preference.

Preferred place of death according to age

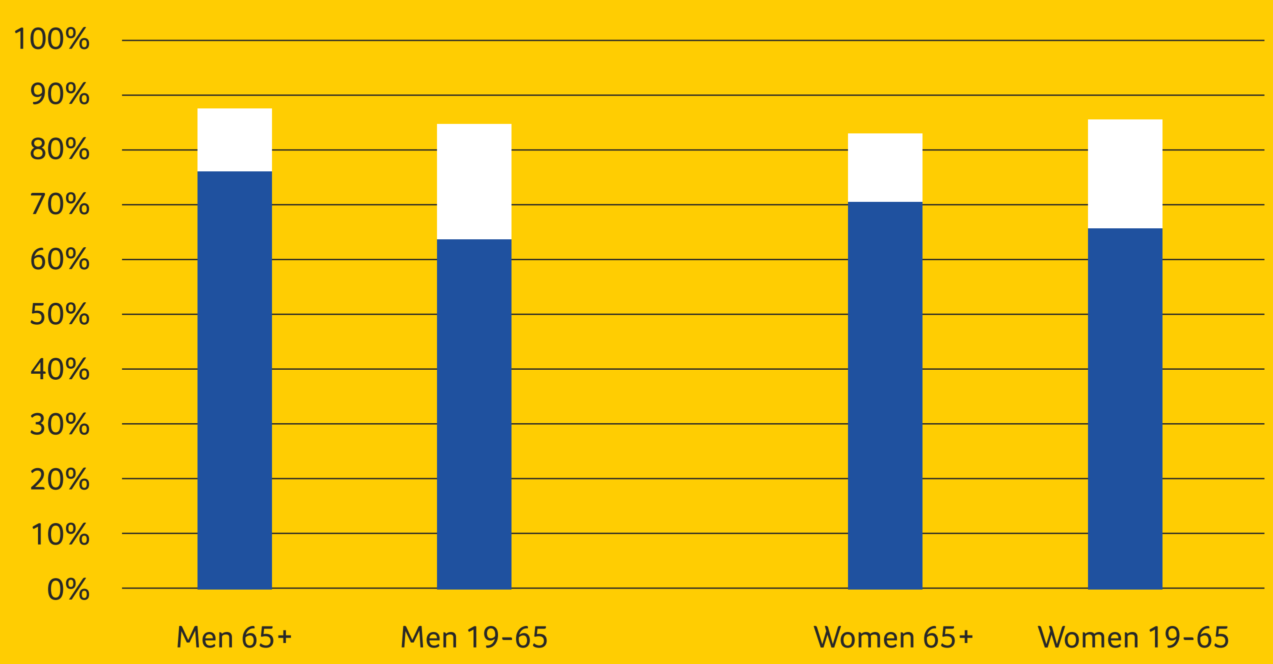
If we look at preferred place of death through an older age lens, there does appear to be a slight difference between men and women: 76% of men aged 65 and over stated home as their preferred place of death, in comparison to 71% of women aged 65 and over. This difference is not as noticeable among working age people, with 55% of younger men (aged 19-65) and 56% of younger women preferring to die at home.

As above, considering existing international evidence around why fewer women than men may want to die at home, we should be investigating this further with an added consideration of how age may have an intersecting effect.

If we compare younger people and older people, figure 2 shows that older men and women were less likely to choose hospice as their preferred place of death in comparison to younger men and women (although home remained the preferred place of death for the majority).

As discussed later in the paper, healthcare professionals in focus groups mention how older people tend to be more ‘stoic’ in their approach to care, while younger generations are considered more proactive in seeking and accepting help. These assumptions could be one explanation for figure 2, with hospices perhaps perceived to have quicker and easier access to care and support. No evident differences between men and women come to light in figure 2, but as women typically live for longer, we should be investigating whether these suggested generational differences in approaches to care are leading to invisible gender inequities.

Figure 2: Preferred place of death



Conclusion

Analysis of service-level data available in Wales shows that there are no evident differences in how men and women are accessing and experiencing end of life care within Marie Curie services, neither in the Marie Curie Hospice, Cardiff and the Vale, nor in community services. The data has indeed brought to light tentative disparities, specifically in relation to preferences around place of death, but gaps in data have prevented any conclusive findings being drawn. It is clear that further exploration is needed in Wales to understand potential gender differences within palliative and end of life care, not just within specialist palliative services like Marie Curie, but end of life care delivery across the health and social care system.

Wales qualitative findings

In December 2022, focus groups were held with clinical staff from Marie Curie services in Wales to explore their views and experiences regarding the impact of gender on palliative and end of life care. The focus groups consisted of eight individuals and a range of medical professions were represented. Participants were Wales-wide and covered the Marie Curie Hospice, Cardiff and the Vale, and community services. In order to explore understanding, awareness, and experience of gender inequity among professionals outside of Marie Curie services, an external roundtable was held in April 2023. The nine attendees, all working in Wales, included GPs, a district nurse, a PEOLC consultant, a PEOLC paramedic, care home managers, a PEOLC occupational therapist, and a gynaecologist. The themes that arose in internal focus groups and the external roundtable are summarised below.

Within focus groups and in the external roundtable, discussions were focused on gender. **In the following section, the use of 'women' relates to both cis and transgender women, and the use of 'men' relates to cis and transgender men.**

Gender and interactions with palliative care

Key finding: Different ideas around how gender impacts access and referral to PEOLC.

When discussing patterns of referral for different genders in the internal focus groups, it became apparent that there were differing views around when men and women tended to access specialist palliative care. Some believed that men tended to need formal support later down the line, at a more advanced stage of their illness, due to the level care they were receiving from women at home for longer. Participants discussed how these women were not always spouses or current partners, but were sometimes ex partners or estranged relatives. Similarly, some felt that men tended to receive more support from their local community in relation to tasks like chores, shopping, or cooking, potentially enabling them to stay at home for longer.

On the other hand, others thought that men were referred earlier on in their end of life journey, as women were generally more proactive in seeking help and accepting support. Participants also suggested that women may struggle with certain functional tasks that are more physically demanding, such as lifting and washing, and may need to request support earlier or for specific activities.

Whilst discussing admission to specialist palliative care for women, some internal participants discussed receiving referrals for women earlier in their illness due to "male carers reach[ing] carer crisis a bit quicker". In a similar manner, it was felt by some that there is not as much "rallying around" a woman who is terminally ill in comparison to men, potentially inhibiting women from staying at home.

> "The male patients who are admitted tend to be further down the palliative route because generally speaking, generally their wives or partners are better at looking after them than the men are at looking after the women and manage for longer."
>
> - Marie Curie Allied Health Professional, Wales

There was some discussion – specifically in relation to dementia – around women in some cases being referred to palliative care at crisis point in their illness, or even not at all, due to some men's reluctance to accept support in the home. Similarly, this reluctance to accept support for their loved one was mentioned by external roundtable participants in relation to women who provide care, with participants feeling like some women decline additional support due to feeling like "it is their role" to provide the care rather than that of others.

> "When the men are the carers, they tend not to want to accept help. And then often it gets to the crisis and they're still not accepting anything."
>
> - Marie Curie Senior Nurse, Wales

> "He didn't want to obviously wash [his mother] and do her personal care but yet didn't want to get any carers into the home... so put her in a care home. And I tried saying, you know, it's doable at home, it's manageable, we can get everybody in place. No, he didn't want carers coming in and out of the house."
>
> -Marie Curie Senior Nurse, Wales

> "What I'm thinking about here is probably more with younger patients where we sometimes have to push a little bit for community palliative care team involvement. Sometimes the men tend to be quite straightforward because it's mainly about symptom control, whilst with women it is quite often more around psychological issues and family issues with younger patients. It can sometimes feel a little bit harder to get that specialist input, because of the ways the services are changing and where they're having to focus, because of their own resources. Quite often a specialist social worker is needed from the specialist palliative care services, which they don't have as many of."
>
> - GP, Wales

In the external roundtable, a point was raised around how stretched resources and capacity in our workforce could be leading to gender differences in who is receiving community PEOLC care packages, particularly among younger people. An example was given of men being more likely to be referred for symptom management only, while younger women in particular may more often require support for more complex and holistic care needs to enable them to stay in the community for longer. Participants provided the example of how a younger woman with familial caring responsibilities may need a specialist social worker as part of her palliative care package, which could be difficult to arrange. Furthermore, it was discussed that women with dementia are over-represented in the community in comparison to men, and more understanding is needed of how their care needs and expectations may differ.

Key finding: Different ideas around how gender impacts acceptance of PEOLC support.

A theme that arose in the external roundtable was how men as patients tend to be less likely to access healthcare. Although not raised so prominently in internal focus groups, some external healthcare professionals shared thoughts around how gender inequity in PEOLC was negatively impacting men rather than women, in terms of how likely they are to access support. Professionals had not previously considered how gender could be disproportionately impacting women, aside from unpaid caring pressures.

> "There is undoubtedly a difference I think when it comes to psychological symptoms and openness talking about struggling with low mood or with anxiety. And again, it is a generalisation, but my generalisation would be that my female patients are more open to talking about the emotional challenges of being at the end of life and more open about talking about being low in mood really and maybe less likely to put a front on."
>
> - Marie Curie Palliative Care Doctor, Wales

Discussions included how men were less likely to attend peer support groups and more holistic aspects of care beyond symptom management. The roundtable concluded that this could be related to the social gender norms of what is and isn't considered appropriate for men. Whilst discussing palliative occupational therapy groups, the only activity which was believed to have an equal gender split was gardening, a hobby which has traditionally been viewed as more acceptable for men in comparison to other support groups focused on "chatting".

> "I think some of the gender stuff changes when we're doing specific activities, it's not necessarily the referrals to the service... but if I'm running groups of various self-management stuff for example breathlessness management, anxiety management, energy-conservation, fatigue, pacing, that is where we see a difference in the genders attending. I also run a garden group, a patient garden group. That is interesting because it is nigh on 50-50 split because that it is an activity that is viewed as more 'gender-appropriate' for men to attend, you know that it is how we might view that. Whereas some of the support groups that are out there tend to be more female-oriented in their origins."
>
> - Palliative Care Occupational Therapist, Wales

It is clear that more research is needed to understand how gender impacts if, how and when PEOLC is accessed, not just in relation to specialist services like Marie Curie, but across the palliative and end of life care system as a whole. It is widely accepted that earlier access to PEOLC is best practice and leads to better quality of life towards the end, including lower rates of depression[22,23]. However, some recent studies have found that cis women in some instances report lower quality of life and mood than cis men receiving similar early palliative care[24]. To ensure everyone is able to have the best quality of life for longer, and able to stay in the community if this is what they choose, we need to understand more about how gender impacts if and when people are accessing PEOLC, and how beneficial the care and support is once they have been referred.

Gender and the caring role

Key finding: Unpaid caring pressures tend to fall disproportionately on women. When men are in a caring role, they are thought to be less likely to seek and accept support.

There was consensus among internal and external participants that expectations and pressure from society has led to more women (especially adult children) taking on the primary caring role in families at end of life. When calls to 999 were discussed at the external roundtable, professionals believed that there was a roughly equal gender split in who was dialling, but in most instances, it was agreed that there would be a woman in the home who was the primary carer. Internal participants discussed how women appear to take on more "practical dealings of personal care interventions", which could include more intimate tasks like washing and bathing loved ones. When men are involved in caring, staff noted how they were more likely to be caring for other men rather than women, and were generally applauded more than women for doing so. Many of these views likely stem back to long-held gender norms in which a woman's role was seen as the primary caregiver and provider of emotional support, whereas men were more likely seen as the 'breadwinner'.

> "In the main it's always just the daughters. And it's a bit of a joke when you're sat there with the daughter. She [says] 'Yes, I've got three brothers and they all live next door. I live 10 miles away,' but the brothers don't engage in the caring support role and certainly not in the practical dealings of personal care interventions."
>
> - Marie Curie Senior Nurse, Wales

It is worth noting that the findings of the latest 2021 Wales Census show that while more women aged 15-64 report providing more care than men, a slightly higher percentage of men aged 65 and over are providing more care than women. This is also the age group more likely to be providing end of life care[25]. It could be that many women do not consider themselves a carer due to societal norm that suggest this is their 'duty' and thus do not report their caring responsibilities. Additionally, upon further discussion at the external roundtable, attendees noted how even when a man is considered someone's 'primary carer', in most cases there will be another woman, or women, who are also involved in providing care.

Ultimately, a more consistent definition and understanding of unpaid caring is needed.

> "I would say in my experience on an average basis, it tends to rely heavily on the daughters. Whilst the husband or partner may be their main carer, as its perceived, actually in the background you will often find that there's a female relative running around doing the jobs, looking after the children, and still doing things in between."
>
> - District Nurse, Wales

Men and women were also felt to differ regarding how they sought and accepted support while caring for someone who is terminally ill. While it was believed that women tend to be more proactive in seeking and accepting support, both for themselves in a caring role and for the person they are looking after, many participants felt that men were less likely to seek and accept support, again for themselves as carers and for the person they are caring for. Barriers were felt to be harder to break down when organising care and support for or with men. Suggestions from participants as to why we may see fewer men engaging with formal support services included their sense of pride, feelings of shame, a desire to manage by themselves, and a tendency to want to avoid interventions that focus on mental health and wellbeing.

Gender norms evidently still impact how care and support is sought and accepted for both men and women at end of life, perhaps leading to assumptions around who requires support, what that support looks like, and whether needs are met for both people with a terminal illness and those caring for them. Proactive steps need to be taken to eliminate gender-based stereotypes when it comes to caring for loved ones with chronic and terminal conditions, and the role of each carer should be recognised, celebrated, and supported in a manner that is right for them, regardless of their gender.

Following consultation with policy teams in two carers charities in Wales, Marie Curie has also uncovered that there appears to be a gap when it comes to engaging and hearing from bereaved carers who had been providing end of life care. In a recent Marie Curie report, a recommendation was included around introducing a national survey of bereaved people in Wales so their experiences can inform future end of life care policy and strategy[26]. There is an opportunity to use a national survey to dig deeper into the gendered nature of caring, as well as other inequities, and to understand how we better support dying people and their carers.

The Wales Carers Needs Assessment (CNA) provides a tool for exploring and addressing the unique needs of each person playing a caring role and for tailoring support where needed, but uptake of CNAs remains low in Wales. It is advised that CNAs are carried out at least once a year, and with any extreme changes in circumstances. While 310,000 carers were identified in the Wales 2021 Census[27], only 7,341 adults[28] and 1,136 young carers[29] completed a CNA in 2021-22. The possibility of directing patients and carers to a CNA as part of Advance and Future Care Planning (AFCP) conversations should be explored. Furthermore, incorporating CNA signposting into the digital AFCP tool currently being developed by NHS Wales should be considered.

> “Women, they tend to sort of say ‘No, we need to sort this out, we need to get on it, we need to visit the GPs’, they badger, they badger, they badger. And men tend to not want as much support coming in, they refuse help.”
>
> - Marie Curie Clinical Nurse Manager, Wales

Making services inclusive

Key finding: Clinical staff hold some anxiety and concern over initiating conversations and collecting personal patient data, in particular with regards to gender identity.

When discussing equity in access to care and support more broadly, participants in internal focus groups did note a lack of diversity among the patients, families and loved ones that Marie Curie support in Wales, with the vast majority being white, heterosexual, and cisgender (this aligns with the quantitative data analysis). It became apparent that limited experience supporting diverse communities has led to a lack of confidence among healthcare professionals in initiating and having conversations around someone's gender, essentially due to a fear of getting it wrong. Participants were worried about inadvertently offending someone through well-meaning, but clumsy, use of language, or a lack of understanding about the individual and what was important to them. This was especially true regarding supporting transgender and gender diverse people, with anxieties shared around using correct pronouns.

> "We had one patient who wasn't specifically gender non-binary, I don't think they necessarily had a pigeonhole for themself but they did prefer they/them pronouns which, I have to be honest, was very difficult initially in multi-disciplinary team meetings... just because it's a plural pronoun and it just confused us a lot. But ultimately it didn't really affect care in any way, shape or form, as far as I recall. It was just the difficulty with the language at times."
>
> \- Marie Curie Allied Health Professional, Wales

Despite a willingness to learn, this limited confidence in initiating conversations around sex and gender with patients and carers also appears to influence how data is collected on the ground. A number of participants expressed some hesitancy with collecting personal data from patients, with concerns around this being too personal. This was not only discussed in relation to asking about someone's gender, but their ethnicity, sexuality, and marital status.

Collecting personal information can be used to inform service development and delivery, monitor the reach of services into communities, and crucially, deliver care that meets the needs, values, and preferences of each individual and those close to them.

While data on the sex of a patient is compulsory upon admission or referral to Marie Curie services, it is not a requirement to record gender identity. In some Marie Curie services across the UK, there is a follow-up form available to collect data on protected characteristics which includes gender. On the whole, it was suggested by participants that this form is well used in hospice settings but less so in the community. In order to improve care and make services more inclusive, more training and support is needed for healthcare professionals and patient-facing staff. This training should include how and when to sensitively initiate conversations around someone's pronouns and gender identity, as well as collecting other types of personal information. This is something that was widely suggested and supported among internal focus groups, with a positive example cited of training delivered at the Marie Curie Hospice, Cardiff and the Vale, which focused on the collection of data related to ethnicity.

Intersection between gender, age, socio-economic status and rurality

Key findings: Age, socio-economic status and rurality are considered to intersect with gender and lead to differences in access and experience of end of life care and support.

Focus group participants from Marie Curie agreed that the influence of gender on accessing and experiencing care should be considered, but they also identified other factors including (but not limited to), ethnicity, class, geography, financial security, culture, personality, sexuality, and previous experiences, which they personally believed can exert a greater influence on access and experience of palliative care in comparison to gender. The current lack of research dedicated to exploring how gender impacts end of life care could be leading to an uninterrogated, implicit bias among professionals in how gender is or is not considered in the delivery of care.

A theme which was discussed at length was the intersection between gender and age. Participants felt that younger people were more likely to request and accept support than older generations, specifically younger men in comparison to older men. Participants also agreed that both older men and older women tended to be more "stoic" in their approach to accessing care, going longer without support than younger people, who were generally felt to be more proactive in seeking support. It is important to consider how age intersects with people's approach to care and support, and their preferences around place of death, particularly with women generally living for longer and for more years with a disability.

> "There's a definite age difference.
> The older men are far less likely to want help."
>
> - Marie Curie Allied Health Professional, Wales

Socio-economic status was another factor which professionals felt influenced people's engagement with care and support services. Participants noted how families living in smaller and more economically deprived communities in Wales tend to continue living in the same area (the Welsh valleys was cited as an example), which was believed to increase the likelihood of a person receiving informal support from loved ones living locally, and decrease dependencies and expectations on healthcare professionals. Data in the latest Wales Census supports this assumption, with a larger number of unpaid carers in more deprived areas[30]. It is essential that we ensure services are designed and accessible to all communities and that we raise awareness of the care and support available, no matter a person's protected characteristics or circumstances.

> "Older couples, in their 70s, 80s, that generation will just get on with it because that's what they've always done. They won't ring the GP, they won't bother the GP, [they'll think] 'Oh, I can't ring him, he's busy."
>
> - Marie Curie Senior Nurse, Wales

Rurality is a significant factor to be considered in how care and support is sought and accessed in Wales. This was raised in internal focus groups, as well as by the research steering group for the project. Although links between rurality and gender and how this impacts care appear to be less understood, a common perception was that men tend to be more isolated in rural areas. This could either result in men being more proactive in searching for the support they need, or with men less likely to seek formal support and being left alone for longer. Staff who deliver care in mid and west Wales and support rural farming communities also noted how these communities can often have multi-generational households, with more family and loved ones on hand to help provide unpaid care. This could impact how people engage with the care and support systems available. Similarly, external roundtable attendees noted how those who had grown up locally, in close-knit Welsh communities, were much more likely to have larger support networks.

Ultimately, while participants felt that gender did influence some aspects of the end of life experience, it was felt by the majority that gender was in fact “one piece of the puzzle” and it needs to be considered alongside a whole host of other intersecting factors in order to enable person-centred care. Marie Curie staff were confident that any person treated by their services would be treated with dignity and respect, and that understanding the unique and complex needs of each patient and those close to them remains at the centre of delivering palliative and end of life care.

> “It comes down to individualised care, doesn’t it, you have to be able to understand the patient in front of you to try and work out what’s going to be most acceptable and most useful for them.”
>
> - Marie Curie Palliative Care Doctor, Wales

Recommendations for Wales

1. **Palliative and end of life care must be included in the 10-year women and girls' health plan.** End of life care is an area of health which is repeatedly missed from the positive steps being made in the women's health space. We don't want the upcoming women and girls' health plan to take a life-course approach in name only, and we urge the Welsh Government and NHS Wales to include an explicit consideration of palliative and end of life care.
2. **A dedicated section of the Wales women's health research budget should be ringfenced to further understanding of gender differences in palliative and end of life care experience, including for transgender and gender diverse communities.** This research and policy paper is the first step in understanding how gender influences end of life care in Wales, as well as how gender intersects with other factors to exacerbate existing health inequities. We need more research dedicated to exploring unanswered questions and we are urging the Health Minister to reserve a section of the women's health research budget to matters related to dying, death and bereavement.
3. **Improved data collection on sex and gender identity within palliative and end of life care services. This must include comprehensive training for any patient-facing roles and data collectors.** There are clear challenges around consistently collecting service-level data around sex and gender, with the two often considered synonymous rather than distinct concepts. At the minimum, there should be a wealth of options to record gender identity beyond 'man' or 'woman', an option to record pronouns, and preferred name. We would urge other palliative and end of life providers to review their data collection systems and processes and consider how these can be improved to be as gender inclusive as possible. Alongside this, we encourage the Welsh Government and the National Programme Board for End of Life Care to explore developing national guidance on collecting data on sex and gender in Wales. Lastly, Health Education Improvement Wales should look to develop a training package for anyone in a patient-facing role, to increase confidence in initiating conversations around gender identity and other personal characteristics.
4. **The National Programme Board for End of Life Care must commit to adopting a gender lens as part of an inclusive, intersectional, and whole-system approach to eliminating health inequities.** The Welsh Government's Quality Statement for Palliative and End of Life Care, published in October 2022, commits to tackling health inequalities. The End of Life Care Programme Board holds a unique and powerful position in initiating research, carrying out consultation, and planning and delivering services through a gender lens. Future plans and workstreams must consider the influence of gender on access and experiences within primary care, secondary care, specialist palliative services, and care homes.
5. **Services should be equipped and supported to deliver person-centred palliative and end of life care to everyone in Wales, no matter their gender.** We need to ensure that our services are approachable and accessible for everyone in need of PEOLC, no matter their gender or other protected characteristics. Any relevant gender and end of life care research findings in future must be used to improve training for health and social care professionals and patient-facing staff. On a basic level, health and social care professionals should also be encouraged to wear rainbow pin badges and indicate their pronouns on name badges and email correspondence to promote a culture of openness and inclusivity.
6. **A new National Survey for Bereaved People in Wales should be carried out. Alongside this, advance and future care planning conversations and accompanying digital tools should be used to direct more people to Carers Needs Assessments.** Gender-based stereotypes can negatively affect both men and women in how they experience caring for a loved one at the end of life, in particular, in relation to how they seek and accept support. The role of each carer, regardless of their gender, should be recognised, celebrated, and supported in a manner that is right for them. We encourage the Welsh Government and the End of Life Care Programme Board to carry out a reoccurring national survey of bereaved carers to further explore their experiences and unmet needs. The End of Life Care Programme Board should also investigate how we can better signpost to Carers Needs Assessments using Advance and Future Care Planning conversations and digital tools.

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Thank you to everyone who supports us and makes our work possible. To find out how we can help or to make a donation, visit our website **mariecurie.org.uk**

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