



# Wales Carers Assembly 2024 report





# Introduction

Carers Wales's mission is to make life better for unpaid carers in Wales. We provide information and advice on caring, help carers connect with each other, campaign with carers for lasting change and use innovation to improve services.

The Annual Wales Carers Assembly hosted by Carers Wales and funded by the Welsh Government, was held on Monday 19th February 2024. The event was held in a hybrid manner, with in-person attendees returning to Siambr Hywel in the Senedd for the first time since the pandemic began. The Assembly served as a conduit for unpaid carers to elected political representatives and policymakers, ensuring unpaid carers have their voices heard at the highest levels, on the issues most important to them.

80 unpaid carers joined the event in-person and remotely via Zoom. The Assembly was opened by sponsor, Joel James MS and the Deputy Minister for Social Services, Julie Morgan MS. Attendees then posed questions to three, themed panels of experts focusing on unpaid carers' relationships with the healthcare system, social services and employment. Finally, carers led a discussion session at the end of the day, raising priority issues and identifying potential policy solutions.

This report offers a summary of the event, including the contributions from speakers and some of the powerful and emotive contributions from the unpaid carers who gave up their time for the Assembly. The report will be used to further put unpaid carers on the map, giving greater voice to the hundreds of thousands of unpaid carers across Wales discussing the critical issues impacting upon them the most.

# The Opening of the Wales Carers Assembly 2024

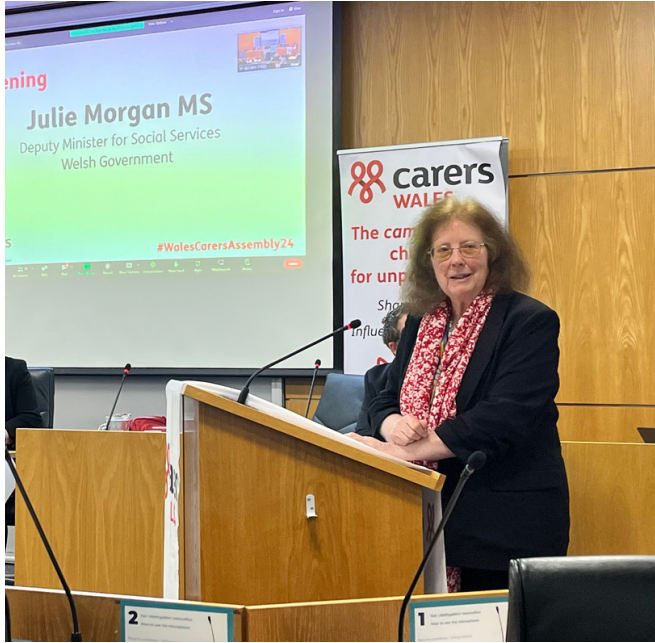
## Claire Morgan, Director of Carers Wales

Claire opened the Assembly, thanking unpaid carers from across Wales for attending and outlining the day. Attendees were reminded that the Assembly would provide a unique opportunity for unpaid carers' lived experience to be seen and heard by such a rich mix of policymakers. The gauntlet was laid down to attendees, to make the most of the day and reflect on the poignancy of sitting where devolved democracy in Wales began, when making contributions.

## Joel James MS, Sponsoring Member of the Senedd

Joel thanked the attendees for being afforded the privilege of sponsoring the event and spoke of the importance of unpaid carers and the role that carers play in our communities. Joel spoke of the pressures that unpaid carers face and of the need to do more to support carers in Wales, to be able to take breaks, continue their caring role and look after their own health and wellbeing.





## **Julie Morgan MS, Deputy Minister for Social Services**

The Minister thanked attendees for giving up their time to participate and contribute to the Assembly, and thanked Carers Wales for organising the event. The Minister also reflected on the poignancy of being in Siambr Hywel and how devolved democracy in Wales has moved the links between people and politicians closer.

Julie spoke of her own lived experience as an unpaid carer, and how this has been a drive for her work as Deputy Minister for Social Services. The Minister listed some of the Welsh Government's initiatives to support unpaid carers, such as funding for respite and breaks, the Carer Support Fund and Social Services and Wellbeing Act.

She said she looked forward to receiving feedback from the Assembly.

# Setting the Scene, Carers Wales

An unpaid carer is a person of any age, who helps to look after and support a family member, friend or neighbour who is disabled, has an illness or long-term condition or who needs extra help as they grow older.

The 2021 Census identified that there are around 310,000 unpaid carers in Wales. Carers Wales estimate that this number is actually closer to 450,000 people, 1 in 6 people across the nation. There are over 144,000 unpaid carers in Wales who juggle their caring responsibilities with paid employment. Research from Carers UK and the University of Sheffield shows that unpaid carers contribute £10.6bn to the Welsh economy over a 12-month period, and that the value of unpaid care has increased by 17% since 2011.

In our most recent State of Caring in Wales reports, it is clear that unpaid carers from across Wales face challenges and difficulties unimaginable to many people.

- Over half of unpaid carers said they felt depressed.
- Nearly 1 in 4 unpaid carers told us they were cutting back on essentials such as food or utilities, due to financial concerns.

- More than 3 in 4 unpaid carers say they feel worried about being unable to provide care in the future.

As part of the Social Services and Well-being (Wales) Act 2014, there is a duty on public bodies to ensure that unpaid carers are involved in the co-production of the services that support them. It is vital that the UK Government, Welsh Government and Local Authorities across Wales work in partnership with unpaid carers and their representative organisations, to avoid deepening the crisis among carers across Wales.

It is abundantly clear, that this is an unsustainable situation and without swift action to ensure unpaid carers receive the support they need, the cost to people and the public purse will be severe.

# Panel Session – Unpaid Carers and Healthcare

## Panellists:

- Gareth Davies MS, Shadow Minister for Social Services
- Dr Lucy Cornish, Deputy Director of Therapies and Health Science, Powys RPB (Regional Partnership Board)
- Nicky Hughes, Assistant Director of Nursing, Royal College of Nursing Cymru

*Question - Despite unpaid carers being critical support for health and social care professionals, many carers that they have to fight to be recognized as somebody's carer, how can we improve recognition but also respect and esteem from health care professionals towards unpaid carers?*

Panellists spoke about the importance of training for healthcare professionals, to better understand and recognise unpaid carers and work with them when caring for people. It was suggested that training for health and social care professionals should be mandatory. Examples of existing good practice within Wales were shared, where health boards and organisations were embedding carer awareness training into cultures at an early point. It was suggested that this good practice in working with carers should be embedded in daily practice across all health boards.

*Question - Many carers have spoken of their anxiety regarding the well-publicized budget issues in relation to the NHS. Are panellists worried about the impact that this may have on service users and unpaid carers and what can be done to mitigate the impact?*

The panel members acknowledged the extreme pressures on the NHS in Wales at present and the knock-on impact this has on unpaid carers. The discussion on how to mitigate impact looked at a broad set of ideas. Gareth Davies MS spoke of the importance of ring-fencing funding provided to the NHS to ensure that it reaches the people and places who need it most.

Nicky Hughes acknowledged the pressure within hospitals specifically and of the need to eliminate corridor care but said that to tackle the pressures in the NHS we need to look wider, into better supporting primary care (such as doctors and dentists) and investing in communities to keep people in their own homes where possible.

Claire Morgan supported this sentiment and echoed a recent contribution in a Senedd Committee, where the NHS Confederation Wales suggested that currently too many people are being cared for in the “most expensive” part of the health and social care system.

It was suggested that systems and activities should be better evaluated, to ensure more effective and impactful investment of funding.

*Question from attendee - The one observation that I would make, having worked partly in the health service, partly in the law, and partly now for a mental health charity, is that and also being an unpaid for my father at one point and my mother. I think the one thing that the NHS and local governments and social services could do at the ground level is to learn the skill of active listening. When budgets are tight, all that you hear is how can I avoid giving this person the service that is being rationed? And let's be honest and that is really painful. So, if you can actually turn it into "How can I help this person, how can I listen to them?"*

Panellists spoke about the importance of training to support professionals to better engage and listen to unpaid carers, and to improve the esteem of unpaid carers within the NHS. This led to a wider discussion about how to better identify young carers within the school system, as well as the opportunity to identify all carers through the new electronic medical records and systems that are being rolled out across the NHS in Wales.

*Question - Do panellists agree with some of our attendees that the process of getting a diagnosis for care for people can be onerous and far too time consuming? If so, how can we tackle this issue?*

The panel agreed that getting a diagnosis for a cared-for person can be an onerous process which impacts on unpaid carers. Gareth Davies MS shared an anecdote from his casework of constituents having to travel huge distances across the UK to get an autism diagnosis for somebody they care for.

Dr Lucy Cornish spoke of ways to improve the system, such as the electronic patient record to avoid duplicating conversations with multiple different healthcare professionals, and the challenges of getting this system into place as well as an instance of specialists having to diagnose via paper files.



*Question - How do we ensure carers views and experience says are rooted within health care services and what steps can we take to enhance this approach?*

Dr Lucy Cornish spoke of the Powys Carers Steering Group, which shapes the Regional Partnership Board (RPB)'s priorities, funding and resources and is showing promising work. Lucy spoke about how more training and support can help more unpaid carers become involved in this, while balancing the time constraints faced.

It was noted that remuneration should be in place for carers to undertake representational roles, in recognition of their time and replacement care costs.

The panel spoke of the importance of co-production being done in a high-quality way, and not as a tick-box exercise, or afterthought.

It was suggested that more co-production best practice should be shared, to demonstrate how it was achieved and its impact.



# Panel Discussion – Unpaid Carers and Social Care

## Panellists:

- Sioned Williams MS, Plaid Cymru's Spokesperson for Social Justice and Social Services
- Cllr Andrew Morgan OBE, Leader, Welsh Local Government Association
- Sue Evans, Chief Executive, Social Care Wales
- Alwyn Jones, President, Association of the Directors of Social Services Cymru

*Question - Many carers have highlighted to us why have existing services not reopened post-pandemic? And how do Welsh government and local authorities plan on addressing this?*

Cllr Andrew Morgan suggested that the issue is less to do with services not having re-opened – noting that many were open throughout the pandemic – but that the pressures relating to respite and breaks is so severe and that there simply isn't enough respite available across Wales.

Sioned Williams MS recognised the pressure that local authorities face but spoke of the need for consistency and expectation regarding local services. Sioned also noted the importance of ensuring people's rights are upheld and making sure that carers are supported to avoid a greater human and economic cost.

Alwyn Jones noted that in Wrexham, respite services are back open, but that the pressure in demand for both respite services and emergency demand is impacting upon capacity. To help mitigate this, Wrexham are working on alternative types of respite and considering how they can change the nature of their services.

Sue Evans spoke of the work Social Care Wales are doing to ensure paid social care professionals know to support unpaid carers, given how vital unpaid care is to the wider health and social care system. It was acknowledged that there is a shortage of paid care workers to provide support and what is being done to mitigate this.

It was suggested that there is not enough communication about what support exists for carers and that many carers do not know where to go for help.

*Question - Many unpaid carers, whether they're in receipt of carer's allowance or not, struggle financially. What practical steps can we take to alleviate the impact of the ongoing cost of living crisis and provide financial security for unpaid carers?*

The panel discussed how the financial pressure on local authorities exacerbates the issue and challenges faced. Several tangible examples that are currently being used in Wales were illustrated, such as food vouchers, fuel and travel vouchers.



The discussion then focussed on how this support varies depending on the local authority area, and that a more uniform picture would be welcome to address the postcode lottery facing unpaid carers.

Panellists discussed the disproportionate impact of the cost-of-living crisis on unpaid carers, and a desire to move away from “sticking plaster” interventions to a more preventative approach when supporting carers financially.

Sioned Williams MS spoke of the need for unpaid carers to be a priority when designing anti-poverty interventions, the importance of a person-centred approach and that this should also be a key consideration when looking to tackle the postcode lottery of support available to carers.

*Question from attendee – We would like to bring up the young carer ID cards because many young carers across Wales are finding them ineffective and this is due to a number of reasons, such as each county has different rules about the costs such as Pembrokeshire where I have my ID card from. I was just thinking of making it a national card, not just county card, because if you can get all of those local authorities to work together to get this one card for the whole country, it'll just be easier for everyone.*

Cllr Andrew Morgan agreed and pledged to work with other council leaders across Wales to assess options in this area.

# Panel Discussion – Unpaid Carers and Employment

## Panellists:

- Jayne Bryant MS, Newport West
- Joshua Miles, Director for Wales, Learning and Work Institute

*Question from online attendee - Parent carers face a lifelong caring role rather than for a time limited period. What can the Welsh Government do or encourage to support working parent carers, so they don't get burnout?*

Jayne Bryant MS spoke of the need to recognise when caring responsibilities are more intense for parent carers and to support parent carers through that process. Highlighting that a significant number of unpaid carers are unable to work, Jayne said that people who want to return to work should also be supported to do so, given the benefit it will provide to them.

Joshua Miles suggested that the Welsh Government should be doing more to promote ways to support unpaid carers during its ongoing engagement with businesses and employers across Wales. The panel spoke about the need to change culture within employers, empowering managers and employers to better understand unpaid carers, but also promoting the business case for better

support for carers – demonstrating that there is a business benefit as well as a human benefit for carers.

It was suggested that there should be more mental health support for carers.

*Question from attendee - I just want echo what you were saying about engaging with employers, because I think it's really important that we have legislation that supports that carers rights and everybody's rights. But I think stick without the carrot and also the stick that is not informed by employers' experience in the private sector is a mistake and I think engaging private sector employers to make it a win win, so actually they understand the benefits of employing people who may not be able to be there 100% of the time when they want to be is really important.*

Joshua Miles spoke about the need to support smaller businesses, who often lack the capacity and expertise to support unpaid carers and cope with changes such as the upcoming Carer's Leave Act.

Panellists discussed how the Carer's Leave Act represents a step in the right direction in supporting more unpaid carers to remain in, or return to, employment. But that paid carers' leave would have the biggest impact in supporting carers in this regard. It was noted that self-employment can provide a more flexible work option for carers and Carers Wales committed to running a session for carers on this.

# The Last Say

At the Carers Assembly the last say was for the carers who had attended online and in-person. 'The Last Say' session encouraged attendees to discuss what they had heard throughout the day and comment on pressing issues affecting carers. Carers discussed a number of issues across the 3 groups, but we have summarised the most commonly recurring topics below.

## **Experiences with health and social care staff**

A number of carers discussed unsatisfactory experiences with health and social care staff. A carer raised concerns that professionals undertaking Carers Needs Assessments do not seem sufficiently knowledgeable about the condition of the person the carer looks after, while another carer said professionals can sometimes make assumptions about what is possible for a carer, with the carer emphasising that some carers are still able to work full-time alongside caring. It was suggested that staff need to be supported to identify people with caring responsibilities as carers, that social workers need better training and that staff need improved training to help recognise invisible disabilities in both children and adults.

Carers Wales has long called upon health boards and local authorities to ensure all of their carer-facing staff are sufficiently trained in understanding and responding to the needs of carers.

The need for staff to be sufficiently trained to support carers was also raised repeatedly by carers who attended the Annual Assembly in 2023. Through the Carer Aware project, Carers Wales has delivered Carer Aware training to over 500 social workers across Wales and will continue to train more social workers moving forward.

## **When caring changes or ends**

It was suggested that there is a lack of support for people who are transitioning out of caring, including financial support. Caring continues to affect mental health even after it has ended, with one carer saying many are traumatised by what they have had to endure. Another carer said it had been a difficult transition for her coming out of her caring role. Needing a "culture change", she became a carer peer support within the NHS which had been a positive experience. It was felt that more needs to be done to recognise the legacy of caring and that there isn't enough support for carers who are grieving following a bereavement.

Carers Wales had produced, in collaboration with carers, a guide on 'When caring changes or ends', providing advice and information for carers in this situation.

## Identification

Several carers raised concerns about carer identification. A carer explained how in their experience carers are not being recognised within A+E. A parent carer explained how her child's disability was not recognised within the education system and she was not recognised as a carer. It was further suggested that information should be targeted at carers within health settings, explaining the support available, to help people identify as carers. The 2022 Carers Wales State of Caring survey found that 52% of carers in Wales took over a year to see themselves as a carer, while a third of carers took over 3 years to be identified as a carer.

## Carers Needs Assessments

Turning to Carers Needs Assessments, it was felt that support needed to be offered in a more proactive manner throughout the caring journey as many carers don't have a Carers Needs Assessments until they are in a crisis. If needs had been assessed earlier and support put in place sooner, the situation may not have developed in the way that it did. Other carers said carers need more information on the eligibility criteria for services and support in advance of Assessments as it was felt they are not well publicised.

Clarity on these points would help carers go into a Needs Assessment with a clearer understanding of what to expect. It was also suggested that local authorities should provide a process map for carers, setting out step by step who will make contact with a new carer at the start and what the next stages will be, including a Carers Needs Assessment.

Carers Wales research has found over multiple years that many carers are not receiving Carers Needs Assessments and even when they are provided they are often not delivered in accordance with the requirements of the Social Services and Well-being Act. Part of the Carer Aware training Carers Wales delivers to social workers is focused on the correct delivery of Assessments, and emphasises the need to be open and honest with carers about eligibility criteria and why decisions are made.

## Services

Many carers spoke about their desire to share their experiences to improve services. It was felt that platforms like Zoom had made it easier for carers to engage but carers needs and the barriers they can face still need to be taken into account, with one carer explaining how they had to use respite time to attend carer training with the local authority.

Carers felt services need to be open to changing to better meet the needs of carers, and carers must feel involved and respected and paid for their time. It was suggested that carers need a better idea of what expectations they can have from services, while many carers said engaging with services often felt like a battle. It was further suggested that more needs to be done to share good practice across the system so improvements and innovations can be rolled out more widely.

Across surveys and previous engagement events with carers, Carers Wales has often heard that many carers do not feel their needs and preferences are meaningfully considered by health and care services. In November 2023, Carers Wales published research into co-production with carers across Wales, finding that while there are good examples of carer voice being acted upon and positive structures of co-production, more action is needed to ensure services are meaningfully responding to the ideas and preferences of carers.

## Employment

Carers spoke of a gap between the theory of supporting unpaid carers in employment settings and the reality, such as the need for flexibility and/or emergency time off. There was a discussion where people spoke about their own experiences combatting a lack of understanding around unpaid care in workplaces and perceptions of unpaid care and carers undermining and limiting people.

Culture change was identified within groups as being key to beginning to remedy this. Training and resources for line managers who support employees with caring responsibilities was a key item of feedback, in particular areas such as what sort of language is or is not acceptable to use regarding unpaid care and what sort of questions may or may not be appropriate.



# Thanks and Acknowledgements

Carers Wales would like to pay tribute to and acknowledge the contributions of everybody who was involved in the Wales Carers Assembly 2024. We believe events like this are vital, to ensure that elected politicians and decision makers in key services are reminded of the challenges that unpaid carers in Wales face every day. Thank you to the key partners below for your support in making the Assembly a reality:

- The Welsh Government
- Senedd Cymru
- Carers UK
- Children in Wales
- Young Carers Advisory Board
- Julie Morgan MS, Deputy Minister for Social Services
- Joel James MS
- Gareth Davies MS
- Sioned Williams MS
- Jayne Bryant MS
- Cllr Andrew Morgan OBE, Welsh Local Government Association
- Nicky Hughes, Royal College of Nursing Cymru
- Dr Lucy Cornish, Powys Regional Partnership Board
- Alwyn Jones, Association of Directors of Social Services Cymru
- Sue Evans, Social Care Wales
- Joshua Miles, Learning and Work Institute

Finally, we want to extend our heartfelt thanks to the unpaid carers who joined us for the Assembly, either in person at Ty Hywel or online. Your continued enthusiasm and determination, despite the many challenges faced, is greatly appreciated. We will continue to work to make life better for unpaid carers across Wales and look forward to working alongside you to make these changes.

**[carerswales.org](https://carerswales.org)**

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