

Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Flaenoriaethau'r Chweched Senedd](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [Sixth Senedd Priorities](#)

HSC PSS 63

Ymateb gan: | Response from: Gofalwyr Cymru | Carers Wales



Question 1: Initial priorities identified by the Committee

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

Q1. Which of the issues listed above do you think should be a priority, and why?

You can comment on as many or few of the issues as you want.

In your answers, you might want to think about:

- What impact or outcomes could be achieved through any work by the Committee?
- How the Committee might address the issue?
- When any Committee work should take place?
- Whether there are any specific groups, communities or stakeholders that the Committee should involve or hear from in any work?

Unpaid carers underpin all the potential priorities you are considering working on during the sixth Senedd. Unpaid carers are a critical pillar of the health and social care system in Wales. By providing care where the statutory services would otherwise have to step in, it is estimated that unpaid carers save Wales £8.1 billion every year, a figure which rose to £33 million every single day at the height of the COVID-19 pandemic. Welsh Government figures show carers provide 96% of all care in Wales. Without adequate support and services, carers often give up work or reduce their hours to care and their mental and physical health can suffer, along with their financial situation and their life outside caring. This risks their ability to continue to provide care for people with complex and ongoing needs. We believe the committee should specifically consider the impact and consequences of actions, or lack of action, relating to unpaid carers as a clearly defined aspect of any inquires or pieces of work.

We have set out below the role of carers in each of the committee's potential priorities.

Public Health and Prevention

Research has found that since the start of the pandemic the number of unpaid carers rose from 1 in 6 to more than one fifth of the population in Wales¹. Their selfless commitment to provide care for someone who is older, seriously ill or has a disability has been vital to ensure the sustainability of our health and social care system.

¹ <https://www.carersuk.org/for-professionals/policy/policy-library/carers-week-2020-research-report>

Research undertaken during the pandemic found that more than a quarter of carers no longer feel they can cope with their caring role. Given the estimated financial contribution that carers make in Wales equates to £8.1 billion a year, it is vital carers are supported properly so they are able to continue to care safely while looking after their own health and well-being.

With winter coming and the number of Covid-19 cases increasing across Wales, there is significant concern that more pressure is going to be put on unpaid carers. Carers are already anxious about the impact of this and what this will mean for them, with 68% being concerned about whether they will be able to cope in further lockdowns. Carers need to be confident that systems and services are in place to support them to continue to care for our most vulnerable during this next phase of Covid-19 and into the future.

Unpaid carers are an indispensable component of the prevention agenda more generally as, by meeting needs and managing conditions in the home, they support ill and vulnerable people to avoid, or delay, admission to hospital or interaction with other primary or secondary health services. Insufficient support for unpaid carers risks accelerating admission into the health service and impedes the ability of hospitals to discharge patients back into the community.

The Health and Social Care Workforce including culture and staff wellbeing

In recent weeks there have been media reports of major difficulties with the recruitment and retention of paid care workers and how local authorities have expected unpaid carers to step in to provide support. Carers are already exhausted from providing care over the last 18 months of the pandemic. It is vital that carers and those they care for have adequate access to support services from local authorities and others. The general failure to invest in social care negatively impacts on unpaid carers and the well-being of the social care workforce by increasing demand and pressures on social care staff.

Unpaid carers also underpin the well-being of the health service workforce by preventing vulnerable people from requiring admission to hospital, thereby reducing demands on health staff.

The inability of hospitals to discharge patients is a significant cause of stress to staff in the health service as well as carers. Adequate support for carers and social care would enable people to be discharged sooner reducing the burden on the NHS.

There is a need to continually raise awareness of the critical role of unpaid carers and ensure health and social care staff take an active role in identify carers and signposting them to sources of help and support. Carers Wales and Carers Trust Wales have been awarded a 3-year grant from Welsh Government to take forward a project called 'Carer Aware'. The aim of the project is to transform the recognition, respect and support unpaid carers receive in health and social care settings. The project will co-produce resources and training sessions for healthcare professionals and social workers, to enable them to better support the carers they interact with, promote carers' rights and support needs across Wales and with relevant stakeholders.

Access to mental health services

Research conducted for Carers Week 2021 found that '69% of carers in Wales said their mental health had deteriorated because of a lack of breaks from caring during the pandemic, and 73% said they felt exhausted and worn out due to providing care throughout the pandemic. 68% of carers in Wales also said their physical health had worsened because of their caring role. A failure to support unpaid carers will inevitably place additional burdens on already stretched mental health services. Furthermore, unpaid carers often play a significant role in supporting people in need of mental health services to access those services.

Evidence based innovation in health and social care

We have heard from many carers that co-production with carers in local authorities, regional partnership boards and other forums is falling short of the aspirations of the Social Services and Well-being Act. This apparent lack of co-production with carers stifles innovation as public bodies are not hearing the diversity of voices needed to help foster innovation in regional and local services.

Too often short-term funding cycles and insufficient funding for third sector carers services impede innovation as the third sector struggles to establish, maintain and embed services. The failure of health and social care commissioning to mainstream innovative projects into their normal day to day functions also impedes progress.

Support and services for unpaid carers

We will address support and services for unpaid carers throughout this response and especially in Question 2.

Access to COVID and non-Covid rehabilitation services

Unpaid carers support people in need of these services to access them and liaise with professionals on their behalf to facilitate this. Carers often need support to be able to access these services, especially if they have significant caring responsibilities or are balancing full or part time employment with their caring responsibilities.

Access to services for long-term chronic conditions

Many people with long-term chronic conditions rely on unpaid carers to manage their needs. We are concerned that, given the longer waiting lists in the NHS for treatment, carers may have to support people with chronic conditions for longer without the support they need. The health and well-being of carers can also deteriorate over time without adequate support, potentially leading to long term chronic conditions among carers.

Question 2: Key priorities for the Sixth Senedd

Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:

- a) health services;**
- b) social care and carers;**
- c) COVID recovery?**

You can comment on as many or few of the issues as you want.

In your answers, you might want to think about:

- What impact or outcomes could be achieved through any work by the Committee?
- How the Committee might address the issue?
- When any Committee work should take place?
- Whether there are any specific groups, communities or stakeholders that the Committee should involve or hear from in any work?

a) Health services

Identifying carers

The repeal of the Carers Strategies (Wales) Measure 2010, which placed a statutory duty on the health service to provide information and support to carers, has had a negative effect on identification of carers. For 3 out of 4 carers, their first point of contact with any statutory agency is within primary or secondary healthcare services. Findings from our annual Track the Act surveys suggest a worrying picture regarding identification of carers. While the Social Services and Well-being Act 2014 says that carers should be offered information and advice on caring upon being recognised as a carer by professionals, only 38% of carers who responded to our Track the Act 5 survey in 2019-20 said that they had received information to help them care, and only 42% had been given advice on caring. This suggests the majority of carers are not being identified by services and communicated with accordingly, even before we consider the proportion of carers who may go on to receive support packages.

Staff in health care settings must receive appropriate levels of training in Carer Awareness so they can understand who unpaid carers are, the issues they deal with and the support they may require. This is important both to support unpaid carers, and to enable them to look after the vulnerable person(s) in their care. The existing level of training for staff in healthcare settings is clearly insufficient on this issue at present, indeed only 54% of carers who had received information on caring in an NHS setting described the information as useful (source: Track the Act 5, 2020), suggesting staff are struggling to inform carers appropriately.

Hospital discharge

Unpaid carers are crucial to enable hospital discharge and ease the pressures on the NHS. Carers however must be adequately supported to ensure there is a 'safe' discharge including their ability and willingness to care and where appropriate, there must also be sufficient social care, healthcare and third sector support for the discharged person and their carer.

Care Planning/Carer Assessments

The 2014 Act states that carers have a legal right to an assessment. This must be taken into consideration and acted upon during the discharge process. Carers must be told of their rights prior to individuals being discharged and adequate support plans put in place for carers and adequate care planning for the person with a disability or in ill health.

Research conducted by Carers Wales in 2019-20 found that 85% of carers had not had a carers' needs assessment in the previous year, and 72% had not had a carers' needs assessment at any time since 2016. Our annual Track the Act surveys have also found that only a very small percentage of carers refuse an assessment after being offered one. These successive annual evaluations appear to indicate substantial and recurring problems with the implementation of the 2014 Act, the result of which is the vast majority of carers are missing out on their legal right to have their needs assessed.

Equipment/adaptations

Adequate adaptations and equipment with appropriate training is vital to support unpaid carers, especially for those helping to care for people with certain chronic conditions. Providing these things helps to relieve pressure on the NHS and the social care workforce and enables carers to provide care safely. Equipment, adaptations and adequate training need to be put in place prior to a person being discharged from hospital.

b) Social care and carers

We welcomed the robust conclusions of the committee's comprehensive 2019 inquiry into the Social Services and Well-being Act and its impact on carers but felt the Welsh Government's response to your recommendations was lacking in detail. We have undertaken further research into carers lives since and disappointingly there is no evidence that the issues covered in your inquiry have improved. The Ministerial Advisory Group on carers is presently taking forward work on a Delivery Plan for the Strategy for Unpaid Carers that was published in March 2021. We would welcome the committee re-visiting the recommendations contained in your 2019 report and seek further clarity on actions that are being taken and whether there have been any improvements in relation to the various recommendations. In addition, the Committee could scrutinise in the future progress on the actions and delivery of the Carers Strategy.

Lack of staff – additional pressure on carers

Although the main focus of this potential topic focusses on the paid workforce, the crucial role unpaid carers contribute to support health and social care in Wales needs to be properly recognised. Unpaid carers provide 96% of care in Wales but there must not be an assumption that families can or are willing and able to provide care, a principle

that is contained within the 2014 Act. We have recently heard of local authorities across Wales who are struggling to provide sufficient paid care workers and are relying on family carers to pick up the pieces.

Long term trends are seeing increasing responsibilities placed upon carers. People are living for longer in ill health. There are more single person households, more families where both adults are in paid employment having to juggle work and care and many people caring at a distance from relative or friends who rely on them for support. Carers already struggle to maintain a life of their own, including paid employment. By 2032 it is projected that the number of carers across the UK will rise from 6.1 million to 9.1 million with the chances of people aged between 30-54 becoming carers increasing by 88%. It is vital that statutory services plan for this rise and commission adequate support, as well as recruit and retain social care workers to meet demand.

The vision in A Healthier Wales to move care closer to home suggests more carers and care workers will be needed to enable people to remain independent for as long as possible. If carers are not adequately supported by the paid care workforce, commissioned services, the voluntary sector or social enterprises, then individuals are more likely to either need more formal support or have to move into residential care settings placing further pressure on the social care and health system.

While we welcome the increasing focus on the needs of the paid care workforce, we feel that the needs of unpaid carers, and their immense contribution to sustaining social care in Wales, has received considerably less attention. There needs to be more support available to carers, including preventative support to enable them to look after their own health and well-being before they reach a crisis point and find themselves in need of more formal support services themselves.

Section 16 of the 2014 Act places a duty on local authorities to promote how social enterprises, co-operative organisations, co-operative arrangements and third sector organisations provide care, support and preventative services in their area. This is an opportunity for local authorities and regional partnership boards to develop new models of care and support which could take on some of the work that the paid care workforce is currently struggling to provide due to the evident challenges in recruiting and retaining staff. Regrettably, carer and other members of the RPBs continue to report that they are not properly included in the process of designing and commissioning services, impeding this work and undermining the principle of co-production with carers contained in the Act. The lack of service provision also undermines the prevention and well-being duties contained in the Act.

d) COVID recovery

As we have mentioned throughout this response, carers have gone above and beyond during the pandemic supporting those that they love. Their mental and physical health has suffered with many carers at breaking point. Services need to be re-instated as soon as possible to give carers the break that they need to recover and ensure their resilience to care moving forward.

We have measured the impact of the pandemic on carers at multiple points during this period, including; Caring Behind Closed Doors survey (April 2020), Caring Behind Closed Doors: Six Months On survey (October 2020), Unseen and undervalued: The value of unpaid care provided to date during the COVID-19 pandemic research (November 2020), Carers Week June 2021 survey. In addition, the Health Social Care and Sport Committee published its findings from the Inquiry into the impact of the Covid-19 outbreaks, its management on health and social care in Wales Report 3 – Impact on the social care sector and unpaid carers.

Unpaid carers must be recognised as an integral part of Wales' COVID-19 recovery. Without sufficient support for unpaid carers, it will be very difficult for the health service to release patients back into the community and tackle the backlog in the NHS. Insufficient support for unpaid carers places additional burdens on the paid care workforce and on the residential care system. People across Wales who are particularly vulnerable to COVID-19 rely on carers and those carers need to be supported to help the people they care for re-engage with society as we emerge from the pandemic.

A failure to invest in additional support for unpaid carers risks placing additional burdens on the NHS, local government and social care when they are already stretched to the limit. All work on the COVID-19 recovery must consider unpaid carers or we risk building recovery plans on crumbling foundations.

Re-configuration of services during the pandemic

There is some anecdotal evidence that services to carers and the people they care for have been cut since the pandemic. Some carers have told us that they must be re-assessed to have services re-instated post-pandemic. There is also some evidence that local authorities have reconfigured services without adequate co-production with their service users and carers (August 2021 – Caerphilly).

Question 3: Any other issues

Q3. Are there any other issues you wish to draw to the Committee's attention?

Welsh Government published their Carers Strategy in March 2021. Key actions and are more detailed delivery plan are currently being developed with a view to publishing in the Autumn. The Committee could in future years, scrutinise the impact of the Strategy.

In the near future the Welsh Government will be considering long term funding for social care in Wales as a result of the planned increase in National Insurance. We would urge the committee to monitor whether any plan for social care brought forward is not limited to the issue of how much individuals pay for care but includes substantial additional funding for the social care system to enable a greater amount of high quality care to be delivered across Wales, with wider eligibility so fewer people miss out on support and for expanded, targeted services to assist unpaid carers.