Cyflwynwyd yr ymateb i ymgynghoriad y <u>Pwyllgor lechyd a Gofal Cymdeithasol</u> ar <u>Gwella mynediad at gymorth i ofalwyr di-dâl</u>

This response was submitted to the <u>Health and Social Care Committee</u> consultation on <u>Improving access to support for unpaid carers.</u>

UC23: Ymateb gan: Ruth Cann | Response from: Ruth Cann



Consultant Nurse Older Vulnerable Adults

Evidence submitted in a personal capacity to inform policy/ service development on Unpaid carers and Respite

Consultant Nurse for Older Vulnerable in the Cardiff and Vale Health Board since January 2023. Dip He Adult Nursing, MSc Advanced Practice. Committed to improving the quality of care and support for older People and making working with older people an attractive career choice, and an area of nursing that is celebrated and valued.

Experience of working as a carer in a dementia registered care home before registering as a nurse 2001 and working in a variety of settings and leadership positions providing care and support for older people, including secondary care and community services. Seconded to Welsh Government in 2014 as part of the 'Trusted to Care' team brought together in response to the Andrew's Report (2014). Awarded for leadership skills and ability to inspire and lead teams engaged with the care of Older People in 2013, winning the Older Person's Commissioner for Wales category and overall RCN Wales Nurse of the Year Award.

I am submitting this evidence in a personal capacity. I can confirm that I am over 18 years of age.

Summary of Key Issues

- Unpaid Carers and Ageing Population
- Support after Bereavement
- Emergency Respite and Dual Admissions
- Respite for People with Dementia
- Community Hospital Respite Beds
- John's Campaign and Carer Inclusion
- Flexible, Meaningful Respite
- Frailty Nurses and Future Care Planning
- Listening to Carers

Unpaid Carers and Ageing Population

Many unpaid carers are themselves older adults, often with multiple long-term conditions. Codependent relationships between the unpaid carer and cared-for can complicate care planning and crisis response. There is a lack of anticipatory planning for when carers become unwell.

Support after Bereavement

Unpaid carers often experience loss of identity and purpose after the death of the person they cared for. There is a risk of social isolation and mental health decline post-bereavement. In older people a bereavement can accelerate physical and cognitive decline. There needs to be bereavement pathways that include emotional support, social reconnection, and practical advice (e.g. finances, housing) along with access to proactive Comprehensive Geriatric Assessment for people at risk of or living with frailty.

Emergency Respite and Dual Admissions

When unpaid carers become acutely unwell, there is often no immediate plan for the cared-for person. This leads to dual admissions (carer and cared-for), which are costly and distressing. There is a need for rapid response respite services that can be activated in emergencies. The respite options must be equipped to support individuals who present with behaviours that challenge, particularly those living with dementia. A change in environment and separation from a familiar carer can cause extreme distress, leading to increased agitation, confusion, and behavioural symptoms. These responses are not simply 'challenging'. They are expressions of unmet need and distress. Therefore, respite services must be designed with dementia-sensitive approaches, including staff trained in deescalation, continuity of routines, and environmental familiarity.

Respite for People with Dementia

Residential respite placements can cause distress, behavioural changes, and accelerated cognitive decline due to unfamiliar environments. Respite requires dementia-sensitive respite models with:

- Continuity of care
- Familiar routines
- Enabling approaches
- Access to specialised and reactive dementia multi-disciplinary support.

Occasional overnight or 24-hour care may offer significant preventative value. A flexible model of planned overnight respite particularly for people with dementia could improve outcomes form both the carers and cared for.

Community Hospital Respite Beds

Community hospitals historically offered short-term respite beds under Continuing Healthcare (CHC). This model provided continuity of care and clinical oversight for people with complex needs and supported the resilience of unpaid carers. A planned and emergency respite model in community hospitals could be explored.

John's Campaign and Carer Inclusion

There needs to be a continued cultural shift toward recognising unpaid carers as partners in care. Hospitals should invite carers and family members in rather than restricting visiting hours. When asking older people 'What Matters' the response is often their family. A shift toward Relationship-Centred care would support this.

Flexible, Meaningful Respite

Respite should be tailored to the unpaid carer's needs, allowing them to rest, engage in hobbies and maintain social connections that can support with continuing sense of purpose in the event of bereavement. Flexibility is key: day respite, overnight stays, home-based support.

Frailty Services, Dementia Connectors and Future Care Planning

Nurses working in frailty roles are well-placed to support anticipatory care planning, identify carer strain early and facilitate relationship-centred care. There is opportunity to embed carer assessments into frailty pathways. If there is a need identified the carer assessment and interventions needs to be reactive and tailored to meet the carer's needs.

Listening to Carers

Unpaid carers' voices should shape care plans, discharge decisions and respite options. There is a need to balance the needs of both carer and cared-for person, and there needs to be awareness raised around the Powers of Lasting Power of Attorneys for Health and Welfare.

Key Recommendations

- Develop Emergency Respite Pathways
- Explore the use of Community Hospital beds
- Design Dementia-Sensitive Respite Models
- Embed carer Support into Frailty Pathways. Include carer assessments as a standard part of frailty assessment and anticipatory care planning
- Support for Carers post-bereavement. Develop bereavement pathways that include emotional support, social reconnection, and practical advice
- Offer proactive Comprehensive Geriatric Assessment for bereaved carers at risk of frailty
- Promote Relationship-Centred Care
- Implement John's Campaign principles across all hospital settings.
- Offer Flexible and Meaningful Respite Options
- Raise awareness of Legal Rights and Planning Tools