The key priorities for carers in Wales

Health and social care organisations from across Wales have come together through the Welsh NHS Confederation's Policy Forum to outline the key issues and priorities for the Health, Social Care and Sport Committee as part of their inquiry into the impact of the Social Services and Well-being (Wales) Act 2014 in relation to carers.

Health and care organisations have come together through the Welsh NHS Confederation Policy Forum to outline the key areas that the Health, Social Care and Sport Committee should consider when undertaking their inquiry into the impact of the Social Services and Well-being (Wales) Act 2014 in relation to carers.

The Welsh Government defines a carer as "*anyone of any age, who provides unpaid care and support to a relative, friend or neighbour who is disabled, physically or mentally ill, or affected by substance misuse*". Carers can be involved in a whole range of practical, physical, personal and administrative tasks. Examples might include: cooking; housework; lifting, washing and dressing the person cared for; helping with toileting needs; administering medication; and providing emotional support.

Three in five of us will become a carer at some point in our lives. There are 370,000 carers in Wales, the highest proportionate figure of all UK countries, with 103,594 people in Wales providing over 50 hours of unpaid care per week. The number of carers continues to rise and it is estimated that by 2037 there will be over half a million carers in Wales, a 40% rise.

Carers provide a significant contribution to society, the economy and the health and social care sector. The care provided by unpaid carers in Wales is worth an estimated £8.1 billion a year. Health and social care services rely on carers' ability and willingness to provide unpaid care, and without carers' support, the health and social care system would collapse. Health Boards and Local Authorities across Wales recognise unpaid carers as key partners in care delivery.

Over recent years the Welsh Government has made great progress towards better supporting carers through innovative policy and legislative change, including the Social Services and Well-being (Wales) Act 2014, the Well-being of Future Generations (Wales) Act 2015 and the recently published long-term plan for health and social care "*A Healthier Wales*". There has been increased awareness of the needs of carers and providing support to them in the community and a strengthening of the partnership approach at a local level between Local Authorities and Health Boards. However, improvements are still required to ensure implementation of legislation, consistency of provision and support provided to empower carers to deliver good care and to prioritise their own wellbeing and life goals.

The following actions should be considered by the Committee to improve the lives of carers in Wales:

1. Increased awareness and identification as carers

A significant number of carers do not identify themselves as carers but see the support they provide as a natural part of their relationship with the cared-for person. When carers do not conceptualise or identify themselves as carers, they may be reluctant to access the support they require or the benefits they are entitled to which could improve their quality of life.

Currently, as highlighted by Carers UK, "*the public is unable to recognise friends and families that care*". Carers have been described as "*hidden*" and "*hard to reach*" and may have been overlooked in the mainstream care discourse. Carers UK's 'Missing Out' report noted that in Wales, 55% of carers took more than a year to recognise their caring role, while 24% took more than five years to identify as a carer.

Identification is a key obstacle, both self-identification and identification by health and care professionals. This has shown to be particularly true in relation to older carers (aged 80 years old or above) looking after a spouse or partner, BME carers, LGBT+ carers, and carers of people with dementia or mental health issues where there may be a perceived element of stigma and a wish to keep things private.

The first step in delivering appropriate support always starts with individuals and professionals being equipped with the information and tools they need to identify carers and to understand the barriers they face.

2. Providing information and advice

When someone has been identified as a carer it is important that advice, information and support is easily accessible to the carer, rather than them having to seek it out. It is key that information about financial matters, along with signposting to organisations such as Citizens Advice, is readily available so that carers understand the financial benefits they are entitled to.

Health Boards and Local Authorities should work together in a person-centred way that provides carers with choice and control in decision-making. Carers Wales, through their Track the Act programme, have monitored the implementation of the Social Services and Well-being (Wales) Act 2014. Early indications found that in the first six months of the Act's implementation (April – October 2016), only 16% of carers had received information from their Local Authorities to support them in their caring role. This increased to 46% in the following six months (October 2016 – April 2017) and 78% of carers said that the information they had received was either useful or very useful.

It is important that carers receive quality information and are aware of the resources available, for example Dewis Cymru. The Dewis Cymru website is a key information hub for carers looking for information or advice about their wellbeing. Funded initially by Welsh Government, the website is now funded and managed by Local Authorities across Wales so that information can be kept up to date and relevant. It acts as a signposting service for up to 6,000 local and national services across Wales but further work is needed to raise awareness of the website and what it provides.

3. Improved data collection around carers

Ascertaining, recording and monitoring the number of carers is integral to developing the services, information, advice and support that carers need.

Public bodies must identify carers and collect the relevant data to ensure that carers receive the correct support and advice. Carers Wales' Track the Act programme highlighted concerns about data not being collected around the number of carers accessing services and how the carer's needs assessment process is working for carers of people under the age of 18. They found that most Welsh Local Authorities do not capture any data on carer's needs assessments for carers of people under the age of 18, partly because systems are not set up to record information if the cared for person is under the age of 18.

4. Delivering and consistency in carers needs assessments

The Social Services and Well-being (Wales) Act 2014 placed new legal duties on Local Authorities to meet a carer's eligible needs following a needs assessment. Carers Wales' Track the Act programme found that 19% of carers in Wales received a carer's needs assessment during the first six months of the Act's implementation (April – October 2016), and this increased to 44% in the following six months up to April 2017. The "Track the Act" programme is informed by people who identify themselves simply as carers – no further information is gathered about how many people they care for, the nature or extent of their caring duties, or how many hours per average week they devote to their caring commitments.

Welsh Government figures from 2015/16 show that while some Local Authorities carry out thousands of carer's needs assessment every year, others carry out a few hundred, so there remains significant variability in the level of assessment. There also needs to be consistency in how carer's needs assessments are carried out, with many Local Authorities choosing to use the What Matters approach, causing confusion for carers about whether they have received a full assessment or a had a basic What Matters conversation.

5. The impact on the health and wellbeing of carers

Information and support must be provided to carers to ensure that their own health and wellbeing isn't impacted by their caring role. If a carer's health deteriorates, it will have a negative impact on their own wellbeing, and the wellbeing of the person or they care for. It may also mean that additional health and social care services are required to provide unplanned, emergency care to the people with care and support needs.

Issues with carers' own health and wellbeing are often exacerbated or caused by their caring role. Research by Carers Wales found that full-time carers are more than twice as likely to be in bad health as non-carers – 59% of carers reported worsened physical health since they had become carers and 70% said they had suffered mental ill health. Three quarters of those providing care to a child with a disability said they had suffered mental ill health such as stress or depression as a result of being a carer.

Carers Trust found that 65% of older carers (aged 60–94) have long-term health problems or a disability themselves, and 68.8% said that being a carer has an adverse effect on their mental health. One third of older carers say they have cancelled treatment or an operation for themselves because of their caring responsibilities.

6. The financial impact of being a carer

Carers are unpaid but they are not cost-free. They require their own levels of care and support to enable them to care without struggling financially.

Some carers face significant pressures on their working lives and personal finances. Forty-seven percent of carers live on a household income of less than £1,500 per month, and 47% of carers describe themselves as struggling to make ends meet. In research carried out by Carers Wales about how carers cope with financial challenge, 40% of carers said that they had reduced costs by cutting back on seeing friends and family and 56% said that they had cut back on hobbies and leisure activities.

As highlighted in the Macmillan report “Under pressure – The growing strain on cancer carers”, almost one in three carers (30%) said their income or household finances are affected by caring, rising to 42% of those in their 40s and 50s. Some of the most common costs include spending more on travel, either when taking someone with cancer to hospital or GP (affecting 18% of carers) or when visiting them at home (14%).

Despite the significant financial impact on carers, and the estimated savings unpaid carers provide the UK economy, the Carer’s Allowance is the lowest paid benefit of its kind at just £64.60 per week.

7. Impact on future training and employment prospects

Working and continuing in education improves carers emotional wellbeing and personal fulfilment as well as widening their options for future employment, education or training. While the nature of some caring responsibilities is so intense that working alongside caring would be impossible, many carers want to combine work and caring but cannot access the support to do so.

The 2011 census showed that 181,135 carers in Wales are working, with 100,260 working full-time and 52,480 working part-time. A Carers Wales survey recently highlighted that almost a third (29%) of carers in Wales reported being in paid work as well as caring for a loved one. Almost a quarter (24%) reported caring for a loved one for over 50 hours per week as well as being in paid work.

Carers UK have highlighted that 51% of carers had given up work to care; 65% of carers said the stress of juggling everything meant they gave up work; 53% said expensive or lack of suitable services saw them give up work or retire early to care and 44% had taken annual leave to care. UK-wide research carried out by a wide range of third sector organisations, including Carers UK, Age UK and Macmillan Cancer Support, found that 44% of carers who responded to a survey said that caring responsibilities had affected their career progression. Only one in four carers stated that they had not let their caring responsibilities affect their work or career.

8. Recognising the needs of young carers and providing support

According to Social Care Wales there are approximately 30,000 young carers (under the age of 25) in Wales, the highest proportion of all UK countries.

Young carers miss an average of 48 school days per year as a result of their caring commitments, with those aged between 16 and 18 twice as likely not to be in education, employment or training (NEET). Sixty-eight percent of young carers reported that they were bullied at school and only half of young carers have a particular person in school who knows that they are a carer and who helps them. Forty-five percent of young adult carers reported they had experienced mental health problems, and this figure rose to 88% for lesbian, gay, bisexual and transgender carers.

9. The importance of respite care

Carers value flexible breaks and respite care because they help them to remain well and able to continue to provide care.

The Social Services and Well-being (Wales) Act 2014 places carers on the same legal footing as those they care for and places a duty on Local Authorities to promote and provide preventative services. However, due to austerity and cuts to Local Authority budgets, services across Wales providing quality breaks and respite for carers have been squeezed and there has been a significant decrease in people accessing day services or respite care since 2012.

Some carers who responded to the Carers Wales survey said that they had not had a break or day off in 17 years; had been on a waiting list for three years for overnight respite; and that the only break some carers received was when they continued to provide 24-hour care but had non-caring responsibilities ease up.

10. The impact of bereavement on carers

It can be extremely difficult for carers if the cared-for person dies. As well as having to cope with grief, they may feel a bit lost without their caring responsibilities keeping them busy.

The Alzheimer's Society found that carers often feel a sense of emptiness and numbness, perhaps even anger and a refusal to accept the death of the person. To address the bereavement needs of carers, Cruse Cymru and the Alzheimer's Society Cymru have joined in partnership for the three-year 'bereaved by dementia' project. The focus has been on increasing and improving access to Cruse Bereavement support across Wales for this vulnerable group.

According to Winston's Wish, the impact of bereavement on young carers can be even more acute because they often feel sad at the death, but also because of the loss of role or identity as they are no longer required to carry out their caring duties.

11. Sharing good practice

The collating, sharing and learning of good practice has become a priority for many organisations across Wales. The Parliamentary Review of Health and Social Care said that Wales needs to be a listening nation – this means having the structures in place to share best practice and team-based learning.

The Good Practice Wales Portal is a step in the right direction. The portal aims to be the single point of access to a wide range of examples of good practice available across Welsh public services, including support, advice and information for the social care workforce in Wales. The Welsh NHS Confederation, the Care Council for Wales, the Welsh Local Government Association and the Welsh Government are all registered partners of the portal.

Following a Welsh Government announcement in April 2018, Social Care Wales are supporting the aim of sharing best practice. They are leading on service improvement across the sector and committing to providing the social care sector with a range of high quality written materials and information with the aim of developing this into a ‘one stop shop’ for all social care improvement information in future.

12. Recognising the significant role of the third sector

As the Parliamentary Review made clear, the health and social care system in Wales is more than just NHS services and Local Authorities – it includes the third and independent sectors, and particularly their crucial role in supporting the social care workforce.

The third sector provides a range of advice, information and support to carers that are specific to their individual needs. It is key that the Welsh Government, Assembly Members and public sector recognise the unique capabilities that the third sector possesses, particularly in relation to addressing local needs and supporting the role of Regional Partnership Boards under *A Healthier Wales.*

13. Community infrastructure

Improving the local community infrastructure can support carer’s mental health and help prevent loneliness and isolation. It is important to recognise the impact that participating in meaningful occupations or activities, such as the arts, physical and social activities, including through social prescribing routes, can have on carer’s health and wellbeing. There need to be facilities and places for people to go to express themselves and connect with others.

14. Welsh Government policy

While we have highlighted where improvements can be made, we must recognise the very difficult budgetary decisions that both the Welsh Government and Local Authorities have had to make due to austerity.

The Wales Public Services 2025 report recently highlighted that between 2009-10 and 2016-17, Welsh Government resource spending, excluding depreciation, fell by 6% and Local Authority revenues fell by 7.5%, equivalent to £529 million. While there have been cuts to Local Authority budgets in Wales and difficult decisions have been made around services, the cuts to Local Authorities in England have been more severe. Analysis by the Institute for Fiscal Studies shows that local government funding in Wales has been cut less than in England and there has been less of a sense of crisis in social care in Wales.

We are pleased that from April 2018, people in residential care can keep £40,000 of their savings and assets and the Welsh Government has pledged to raise this figure to £50,000 by the 2021 Assembly election. According to the Welsh Government, over 400 people benefitted from the first increase, with around 4,000 people in Wales currently paying the full cost of residential care. In England, those with assets and savings in excess of £23,250 must fund all of the social care they receive – only those with less than £14,250 are entitled to cost-free social care.

In addition, in 2011 the Welsh Government introduced a limit on the amount Local Authorities can charge a person for the care they receive at home or within the community. The limit in place is currently £80 per week. In England, there is no such cap and Local Authorities can choose to charge for nearly all the services they provide. Statutory guidance in England says Local Authorities can choose whether or not to charge and “*the overarching principle is that people should only be required to pay what they can afford*”.

The following organisations have endorsed this briefing:

abpi
Bringing medicines to *life*
Dod a meddyginiaeth i *fywyd*
Cymru | Wales

age Cymru

British Red Cross

Alzheimer's Society Cymru
Unedig Yn Erbyn Dementia
United Against Dementia

Bowel Cancer UK
Beating bowel cancer together

carers WALES

Campaign to End Loneliness
CONNECTIONS IN OLDER AGE

Ymgyrch i Drechu Unigrwydd
CYSYLLTIADAU POBL HŶN

PLANT YNG NGHYMRU · CHILDREN IN WALES
Children in Wales
Plant yng Nghymru

carerstrust
Wales
action·help·advice

cyngor ar bopeth
citizens advice

CHARTERED SOCIETY OF PHYSIOTHERAPY
CYMDEITHAS SIARTREDIG FFISIOTHERAPI

MACMILLAN CANCER SUPPORT

hospice UK

CYMORTH CANSER MACMILLAN

MS Society
Cymru

Marie Curie
Gofal a chefnogaeth drwy salwch terfynol
Care and support through terminal illness

RNIB
Cymru
Golwg gwahanol
See differently

ROYAL COLLEGE OF SPEECH & LANGUAGE THERAPISTS

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CYNGHRAIR CANSER CYMRU
WALES CANCER ALLIANCE

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

THE WELSH NHS CONFEDERATION
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