

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Gwella mynediad at gymorth i ofalwyr di-dâl](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Improving access to support for unpaid carers.](#)

UC12: Ymateb gan: Marie Curie | Response from: Marie Curie

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## Support for unpaid carers

Marie Curie response to the Health and Social Care Committee Inquiry

**September 2025**

### 1. Introduction

Marie Curie is the UK's largest palliative and end of life care charity. We work hard to enable people who are living with a terminal illness, and their loved ones and carers, to have the best possible experience at the end of life. We offer expert care across Wales, in people's communities and in our Cardiff and the Vale Hospice and deliver specialist care, guidance and support to families with matters related to dying, death and bereavement through our free information and support services. We are also the largest funder of palliative and end of life care research, and we work with Members of the Senedd and policymakers to ensure that more people in Wales have the best possible end of life experience.

We provide a range of support to unpaid end of life carers. Our support line offers free information and support over the phone, via web chat and email and we have a number of dedicated information pages for carers. Our companion services, both in-person and over the phone, provide respite and peer support, while our dementia service provides specific support for carers.

Our detailed response below provides insights into the experiences of end of life carers and the extent to which their support needs are being met.

### 2. End of life carers

2.1. End of life carers are a distinct group with distinct needs. While some of their experiences and challenges will reflect those of unpaid carers more generally, there are specific issues that end of life carers are likely to face given the nature of the care they are providing.

2.2. While some end of life carers find supporting someone at home who is nearing the end of life challenging, they also describe it as a fulfilling and

positive experience.<sup>1</sup> However, caring can have a lasting impact on an individual's health and well-being both before and after bereavement.<sup>2</sup>

- 2.3. End of life carers are often providing a wide range of support to the cared-for person. A post-bereavement survey in 2022 found that in Wales, 54% of respondents had helped the person who died go to appointments, 56% helped with medical procedures and 76% spent time 'on call', typically for more than 50 hours per week.<sup>3</sup> In many cases carers are themselves frail or in poor health.<sup>4</sup>
- 2.4. We lack reliable data for how many end of life carers there are in Wales, or across the UK. Analysis of the UK Household Longitudinal Survey suggests that the number of end of life, household carers represents approximately 4% of all household carers in a given year.<sup>5</sup> The data also suggest that 16% of households carers will become end of life carers at some point.<sup>6</sup> It is likely that figures underestimate the number of end of life carers due to the tendency of carers to not identify as such.
- 2.5. We also lack evidence about the experiences of end of life carers. To overcome this, and inform our response to this inquiry, we ran a short survey to gather the views and experiences of end of life carers. The below evidence draws on the 63 responses we received to the survey and key points from discussions held with carers supported through Marie Curie services. While not exhaustive, this evidence provides important insight into the support needs of end of life carers.
- 2.6. Due to sample size we have not been able to disaggregate evidence by personal characteristics or location. There is scope for further research with end of life carers to explore different experiences and better understand what is shaping positive experiences, as well as identify gaps in provision.

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<sup>1</sup> S.J. Gould et. al. "British unpaid carers' perspectives on what impacts their resilience when providing end of life care at home: a scoping review" *International Journal of Care and Caring*, 16<sup>th</sup> December 2024

<sup>2</sup> Ibid.

<sup>3</sup> Marie Curie (2024) *Better End of Life 2024 Time to Care in Wales Implications for Wales of 'Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales*

<sup>4</sup> Ibid.

<sup>5</sup> C. Gardiner et. al (2024) *Exploring the financial and employment impacts of end of life unpaid care giving in the UK: Executive Summary*

<sup>6</sup> Ibid.

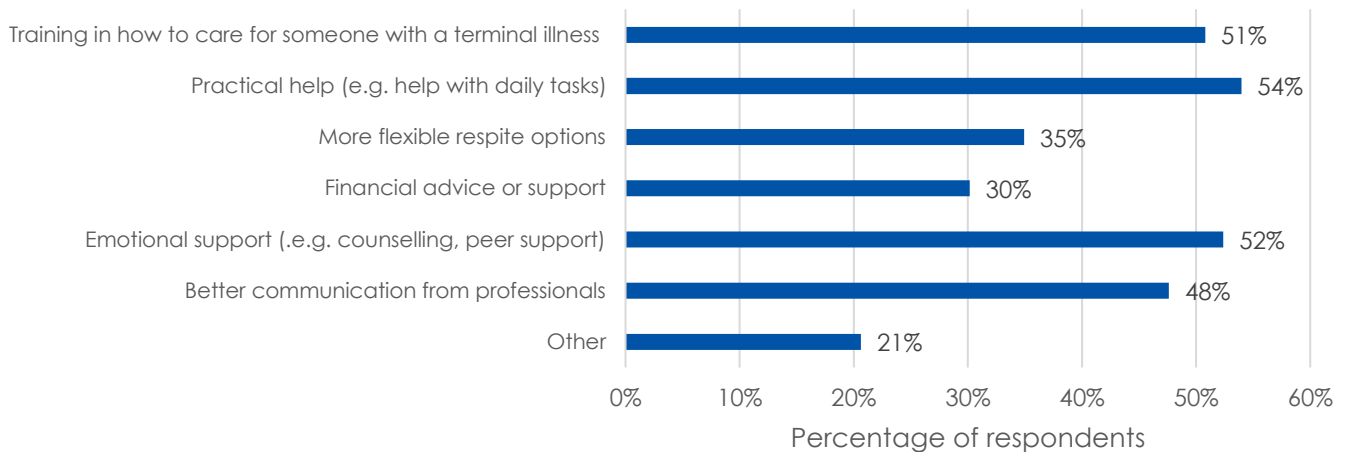
### 3. Accessing support

- 3.1. We asked end of life carers whether they had received the support they needed. Just 37% answered yes. **56% of respondents said that they had not had the support they needed.**
- 3.2. When asked what prevented them from getting support, answers were wide ranging. After grouping responses thematically the most commonly cited reason related to a lack of capacity in the system (e.g. no staff being available, services being stretched, lack of paid carers) and a lack of information or signposting to sources of support.
- 3.3. Similar themes were reflected in the discussions held with end of life carers at our Cardiff and the Vale Hospice. They cited challenges navigating the system, with some giving up work in order to manage caring responsibilities - *"I'm expected to do the job of social workers, health professionals – I am running around, had to give up work, look after my wife and kids and keep us safe."*
- 3.4. A lack of support from social services was also highlighted – *"you feel abandoned with the onus on you to do everything."*
- 3.5. These findings closely align with those of our 2024 *Time to Care in Wales* report which found that many bereaved people felt they had lacked the knowledge or skills to care for the person who was dying but were unable to access sufficient support, with poor communication from healthcare professionals and poor care coordination a cause of significant stress.<sup>7</sup>
- 3.6. Respondents to our survey of end of life carers were also asked what kind of support would have made the biggest difference to them, with a list of options from which to select. Respondents could select as many answers as they wished. The most commonly selected options were practical help (e.g. help with daily tasks), training in how to care for someone with a terminal illness, emotional support (e.g. counselling, peer support) and better communication from healthcare professionals.

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<sup>7</sup> Marie Curie (2024) *Time to Care in Wales*

## Type of support that would have made biggest difference



3.7. Those who selected 'other' noted bereavement support, better support with symptom management and overnight care.

3.8. These findings closely align with those found in the literature. A 2024 scoping review exploring the factors that impact end of life carers' resilience, identified a range of organisational factors that were most frequently cited as supporting carers' resilience.<sup>8</sup> These include:

- Multidimensional support
- Practical advice
- Timely information from professionals
- Trust in health and social care professionals
- Carer inclusion in decision-making
- Continuity of staff
- Continuity across services
- GP contact
- An appreciation of the complexity of the carer's role
- Information about the dying process

3.9. A 2025 report from Hospice UK exploring end of life care in rural areas found similar challenges for end of life carers. "Carers wanted practical help with daily tasks such as collecting medication or food shopping. They needed

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<sup>8</sup> S.J. Gould et. al. "British unpaid carers' perspectives on what impacts their resilience when providing end of life care at home: a scoping review"

access to respite, whether in someone's home for a few hours during the day or overnight, day care services or short breaks. However there are limited respite services in rural areas, or these are several hours drive away, which defeats the point of using them."<sup>9</sup>

- 3.10. Respondents were also provided with an opportunity to note the single most important thing that would have helped them in their caring role. Some respondents did get the support that they and the person they cared for needed, but many others noted a wide range of things that would have made a difference such as financial support, better knowledge of what to expect at the end of life, access to respite and better information and signposting to sources of support.
- 3.11. There was a sense from some who responded to this question that they simply did not know what support they needed or where to turn. From others, there was a sense that it didn't matter what support they needed as they had no faith that the system could provide it.
- 3.12. The following quotes provide some further insights into the support that unpaid end of life carers are calling for.

*"Better quality of carers - the ones that came 4 times daily in mum's final weeks were clearly not trained in caring for completely immobile patients at end of life."*

*"The support was amazing once we were in the system, however I felt the final discharge from the hospice was too soon and I can only think that this was due to the urgent need for beds for others. More capacity is desperately needed for this essential service."*

*"More practical help and not to have to wait so long for it. Also had no emotional support"*

*"...I don't really see what anyone else can do at the moment"*

*"Being told I was doing enough for my husband, and that someone would be with me until the end"*

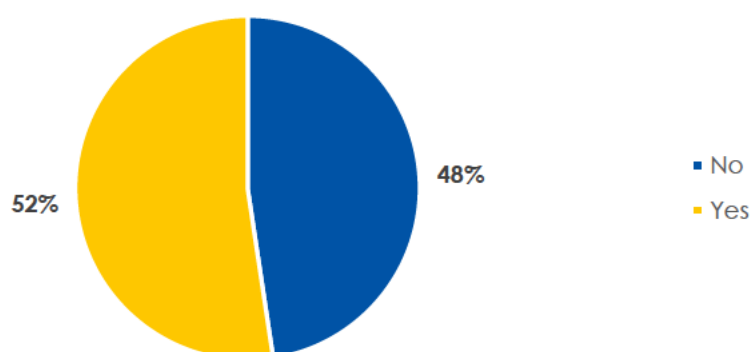
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<sup>9</sup> Hospice UK (2025) *Bringing care closer to home Improving palliative care in remote rural and island communities*

## 4. Respite care

4.1. 52% of respondents to our survey had accessed some form of respite care, but 48% had not.

### Have you been able to access any respite?



4.2. Of those who provided reasons for not accessing respite, 35% said they did not know what was available, 23% that there was no-one else to help and 21% did not feel comfortable leaving the person they care for. This reflects findings from Scotland, which showed that access to respite is important for carer's physical and emotional health, but is not without challenge for end of life carers.<sup>10</sup>

4.3. Respondents who had accessed respite had used a variety of respite services. Some had accessed multiple types of respite.

Type of respite	Percentage of respondents
In-home support	24%
Day services	14%
Residential respite	11%
Volunteer/ companion services	5%
Other	19%

4.4. Of those who selected 'other' the most commonly cited type of respite was support from family.

4.5. From the discussions held with end of life carers it's clear that respite is limited. For some it offers an opportunity to get essential tasks done, such as

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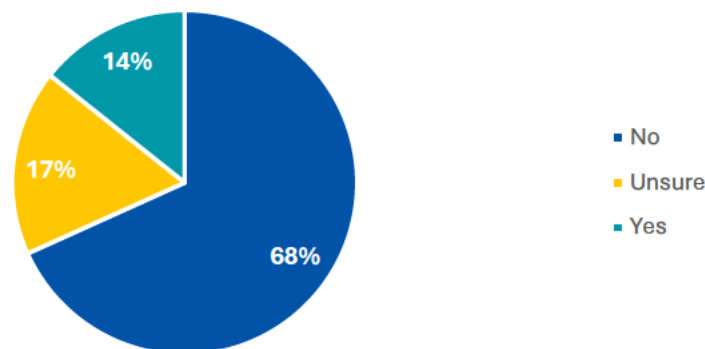
<sup>10</sup> S. Swan et. al (2022) "Factors affecting adult carer support planning for unpaid caregiving at the end of life in Scotland: Qualitative insights from triangulated interviews and focus groups" *PubMed*

going shopping or attending medical appointments for their own needs, but it does not necessarily offer time for themselves.

## 5. Carer's needs assessments

5.1. The majority of respondents to our survey had **not** been offered a carer's needs assessment.

**Have you been offered a carer's needs assessment?**



5.2. The most commonly cited reason for not having an assessment was not being aware of their entitlement (67%).

5.3. A small number of respondents provided quite concerning responses when asked why no assessment had been offered or taken place, which suggest some fundamental issues with the system.

*"Social worker told me there was nothing, so no point"*

*"No point, no services"*

*"I was asked to write my own. They lost it, then asked me again but technically there wasn't an active one."*

5.4. As carer's needs assessments are a legal right and a key route through which people can access the support they need, urgent action is needed to address the issues highlighted.

5.5. While awareness of carer's needs assessments was low among our survey respondents, there are many opportunities for end of life carers to be made aware of their entitlement to an assessment, as they interact with a wide range of healthcare professionals.

5.6. Making sure that all healthcare professionals are able to operate in a carer aware manner and signpost or refer end of life carers to their local authority

for a carer's needs assessment, should they want one, has to be made an urgent priority.

5.7. It's also important to note that the needs of end of life carers are likely to change as the needs of the person they care for change. Therefore any carer's needs assessment undertaken, and support package put in place, must be subject to regular review to ensure carers are receiving the support that they need.

5.8. The fluctuating nature of terminal decline results in a dynamic experience for carers, which necessitates frequent reassessment to determine if support needs have changed."<sup>11</sup> Ongoing assessment at key junctures of diagnosis, hospital admission, terminal decline and after death is needed.<sup>12</sup>

## 6. Conclusion

6.1. The evidence from our survey, which has shaped this response, provides important insights into the lived experiences of those caring for someone with a terminal illness. While not exhaustive, the responses paint a worrying picture.

6.2. Many end of life carers are simply not getting the support that they need. The reasons for this vary but some clear themes emerge:

- **Appropriate and timely support for the person they care for** is essential. When the person living with a terminal illness is not getting appropriate care this has a very real impact on the person caring for them. Navigating systems is complex and time-consuming and when care is not forthcoming or well-coordinated, end of life carers are picking up the slack.
- **Better communication from healthcare professionals** is needed, in relation to the care and prognosis of the person living with a terminal illness, what to expect as someone enters their final weeks and days of life, and making sure that unpaid carers are getting the support they need.
- **Access to respite** is important. A majority of our respondents had accessed respite, but a significant minority had not, and it was commonly cited as something that would make a difference. This will need to take different forms for different people, but consistency, accessibility and flexibility are crucial.
- The need for **emotional support and reassurance** is clear. End of life carers are often dealing with a complex and dynamic caring situation, as well as experiencing anticipatory grief and many of the emotional pressures experienced by all unpaid carers. Support for them must be holistic, and

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<sup>11</sup> S. Swan et. al "Factors affecting adult carer support planning for unpaid caregiving in Scotland"

<sup>12</sup> Ibid.

cover emotional support as well as practical, financial and clinical support.

- 6.3. There are clear issues with the way in which carer's needs assessments are operating, with the vast majority of end of life carers not being offered one. Action is needed urgently to ensure that carer's needs assessments are being offered consistently to all who require them, that support packages are put in place and are regularly reviewed.

## 7. Recommendations

- 7.1. Information and training resources on the needs of unpaid carers should be made available for the palliative and end of life care workforce.
- 7.2. Training should be developed for unpaid carers in the essential skills needed to care for someone at the end of life. This should be based on existing evidence-based models such as Last Aid and EASE in Scotland.<sup>13</sup>
- 7.3. Carers should have access to key healthcare contacts including 24/7 palliative and end of life care and support.
- 7.4. Further investment should be made to improve the availability of accessible and flexible respite for end of life carers.
- 7.5. Steps should be taken to ensure that all healthcare professionals are able to operate in a carer aware manner and signpost or refer end of life carers to their local authority for a carer's needs assessment, should they want one.
- 7.6. Carer's needs assessments must be undertaken consistently and regularly reviewed.

For more information please contact:

Natasha Davies  
**Senior Policy Manager, Wales**

Dr Tomos Evans  
**Policy and Public Affairs Manager, Wales**

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<sup>13</sup> <https://highlandhospice.org/what-we-do/education-learning-development/last-aid/> / [https://www.goodlifedeathgrief.org.uk/plan-illness-ease/#:~:text=End%20of%20Life%20Aid%20Skills%20for%20Everyone%20\(EASE\)%20is%20a,Scottish%20Partnership%20for%20Palliative%20Care](https://www.goodlifedeathgrief.org.uk/plan-illness-ease/#:~:text=End%20of%20Life%20Aid%20Skills%20for%20Everyone%20(EASE)%20is%20a,Scottish%20Partnership%20for%20Palliative%20Care)