

Public Policy Statement Carers

August 2019

Summary

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”¹.

According to the 2011 census, there were 369,186 carers² living in Wales, representing 12% of the population, the highest proportion of carers of all UK countries. 87,173 of these carers were aged 65 and over, and 131,120 aged between 50 and 64. 103,594 people in Wales provide over 50 hours of unpaid care per week.³ It is likely that the actual proportion of older carers is higher than these results. It is estimated that by 2037 there will be over half a million carers in Wales, a 40% rise on current levels.

Carers play a vital role, both economically and socially. There are twice as many informal, unpaid carers as paid staff working in the combined health and social care systems⁴. It is these carers, rather than health and social care professionals, who provide the bulk of care to those who need it. The health and social care systems simply could not cope without them. Estimations of the value of the contribution of carers of all ages across the UK range from £55 billion⁵ to £132 billion⁶ annually.

Carers can be involved in a whole range of practical, physical, personal and administrative tasks. Examples include: cooking; housework; lifting, washing and dressing the person cared for; helping with toileting needs; administering medication, and providing emotional support. Support provided by carers also goes well beyond providing personal care and also includes activities such as managing finances, negotiating with health and care services and acting as the person’s advocate, particularly if the person lacks mental capacity to make decisions. Carers may

¹ Welsh Government (2013): [The Carers Strategy for Wales 2013](#), WG 18868

² Carers is used throughout this paper to refer to individuals who provide unpaid care to family members or friends. The term is distinguished from care workers who are paid to provide care.

³ Carers Wales, October 2017 Welsh Policy Forum – Policy Commission on Welsh Carers. Evidence submitted from Carers Wales <https://www.carersuk.org/help-and-advice/practical-support/managing-someone-s-affairs/66-wales/news/5796-carers-wales-evidence-submission-welsh-policy-commission-policy-commission-on-welsh-carers>

⁴ House of Lords Select Committee, 14 March 2013

⁵ C McNeil and J Hunter (2014): [The Generation Strain](#) (IPPR, London): p3

⁶ S Yeandle & L Buckner, Valuing Carers 2015 – the rising value of carers’ support, p5

continue to play these roles even where a person is receiving help from professional carers.

Providing care has a significant impact upon the carer. This impact takes multiple forms: health, both physical and mental; finances (including working life), especially future financial security; emotional strain; and inadequate support. Reaching crisis point can have significant implications for the carer's future, as well as the potential health impact. It can result in short-term decisions being made that can place future financial security at risk, for example leaving a job or selling a house.

A health crisis for a carer can rapidly develop into a crisis for both the carer and the individual cared for. In order to prevent the need for a crisis intervention, for example a double hospital admission, there is a need for contingency plans to be in place if the carer is unavailable to provide care. This would serve to reduce the distress and disruption for both the carer and the individual cared for, as well as reducing costs for the emergency services generated by unavoidable admissions.

The contribution made by unpaid carers too often goes unrecognised. Many are left feeling invisible and unsupported by government, the welfare system, health and social care professionals, family and friends, as well as by society more broadly. More people risk being trapped in avoidable circumstances of poor health and financial deprivation, with energy and money having been devoted to those for whom they care. In addition to the individual toll, the health, wellbeing and financial pressures being placed upon today's carers can only be storing up problems for society for the future.

Older carers

The peak age for caring in the UK is estimated to be between 45 and 64⁷; the number of those aged 65 or over providing care is increasing more rapidly than the increase among the general population. The number of hours spent caring increases with age, with 28 per cent of people aged 85+ providing care⁸. Women care at greater intensity than men and make up a higher proportion (59 per cent) of family carers⁹. Over 16% of older carers are caring for more than one person.¹⁰ This is more common for those aged 60-75, where significant numbers care for a parent as well as an adult child, grandchild or someone else with a disability or long-term condition.

⁷ Carers Wales, Health and Social Care Committee – Inquiry into the impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to carers, September 2018
<https://www.carersuk.org/wales/policy-resources-for-professionals/policy-library/health-and-social-care-committee-inquiry-into-the-impact-of-the-social-services-and-wellbeing-wales-act-2014-in-relation-to-carers>

⁸ State of Health and Care of Older People, Age UK 2019 – To be published

⁹ Kathryn Petrie and James Kirkup, Caring for Carers - the lives of family carers in the UK, 2018

¹⁰ Carers Trust, Caring About Older Carers: Providing Support for People Caring Later in Life, 2015

Older carers comprise a sub-group of carers who have needs that are specific to their situation which are not necessarily being met by current service arrangements. In addition, pressure continues to grow on older people who provide care as they are required to provide more intensive care for individuals with increasingly complex needs.

For older people living with frailty or complex needs, their health and their quality of life is vulnerable to sudden change. A 'trigger event' such as the loss of a carer, can mean an older person experiences a rapid deterioration in their health and or a significant loss of their independence. This becomes all the more likely where carers are stretched to their limits.

Key issues for older carers include:

- Lack of recognition of their own health needs and the impact of caring on their own health and wellbeing;
- Isolation and loneliness, especially in relation to unavailable, inappropriate or inaccessible transport;
- Complex management and navigation models of health and social care systems with no support;
- Lack of preparation including a lack of awareness of the likelihood of caring in later life, especially for carers of adult children who were previously unlikely to reach old age but are now doing so in increasing numbers;
- A strong sense of a "duty to care", often reinforced by health and social care professionals, which means that they feel they have no choice but to continue to care longer than they are able;
- Lack of information on financial planning, including information on lasting power of attorney not being provided early enough.

Family and friends are increasingly being expected to provide care for their loved ones, but there are limits to what they can do. Changing family structures, greater geographical dispersal, demands of the workplace (likely to increase with rising State Pension age) and a reliance on older carers, often experiencing poor health themselves, all impact on the capacity of people to care for loved ones. There are likely to be many cases where families are providing significant levels of support but are simply unable to provide enough.

As eligibility criteria are tightened year on year, fewer and fewer people are eligible for state-provided social care. Sadly, many carers and those they care for do not receive help until they are at crisis point. By this stage, not only are the health – physical and mental – and the financial future of the carer deeply compromised, but the required intervention is significantly more costly and intensive than preventive measures implemented at an earlier point.

Sustainability

Reliance on carers is not a sustainable basis for meeting growing demand, with the number of older people needing care expected to outstrip the number of adult children available to provide it as early as 2017, and other factors such as women's rising participation in the labour market¹¹.

Care provision by spouses is growing and is projected to continue to increase in importance. However, older spouse carers are increasingly likely to be living with disabilities themselves, resulting in mutual care relationships that are not yet well recognised by existing care policy and practices. Extending the retirement age of the UK population is likely to further reduce the informal and unpaid carer pool, who have traditionally provided for older family members, and so shift this responsibility to the state. These forces will unite to add further stress to social care budgets that help people to maintain independence within the community or fund long-term care needs.

Forecasts highlight the importance of ensuring that health and social care services adapt so that they can adequately respond to the needs of an increasing older population with complex care needs.¹² Public policy needs to recognise the vital role carers play and reward them with specific financial and practical support.

Transformation and funding of social care

2019 onwards will be an important period of policy development on social care funding and paying for care in Wales where the pathway forward will be complex, uncertain and the potential solutions emerge over a prolonged period. Age Cymru has developed a separate Social Care Funding policy statement, to enable us to engage in evolving public debate about any Welsh government proposals for service transformation and new models of funding. We believe that proposals for the transformation and future funding of social care should deliver considerably greater support for carers.

Summary of Public Policy proposals

- Carers should have a statutory entitlement to the support needed to be able to achieve an acceptable quality of life, defined in terms of mental and physical

¹¹ State of Health and Care of Older People, Age UK 2019 – To be published

¹² A Kingston, *Forecasting the care needs of the older population in England over the next 20 years*, The Lancet, 30 August 2018

health and opportunities for social and economic inclusion. Carers should not be expected to sacrifice mental and physical health, or opportunities for employment, education and personal development in order to carry out their caring role.

- Strategies aimed at promoting the mental and physical health of communities must include measures specific to carers and include indicators for evaluating success.
- Health professionals should ask whether individuals are carers during consultations to improve early identification.
- GP practices should adopt the Investors in Carers framework of good practice to develop carer awareness, using the Quality and Outcomes Framework option to keep a register of carers to identify ways of working that support carers.
- GPs should offer carers an annual health check to explore any changes in physical or mental health and offer appropriate advice, support and treatment.
- The Welsh Government should raise awareness of the importance of carers looking after their own health, with responsive health systems and flexible forms of support and respite care available to support this.
- Local Authorities and Local Health Boards should ensure that carers receive training for specific tasks that they conduct which potentially impact upon their own health and/or that of the person cared for e.g. lifting. Carers should not feel obliged to undertake training or provide care of types they are uncomfortable delivering.
- All areas of Welsh Government policy should be aware of and responsive to the specific issues faced by carers.
- The benefits system should be reformed to ensure all carers have adequate incomes. This should include financial support for older carers who often receive no financial recognition of their role and simplified application processes.
- Carers should be able to build up adequate retirement income. State pension changes aimed at ensuring that carers who have missed National Insurance Contributions are able to obtain a full state pension, should apply to people who reached the state pension age before 2010. Carers should be entitled to claim a credit towards their private pension, so that their own pension is not reduced through caring.
- Employers should be required to introduce carer-friendly employment conditions (unless it can be explicitly demonstrated to contradict job specification requirements) with a minimum of five days statutory paid carers leave and the option of a further period of unpaid leave, as well as flexible working rights for carers.
- Local authorities must meet their legal duty to provide carers' assessments and do more to promote them, particularly if the person they look after is not eligible for local authority funded support.
- Local authorities should ensure that carers' needs for independent advocacy are being appropriately considered and met under the Act.

- When carer's assessments, and assessments of those cared for, are carried out under the Social Services and Well-being (Wales) Act 2014, both willingness and ability to provide care should be taken into account, without carers feeling under pressure to take on full care. Provision should be made for any discussion on willingness and capacity to take place confidentially with the carer.
- Local authorities should ensure that no assumptions are made that a person does not have needs to be met because a carer is available.
- The assessment process to determine the support needs of an older carer should be multidisciplinary wherever appropriate. Public bodies should work together to overcome any institutional barriers to this.
- Local authorities should not equate rates of refused care with a lack of need. Local authorities should consider whether their own practices may be driving up the numbers of recorded refusals.
- Local Authorities must refresh their carers' strategies and put in place coherent commissioning plans for carer support services.
- Local Authorities should undertake a fundamental rethink in the design and delivery of respite services for carers. Carers and people living with dementia should be instrumental in the design of respite support services, in partnership with a range of sectors, including hospitality, the environment, sports, arts and leisure.
- The needs of carers of dying people should be included in Population Needs Assessments, and hospice care providers should play their part in collecting the relevant data.
- Local authorities should include bereavement support in the assessment of carers' needs.
- Hospices and NHS services should identify and support carers, and refer them to the local authority for statutory support, where appropriate.

Carers

This policy statement covers:

- The health impact of caring
- The financial impact of caring
- Assessment, support and respite care
- Care of dying people and bereavement
- Recognition

Public policy proposals

The health impact of caring

Providing care to a family member or friend can create considerable physical and emotional strain for the person providing care. For older carers, this may happen at a stage in their life where their own health has begun to deteriorate. This situation can be aggravated further by insufficient support from health and social care services.

Providing care can be physically exhausting as carers engage in a whole range of activities from boosting morale through to lifting the person being cared for. Some of these tasks, such as lifting, would only be undertaken by two paid care workers in tandem on the basis of health and safety concerns. Fewer than 50% of carers over 70 who have to lift the person they care for, think that they do this confidently or safely.¹³ Many older carers caring for a partner find themselves having to provide personal care alongside having to do all the household jobs that once were shared, resulting in high levels of stress and fatigue.

This physical exhaustion may be further compounded by a lack of sleep. Lack of sleep could relate to the person cared for, if they have trouble sleeping, get up frequently in the night, or engage in challenging behaviour. It may also derive from worry and anxiety about the many challenges of being a carer or concerns about the future.

According to a survey carried out by Carers Wales, 75% of respondents said they had suffered mental ill health such as stress or depression as a result of caring, while 61% said their physical health had worsened as a result of caring.¹⁴ In a survey specifically of older carers across the UK, more than 75% of carers aged between 60 and 69 reported that caring had had a negative impact upon their mental health¹⁵.

¹³ Carers Trust, Caring About Older Carers: Providing Support for People Caring Later in Life, 2015

¹⁴ Carers Wales, State of Caring 2018

¹⁵ The Princess Royal Trust for Carers, 2011.

The GP Patient Survey of 2015-16 found that 83% of carers aged 65 and over had a long-standing health condition.¹⁶ The survey also found higher levels of arthritis, long-term back problems, high blood pressure, diabetes, mobility problems anxiety and depression when compared to non-carers. One third of older carers report having cancelled treatment or an operation they needed due to their caring responsibilities.¹⁷ People living with dementia may be carers in their own right.

Carers are at risk of being abused by the person they are caring for (and vice versa).¹⁸ It is therefore essential that health and social care professionals are able to recognise the risks to a carer and to the person they care for in a potentially abusive situation. However, capacity issues may limit the time which social workers have to establish trusting relationships with older people.

Health systems can be inflexible and unresponsive to carers' needs,¹⁹ eg, in relation to booking appointments and the difficulty carers have attending last minute appointments. Carers face challenges getting a home visit and feel frustrated when having to explain their situation multiple times.

Carer wellbeing is a key factor in hospital admissions, readmission and delays in transfers of care, and in admission to nursing and residential care.²⁰ Giving carers extra support to manage their caring role more effectively and maintain good health could reduce unwanted residential care admissions.

Welsh Government allocated £1m in 2018/19 to health, local authority and third sector partners to support GP practices to develop their carer awareness and ways of working to support carers.

Good quality, appropriate housing can greatly improve the life of someone with care and support needs and someone who cares for them. However, carers experience: not being prioritised for housing; not being recognised as needing a second bedroom; inheritance or tenancy rights not being recognised if a carer is not on the deeds or tenancy agreement; challenges in securing adaptations or an adapted home.²¹

¹⁶ Ipsos MORI 2017, Experience of carers: What does GPPS data tell us?
<https://www.ipsos.com/sites/default/files/migrations/en-uk/files/Assets/Docs/Infographics/gpps-carers-infographic-2017.pdf>

¹⁷ Carers Trust, Caring About Older Carers: Providing Support for People Caring Later in Life, 2015

¹⁸ Welsh Government, Dementia Action Plan for Wales, 2018

¹⁹ Older People's Commissioner for Wales, GP Services in Wales, 2017

²⁰ The Princess Royal Trust for Carers and Crossroads Care, Supporting Carers: The Case for Change, 2011

²¹ The Princess Royal Trust for Carers, Carers and Housing: Addressing their needs, 2010

Public policy proposals:

- Carers should have a statutory entitlement to the support needed to be able to achieve an acceptable quality of life, defined in terms of mental and physical health and opportunities for social and economic inclusion. Carers should not be expected to sacrifice mental and physical health, or opportunities for employment, education and personal development in order to carry out their caring role.
- Strategies aimed at promoting the mental and physical health of communities must include measures to promote the health and wellbeing of carers, regardless of their age. All initiatives must have built in indicators for evaluating the success of such policies.
- Health professionals should ask whether individuals are carers during consultations to improve early identification.
- GP practices should adopt the Investors in Carers framework of good practice to develop carer awareness, using the Quality and Outcomes Framework option to keep a register of carers to identify ways of working that support carers.
- Once identified, GPs should offer carers an annual health check to explore any changes in physical or mental health and offer appropriate advice, support and treatment.
- The Welsh Government should raise awareness of the importance of carers looking after their own health, with responsive health systems and flexible forms of support and respite care available to support this.
- Local Authorities and Local Health Boards should ensure that carers receive training for specific tasks that they conduct which potentially impact upon their own health and/or that of the person cared for e.g. lifting.
- Local Authorities and Health Boards should actively promote awareness of the hidden problem of domestic abuse experienced by older people, and implement a co-ordinated community response.
- Welsh Government housing policy should be aware of and responsive to the specific issues faced by carers.

The financial impact of caring

Providing care can have a range of significant financial implications for carers, including: changes to their job situation with implications for income and pension savings; increased utility bills; paying for services and respite care; and depletion of savings intended for their own retirement and future care. In addition, welfare regulations and changes to the welfare system are also impacting directly upon the financial prospects of carers.

People who are caring for others are more likely than those who are not to be living in material deprivation.²² UK-wide, 53% of carers have borrowed money as a result of their caring role and 60% have used all of their savings to cover the cost of caring.²³

Employment

Many of those who are working when they become carers end up either quitting their jobs or reducing their hours. Becoming a carer creates a clear risk of withdrawal from the labour market, even if someone is caring for as little as five hours a week. Once a person starts to care for 10 hours or more, that risk of withdrawing from the labour market becomes more marked²⁴. For those whose caring duties come to an end, for whatever reason, returning to the labour market can be difficult, especially if they have not worked for a number of years²⁵.

In a Carers Wales survey in 2018,²⁶ 40% of carers in Wales reported that they had given up work to provide care, with a further 14% saying that they had reduced their hours of work in order to support the person they care for. 20% said they had taken a less qualified job or turned down a promotion as a result of their caring responsibilities or that they had retired early in order to provide care. 11% said that they work the same hours as they did before they started caring but that their job has been negatively affected by it as a result of tiredness, lateness or the impact of stress. Only 4% of carers said that caring had had no impact upon their capacity to work.

A lack of flexible working arrangements is most commonly cited as the biggest barrier to carers remaining in work. Consequently carers who wish to remain in work have to make compromises in order to do so, for example using annual leave to provide care. Being a carer can also make it more difficult to pursue professional training and advancement opportunities. A lack of suitable and/or affordable care services also creates a barrier to remaining in work. For those who do remain in work, juggling multiple commitments can have implications for physical and mental health.

Leaving the labour market impacts upon a carer's income, while they may be facing the additional costs highlighted above. There is also the psychological and emotional

²² National Survey for Wales 2016-17 Statistical Bulletin "Volunteering and Caring", December 2017

<https://gweddill.gov.wales/docs/statistics/2017/171220-national-survey-2016-17-volunteering-caring-en.pdf>

²³ Carers Trust, Key facts about carers and the people they care for <https://carers.org/key-facts-about-carers-and-people-they-care>

²⁴ Carers UK & Age UK (2016): [*Walking the Tightrope. The challenges of combining work and care in later life.*](#)

²⁵ D Ben-Galim & A Salim (2013): [*The Sandwich Generation*](#) (IPPR, London)

²⁶ Carers Wales, State of Caring 2018

impact of giving up work; carers may feel they have lost a part of their identity, lose confidence and feel more lonely or isolated than previously²⁷.

Leaving work to care has significant implications for the financial future of the carer. Many carers have serious concerns about the future. Two thirds of carers say they have focussed on the care needs of the person they care for, rather than their own needs, and over half (53%) of those who have yet to retire are unable to save for their retirement.²⁸

As a consequence, many people who are currently carers for a family member or friend will have to rely on social security and state-funded care in later life. Given the current financial circumstances, and especially the severe lack of funding for the social care system, this situation is unsustainable.

Many of the issues discussed here have an unequal impact on women, compared to men, as older women are more likely to have given up work or reduced their hours as a result of caring responsibilities. The situation is particularly acute for older women who are or were in receipt of a lower income²⁹.

Losing staff who are unable to balance their working and caring responsibilities also has implications for employers. This can take the form of employee absence and stress when staff are not supported by flexible working arrangements or the loss of expertise and cost of replacing staff who leave. The peak age for caring, 45-64, is often when workers are at their most skilled and experienced³⁰.

It is estimated that in 2013 the cost to the UK public purse of people leaving the workforce due to their caring responsibilities was £1.3 billion per year³¹. Carers UK estimated that paid care leave of at least five days per year could save the UK economy around £3.5 billion a year.³²

There is evidence to suggest that business can benefit from implementing policies that help employees to balance work with other family responsibilities³³. Potential benefits include productivity gains, cost savings, reduced sick leave and lower staff turnover. £45k was awarded to Carers Wales in 2018/19 to take forward the

²⁷Carers UK & Age UK (2016): [*Walking the Tightrope. The challenges of combining work and care in later life.*](#) p30

²⁸ Carers UK, State of Caring, 2019.

²⁹ D Ben-Galim and A Salim, The Sandwich Generation, 2013.

³⁰ Carers UK (July 2014): [*Care Leave: Impact on Business Research Report*](#)

³¹ Linda Pickard, Helping carers to stay in employment would save the Exchequer over a billion pounds a year, London School of Economics 2013 http://eprints.lse.ac.uk/48620/1/blogs.lse.ac.uk-Helping_carers_to_stay_in_employment_would_save_the_Exchequer_over_a_billion_pounds_a_year.pdf

³² Carers UK, Juggling work and unpaid care, 2019

³³ Carers UK & Age UK, 2016; Carers UK, July 2014; S Yeandle et al (2006): *Who cares wins: The Social and Business Benefits of supporting caring workers* (Centre for Social Inclusion, Sheffield Hallam University)

Employers for Carers Wales hub, which has been established to support organisations based in Wales to be more carer-friendly.³⁴

Welsh Government's national strategy, Prosperity for All,³⁵ introduced an accredited qualification for carers, to provide carers with recognition of their skills and opportunities to develop them. However, there is concern that the accreditation programme may pigeonhole carers' skills within a social care context. It is essential that no carer feels obliged to undertake training or to deliver types of care which they are uncomfortable delivering.

Expenses

The cost of living continues to rise. Utility bills often become more expensive as heating may be used more often in order to provide warmth and comfort to the person cared for. Appliances are used more often due, for example, to people being in the house all day or because of increased laundry needs. For those who provide long distance care, as adult children have often moved away to establish their careers and families, fuel or transport costs often increase significantly.

For those caring for individuals who are not deemed eligible for social care under the current criteria, the costs of care are high. This is especially true when carers are already facing a loss of income and higher household bills. The cost of respite care is seen as a particular problem.

A survey carried out by Carers Wales reported that over a third of carers (34%) described their financial situation as 'struggling to make ends meet'. Only half (48%) of carers in Wales said that they could afford their bills without struggling financially. Of those struggling financially, 57% said they had to cut back on hobbies/leisure activities, 57% said they cut back on luxuries and 41% said they cut back on seeing family or friends.³⁶

Entitlements

To be entitled to claim Carer's Allowance (£66.15 from April 2019), a carer must provide care for a minimum of 35 hours. The allowance is therefore paid at £1.89 an hour which is just a quarter of the 2019/20 National Living Wage of £8.21 an hour. Carer's Allowance is also reduced by any State Pension received, meaning a lot of older carers do not receive any financial support.

³⁴ <https://www.employersforcarers.org/about-us/wales-hub>

³⁵ Welsh Government, Prosperity for All: the national strategy, 19 September 2017, p25

³⁶ Carers Wales, State of Caring 2018

Individuals who are on a low income may still benefit from claiming the Carer's Allowance even if they do not receive it, as it can increase the level of other means-tested benefits that they do receive. However, in certain circumstances it can also negatively impact upon the benefits received by the person cared for. The complexity of such a system is an additional frustration for many, and the change in entitlement upon drawing State Pension can create a sense of injustice for those who feel they no longer receive recognition for the contribution they make.

Attendance Allowance is a non-means-tested benefit that helps with the extra costs of long-term illness or disability, which can be either physical and/or mental, for people over their state pension age. Carers who have care needs can claim Attendance Allowance for themselves, and this will not affect their Carer's Allowance. The person who is cared for may also be eligible for this benefit. There are concerns that Attendance Allowance is not reaching all those who need it, and that older people may not see themselves as being entitled to claim benefits. Raising awareness of benefits such as Attendance Allowance could be one step towards improving the financial situation of carers.

Many carers do not take up the entitlements to which they have a right, either because they are not aware that these are available to them, because of the complexity of the application process, or because of knock-on implications for the financial situation of the person for whom they care.

UK wide, 35% of carers had missed out on state benefits because they had not realised that they could claim them. 9% had missed out on Carer's Allowance for 3-5 years, 10% for 5-10 years and 14% for over 10 years.³⁷ 97% of carers do not claim Carer's Credit (which fills in gaps in their National Contributions record) with an estimated 155,000 carers missing out on over £700m of entitlements³⁸. Up to 100,000 people are missing out on a 25 per cent council tax discount available if they are living with someone with 'severe mental impairment' such as dementia³⁹.

Public policy proposals:

- The benefits system should be reformed to ensure all carers have adequate incomes. This should include financial support for older carers who often receive no financial recognition of their role. Entitlement to the provision of the carer's amount in Universal Credit needs to be understood by carers and benefit advisers and promoted.

³⁷ Carers Trust, key facts about carers and the people they care for <https://carers.org/key-facts-about-carers-and-people-they-care>

³⁸ Steve Webb, New FOI reply reveals 97% of eligible carers do not claim 'carer's credit' - Royal London, 2018 <https://www.royallondon.com/media/press-releases/2018/january/new-foi-reply-reveals-97-of-eligible-carers-do-not-claim-carers-credit-royal-london/>

³⁹ Kirsty Good, Steve Nowotny, Megan French and Sabrina Dougall, The Disregarded Discount - MoneySavingExpert.com report into the 'Severely Mentally Impaired' (SMI) council tax discount, 2017

- Carers should be able to build up adequate retirement income. State pension changes aimed at ensuring that carers who have missed National Insurance Contributions are able to obtain a full state pension, should apply to people who reached the state pension age before 2010. Carers should be entitled to claim a credit towards their private pension, so that their own pension is not reduced through caring.
- The UK Government should increase Carer's Allowance substantially, in line with changes in Scotland (where carers will receive an additional £221 every 6 months). Earnings rules for Carer's Allowance should be reviewed so they do not serve as a disincentive to employment.
- There should be a new 'cost of caring' allowance to help with the financial impact of caring for all carers including those over State Pension age.
- The UK Government should ensure that the Carer's Allowance is pegged to increases in the National Living Wage to ensure that working for 16 hours a week on the National Living Wage never exceeds the eligibility threshold for Carer's Allowance
- The UK Government should simplify both the application process for Carer's Allowance and the confusing system of current entitlements, with the UK and Welsh Governments working together to raise awareness of the support available.
- The UK Government should introduce a minimum of five days statutory paid carers leave with the option of a further period of unpaid leave, as well as flexible working rights for carers.
- Employers should be required to introduce carer-friendly employment conditions unless it can be explicitly demonstrated to contradict job specification requirements.
- Employers should support their employees to help balance their caring responsibilities and work.
- Carer accreditation policies and schemes must ensure that no carer feels obliged to undertake training or to deliver types of care which they are uncomfortable delivering.

Assessment, support and respite care

Many carers feel that they do not receive the support they require in order to care effectively⁴⁰. In addition to a lack of financial support, there is often a lack of direct support in terms of assistance, easily accessible and comprehensible advice and information and a lack of support in accessing help and benefits. More needs to be done to ensure that carers' needs for independent advocacy are being appropriately considered and met under the Act.⁴¹

⁴⁰ Carers Wales: State of Caring 2018

⁴¹ Older People's Commissioner for Wales, Making Voices Heard: Older People's Access to Independent Advocacy, 2018

Welsh Government set up a Ministerial Advisory Group (MAG) for Carers in 2018, to steer the delivery of improvements for carers and provide a cross-government response to delivering against three National Carers' Priorities: supporting life alongside caring; identifying and recognising carers, and providing information, advice and assistance.

In 2018, Welsh Government announced it would be investing part of an additional £15m allocation to the Integrated Care Fund to improve direct support for carers.⁴² £3m funding was awarded to local authorities across Wales to support additional respite for carers. £1m was allocated to health, local authority and third sector partners to support GP practices to develop their carer awareness and ways of working to support carers. £10k was awarded to the All Wales Forum for Parents and Carers to expand their work programme to improve the awareness and knowledge of carers across Wales in relation to the Social Services and Well Being Act. £45k was awarded to Carers Wales in 2018/19 to take forward a project which will support employers across Wales to create a more carer-friendly workplace.

The National Assembly of Wales Health, Social Care and Sport Committee opened an inquiry into the impact of the Social Services and Well-being (Wales) Act 2014 in relation to carers in 2018. The inquiry report is being drafted at the time of writing.

Identification

Many older people do not recognise themselves as carers, as they view care as a normal part of their relationship with the individual they are helping. This means they may lose out on the support that is available to them. In one survey,⁴³ 55% of carers had taken over a year to recognise their caring role, and 24% took over five years to identify as a carer.

Many carers do not live with the person they care for, with more than half of those aged 60-69 providing care outside the home⁴⁴. In some cases they may be friends or neighbours rather than relatives providing support. Carers in this situation are often overlooked and may not be included in the person's Carer's Assessment or have access to support services.

If carers are not identified early enough, they may reach a crisis point later which has long term implications for their own health and wellbeing and often leads to the person they care for being admitted to residential care.

⁴² Welsh Government Written Statement: Investment of £15 million for adults with care and support needs, and carers who need support, 30 November 2018

⁴³ Carers UK, Missing out; the identification challenge, 2016.

⁴⁴ Social Market Foundation, Caring for Carers, 2018

The 2010 legal framework for recognising and informing carers has been dismantled. The Carers Strategies (Wales) Measure 2010 was repealed in April 2016 when the Social Services and Well-being (Wales) Act 2014 came into force. The Carers Measure had placed a legislative duty on local authorities and NHS bodies to work together to support family or unpaid carers, and Health Boards were designated as the lead agencies when developing local carers' strategies.

The SSWB Act recognises the key role played by carers, giving them equivalent rights to support to those of the people for whom they care, and there is a general requirement for Public Services Boards to publish local well-being plans. However, there is no proactive duty on social workers to seek out and identify carers.

Most carers' first point of contact with a statutory agency is still with the NHS – in four out of five cases, within primary care.⁴⁵ Secondary care NHS services also have an important role in identifying and signposting carers in hospital and other secondary care settings.

A vital statutory role therefore has been lost within the NHS in identifying carers and signposting them to sources of support. 68% of carers in Wales said their GP was aware of their caring responsibilities. 34% were offered a free flu jab but 50% said they were not offered any further advice, information, support or where to could go for help.⁴⁶ There is also concern that existing carer lead roles within the NHS will not be prioritised once transitional funding comes to an end.⁴⁷ It is essential that the NHS continues to be responsible alongside health authorities for identifying carers and signposting them to sources of help.

Information and advice

According to Welsh Government statistics for 2017-18, only 50,452* adults received advice and/or assistance from the Information Advice and Assistance (IAA) Service in relation to their own care and support or that of their friend/family member/person they care for/advocate for.⁴⁸ This may be because carers often do not identify themselves as carers.

⁴⁵ Carers Wales, State of Caring, 2018

⁴⁶ Carers Wales, State of Caring, 2018

⁴⁷ Carers Trust Wales, Health, Social Care and Sport Committee inquiry into the impact of the Social Services and Wellbeing Act 2014 in relation to carers, <http://senedd.assembly.wales/documents/s79500/C%2023%20-%20Carers%20Trust%20Wales.pdf>

⁴⁸ Welsh Government Statistical First Release: Adults receiving care and support in Wales, 2017-18 (Experimental statistics) 30 October 2018 <https://gov.wales/sites/default/files/statistics-and-research/2018-12/181030-adults-receiving-care-support-2017-18-en.pdf>

It may also be due to the nature of local authorities' first point of contact systems. Although a single point of access to social services has been welcomed in some areas, it has been indicated to us that people contacting local authorities, by telephone or in person, are being referred to third sector agencies without appropriate consideration of their circumstances. We have been told that some local authorities allocate a fixed number of call-backs to residents at the beginning of each day, referring the unsuccessful callers to other agencies.

Local authority staff awareness of the 2014 Act is often poor. Information and advice staff are not adequately trained to recognise carers and give them the information that they need. Older carers we have spoken to also raise concerns about: waiting times for assessments; being signposted inaccurately and referred inappropriately; difficulty in finding out what is available, and the use of jargon and duplication in the assessment process.

Social Care Wales is leading work to develop a hub of information with resources and tools to support social work for carers, including an e-learning resource focussed on increasing carer awareness, aimed at both professionals and carers themselves. £10k was awarded to the All Wales Forum for Parents and Carers in 2018, to expand their work programme to improve the awareness and knowledge of carers across Wales in relation to the Social Services and Well Being Act.

Carers' assessments

Under the Social Services and Well-being (Wales) Act 2014, carers are legally entitled to a carer's needs assessment, irrespective of the number of hours of care provided, the nature of the support, or their financial means⁴⁹. A carer can receive this assessment whether or not the person for whom they care has an assessment. However, according to Welsh Government statistics for 2017-18,⁵⁰ only 6,178 assessments of need for support for carers were undertaken, and only 2,027 support plans for carers were provided. In 2018, 61% of respondents to a Carers Wales survey said that they had not been offered or requested a carer's assessment in the last twelve months.⁵¹

Data collection about assessment and support varies between local authorities. Current data sets do not accurately reflect the carer experience of accessing assessments, and there appears to be no follow-up mechanism to record whether carers' needs have been met or not. At the time of writing, Welsh Government is

⁴⁹ Carers Wales (2016): [Assessments. A guide to getting an assessment in Wales from 2016](#)

⁵⁰ Welsh Government Statistical First Release: Adults receiving care and support in Wales, 2017-18 (Experimental statistics) 30 October 2018 <https://gov.wales/sites/default/files/statistics-and-research/2018-12/181030-adults-receiving-care-support-2017-18-en.pdf>

⁵¹ Carers Wales, State of Caring 2018

developing a new code of practice and data set for measuring social services performance.

There is ambiguity and inconsistency in how “What Matters” conversations are being used in the assessment process. Some local authorities use “What Matters” conversations as a pre-assessment step, others as the assessment itself. This can create confusion for carers and, in some cases, can be used to justify a reduction in support.

Assumptions can be made at the assessment stage about the extent to which people are willing and able to provide care. In April 2018 Age Cymru and Age Alliance Wales conducted a series of four focus group events with people aged 50 and over, in Wrexham, Bangor, Swansea and Newport, looking at issues including social care. We asked participants about their attempts to obtain the assistance of social services departments, from first point of contact onwards.

Mrs G told us that her husband was discharged from hospital with advanced dementia. No care assessment was carried out. Unable to cope without night time support, Mrs G arranged for a private care service to assist her husband for several nights per week, costing over £2000 a month. When Mr G was finally assessed, the care plan noted the need for night time care, but did not treat this as a responsibility of the local authority as it was judged that the family had managed to cover these requirements themselves. The expense of this privately arranged care meant that Mrs G tried to carry out as much of the care as she could manage herself, a situation she found very difficult.

Mrs G’s lack of formal support and respite had a very negative impact on her health and well-being and she confessed to feeling lonely and desperate. Our concern, illustrated by this case, is that unreasonable assessments made by local authorities about the level of support needed, are pushing more and more individuals and carers to crisis point, ultimately costing the NHS more. The aim of the eligibility criteria is to increase access to and use of locally based preventative services, but we fear that it is actually being used as a means to deny much needed formal support.

It is important that when carer’s assessments, and assessments of those cared for, are carried out under the Social Services and Well-being (Wales) Act 2014 that both willingness and ability to provide care are taken into account, without carers feeling under pressure to take on full care.

A lack of person-centred assessment was not uncommon among focus group participants. One older carer of an older person said, that social services did not listen or respond to the concerns of the family of the person requiring care, or that person’s carers. They believed that “more concern was given to benefits and who

was going to pay for extra care". Whilst some were ultimately happy they believed it took staff too long to properly assess and respond to the situation.

The law allows local authorities to carry out a combined assessment of the needs of the carer and the cared for person. This can make it difficult for the carer to distinguish their own needs from those of the person for whom they care. Where the person cared for is half of a couple, it is often assumed that their partner will be able to cope. A partner may also assume incorrectly that their own savings have to be taken into account in any financial assessment, and therefore contribute financially more than necessary to the costs of care.

The Social Services and Well-being (Wales) Act requires local authorities to consider whether an individual may need Independent Professional Advocacy (IPA) at every step of their journey through the social services system. We suspect that many carers are not receiving the advocacy support they need. The current lack of data collected on the offer of independent advocacy during the assessment process makes it unclear whether lack of the carer having an effective voice during the process and not knowing their rights may be a factor in the low number of support plans resulting from carers' assessments.⁵²

Alternatively, the attitude of carers can also present an obstacle to requesting support if they feel a responsibility to take on the full care of the individual they are supporting by themselves. Carers may experience a whole range of feelings as a result of the change in the nature of their relationship with the person cared for. Some may not view themselves as a carer, but see caring as a natural development when it is required. Others may feel guilty at wanting respite and the opportunity to do something for themselves. All of these attitudes can have implications for the assessment and the provision of support.

Some carers feel that the assessment is being used to judge their ability to care, rather than what support they need. Too often, carers feel that the situation has to reach crisis point before an intervention takes place.

Older carers' complex health and social care needs mean that the assessment process to determine the support needs of an older carer often needs to be multidisciplinary. For this to be effective, a number of institutional barriers need to be overcome, including some fairly fundamental issues such as data-sharing underpinned by ICT. We welcome Social Care Wales and Data Cymru's work to develop a social care "one stop shop" data set. However, current data gathered about unpaid carers is weak and should be more comprehensive and accurate.

⁵² Older People's Commissioner for Wales, Response from the Older People's Commissioner for Wales to National Assembly for Wales, Health, Social Care and Sport Committee: Inquiry on the Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to carers, September 2018

Older carers of younger dependants may be most fearful of what will happen to the person for whom they care after the carer's death. This may dominate their thinking and yet not be addressed during the assessment. There is anecdotal evidence of older carers with terminal illness considering ending both lives together.

Not all carers may need an assessment and some refuse it when offered. 6,891 carers are recorded as having refused an assessment in 2017/18.⁵³ However, rates of refused assessments cannot be equated with a lack of need. There are numerous barriers to carers accessing assessments, which include:

- Stigma or fear about asking for or accepting help from social services;
- Fear that social services will remove the person being cared for if the carer cannot cope;
- Poor knowledge of rights or ability to self-identify as a carer;
- Belief that the assessment will not lead to the type of support the carer needs;
- Low levels of awareness about the types of support that are available;
- A lack of support to navigate what can feel like a complex and overwhelming system.

Local authorities' own practices are also driving up the numbers of refusals. Some local authorities send out letters and forms for carers to complete, and count it as an offer of assessment. Some carry out assessments by telephone, and so do not get a true picture of the carer's circumstances. There are examples of local authorities discouraging carers from taking up an offer of assessment on the grounds that the menu of services they can offer does not meet that individual carer's needs. This is contrary to the obligations imposed on local authorities by the Social Services and Well-being (Wales) Act 2014, and feels inconsistent and tokenistic to the person being assessed

Support

Older people tell us that what matters most to them is a lot more tangible support for carers, especially for those caring for an older person with dementia, alongside a reliable service, committed staff with enough time, and some progress towards meeting unmet needs. Good quality, properly funded support for carers enables older people to live independently for longer in their own homes and communities whilst enabling carers to receive respite and maintain their own health and independence as they age.

⁵³ Welsh Government Statistical First Release: Adults receiving care and support in Wales, 2017-18 (Experimental statistics) 30 October 2018 <https://gov.wales/sites/default/files/statistics-and-research/2018-12/181030-adults-receiving-care-support-2017-18-en.pdf>

Carers have consistently identified the same gaps in service provision over many years: transport; access to social activities and peer support; access to information; access to advocacy; respite care, especially during emergencies, financial advice including information about Lasting Power of Attorney, and a simplified way of finding information about services which are available.⁵⁴ Social isolation, poverty, deprivation, lack of transport and long distances to travel to access health and care services mean that rural carers face additional challenges in accessing services.

However, Care and Social Services Inspectorate Wales acknowledge that, “in the drive to transform services in line with the SSWBA, support for carers has slipped down the agenda”.⁵⁵ Carers Trust Wales report a fundamental lack of services for carers.⁵⁶ In 2018, eligibility criteria for services were being set at critical and high-level need and the availability of specific services had been reduced. Some social work teams are reluctant to undertake assessments for carers because of the lack of services to which to signpost them.⁵⁷ When carers are caring for an individual in receipt of Continuing Health Care funding, there can be a lack of clarity as to which public body is responsible for supporting the carer, and consequently a lack of support.

Even where eligibility for support has been established, the services provided are often described as inadequate, unreliable or being of poor quality. Support may be limited to provision of aids and adaptations or short breaks. 25% of carers who responded to a Carers Wales survey in 2018 said that they had refused support because of quality or suitability.⁵⁸ Refusal of care can be to the detriment of the carer’s own wellbeing.

Carers of people with dementia are less likely to use services compared to the general carer population⁵⁹ Lack of knowledge of and barriers to service use, transportation and location are more important factors than either need or predisposition.⁶⁰

⁵⁴ Glamorgan Voluntary services, response to the national assembly Health, Social care and Sport Committee inquiry on how much support is there for carers in Wales, September 2018

<http://senedd.assembly.wales/documents/s79491/C%2014%20-%20Glamorgan%20Voluntary%20Services.pdf>

⁵⁵ Care and Social Services Inspectorate Wales, “In support of Carers – carers engagement overview report”, June 2017.

⁵⁶ Carers Trust Wales, Health, Social Care and Sport Committee inquiry into the impact of the Social Services and Wellbeing Act 2014 in relation to carers, <http://senedd.assembly.wales/documents/s79500/C%2023%20-%20Carers%20Trust%20Wales.pdf>

⁵⁷ Carers Trust Wales, Health, Social Care and Sport Committee inquiry into the impact of the Social Services and Wellbeing Act 2014 in relation to carers, <http://senedd.assembly.wales/documents/s79500/C%2023%20-%20Carers%20Trust%20Wales.pdf>

⁵⁸ Carers Wales, State of Caring, 2018

⁵⁹ Phillip I, McKee KJ, Meldrum P, Balinger BR, Gilhooly MLM, Gordon DS ... Whittick JE (1995) Community care for demented and non-demented elderly people: a comparison study of financial burden, service use, and unmet needs in family supporters, *BMJ* 310(6993), pp1503-1506.

⁶⁰ Toseland RW, McCallion P, Gerber T, Banks S (2002) predictors of health and human service use by persons with dementia and their family caregivers, *Social science & medicine* 55(7), pp 1255-1266.

Often, it is the lack of appropriate services for the cared for person that increases the pressure on carers. Linked to this is the fact that in many cases the cared for person must agree to have a service in order for the carer to have a break, and not all do. More frequently the cared for person must agree to pay where charges have been implemented, which creates another barrier for carers' access to support.

Direct payments offer one mechanism for securing services to meet individual needs, for both carers and the people for whom they care. However, many carers receive little or no information about them. Some do not know how to use them, and send the money back because they are worried about getting it wrong. Others are overwhelmed by how much time and work is involved in administering direct payments; others have negative experiences of using direct payments account managers.⁶¹ Many find that the amount of money provided by Social Services does not adequately cover the costs, or are unable to find a service provider.⁶²

The National Population Needs Assessment⁶³ identifies that improvements must be made to the involvement of carers in service development. Involving carers in service design and development is essential. However, current processes for engagement are often tokenistic and repetitive. We are very concerned about the effectiveness of carer representation on Regional Partnership Boards in particular. We welcome the recent increases in the numbers of representatives of cared for people, carers and Third Sector organisations on Regional Partnership Boards, but effective engagement will take time to mature.

Key parts of "A Healthier Wales", Welsh Government's plan for health and social care,⁶⁴ address delivering services in the community and tailoring preventative services, both of which are potentially helpful in relieving some of the pressure on carers, to enable them to focus on their social relationship, rather than caring relationship, with the person for whom they care, as well as on other social connections. We await the evidence of how the policy is being implemented in practice.

Respite care

⁶¹ Mencap Cymru response to the Health, Social Care and Sport Committee Consultation on The Impact of the Social Services and Wellbeing Act (Wales) 2014 on Carers, September 2018

<http://senedd.assembly.wales/documents/s79507/C%2030%20-%20Mencap%20Cymru.pdf>

⁶² Older People's Commissioner for Wales, Response from the Older People's Commissioner for Wales to national assembly for Wales, Health, Social Care and Sport Committee: Inquiry on the Impact of the Social Services and Wellbeing (Wales) Act 2014 in relation to carers, September 2018

⁶³ Social Care Wales, Care and support in Wales: national population assessment report, November 2017, p30

⁶⁴ A Healthier Wales: our plan for health and social care, Welsh Government, 2018

Respite care, especially the cost and quality, is a particularly significant issue. Older carers need to have more regular breaks in recognition of the fact that a number of them will tire more easily and/or suffer from their own health and mobility issues in comparison with younger carers. Dealing with challenging behaviour is particularly tiring and frustrating because of the need for constant vigilance. Respite is viewed by many as an extremely valuable service, but there is a need for greater flexibility in terms of the type of respite offered in order to suit individual circumstances⁶⁵.

Due to austerity and cuts to local authority budgets, services across Wales providing quality breaks and respite for carers have been cut and there has been a significant decrease in people accessing day support. In addition, negative experiences of respite in the past may lead to carers refusing to take up an offer of respite care. Effective use of short-break care requires significant forward planning. Information about respite options is not sufficiently accessible, is not delivered at the right time or in the right format, and there is insufficient support to make sense of the options available. Little help is available when short breaks are needed urgently.⁶⁶

Some carers who responded to a 2017 Carers Wales survey said that they had not had a break or day off in 17 years; that they 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 care but had non-caring responsibilities ease up.⁶⁷ In 2018, 40% of unpaid carers said they had not had a day off in over a year, 62% said they had not had a weekend off in over a year and 83% said they had not had a week off in over a year.⁶⁸

The Older People's Commissioner for Wales' report, "Rethinking Respite", found that a fundamental rethink in the design and delivery of respite services for carers is needed and that carers and people living with dementia need to be more involved and should be instrumental in the design of respite support services.⁶⁹ There is a need for more creative forms of respite, in partnership with a range of sectors, covering hospitality, the environment, sports, arts and leisure – such as the respitality scheme in Scotland.

In 2018, Welsh Government awarded £3m to local authorities across Wales to support additional respite for carers. The Welsh Government's Dementia Action Plan for Wales 2018-22 commits to learn from the Rethinking Respite report. Evidence of how the money has been spent, and how carers have benefitted, remains to be seen.

⁶⁵ Older People's Commissioner for Wales (2016): [More than just memory loss. The experience of those affected by dementia in Wales.](#)

⁶⁶ Social Care Institute for Excellence, Preventative support for adult carers in Wales: rapid review, 2018

⁶⁷ Carers Wales, State of Caring, 2017.

⁶⁸ Carers Wales, State of Caring, 2018.

⁶⁹ Older People's Commissioner for Wales, Rethinking Respite for people affected by dementia, 2018

Technology

There has been a rise in available assistive technology in recent years, which offers an opportunity to support both carers and cared-for people. Older carers need good quality information, advice and guidance about what assistive technology is available and how it can help. Digital exclusion and variable broadband coverage across Wales are barriers to the adoption of assistive technology for many older people. Technologies should always be seen as a support mechanism rather than as a replacement for human interaction.

Public policy proposals

- The NHS should be responsible alongside health authorities for identifying carers and signposting them to sources of help.
- Awareness should be raised of the right to an independent carer's assessment under the Social Services and Well-being (Wales) Act 2014 and carers should be encouraged to take up this opportunity.
- Local authorities must meet their legal duty to provide carers' assessments and do more to promote them, particularly if the person they look after is not eligible for local authority funded support.
- Local authorities should ensure that carers' needs for independent advocacy are being appropriately considered and met under the Act.
- When carer's assessments, and assessments of those cared for, are carried out under the Social Services and Well-being (Wales) Act 2014, both willingness and ability to provide care should be taken into account, without carers feeling under pressure to take on full care. Provision should be made for any discussion on willingness and capacity to take place confidentially with the carer.
- Local authorities should ensure that no assumptions are made that a person does not have needs to be met because a carer is available. Needs should be recorded and the contribution that the carer is willing and able to make towards meeting those needs should be shown in the care plan, as should contingency plans if the carer is not in a position to continue to provide care for whatever reason.
- The assessment process to determine the support needs of an older carer should be multidisciplinary wherever appropriate. Public bodies should work together to overcome any institutional barriers to this.
- Local authorities should not equate rates of refused with a lack of need. Local authorities should consider whether their own practices may be driving up the numbers of recorded refusals.
- Welsh Government and local authorities should ensure that they properly understand carers' experiences, the way in which obligations under the Social Services and Well-being (Wales) Act 2014 are realised in practice, and why carers refuse assessment.

- Local Authorities must refresh their carers' strategies and put in place coherent commissioning plans for carer support services.
- The Welsh Government must make greater provision for older carers across Wales in order to ensure they achieve an acceptable quality of life, in terms of mental and physical health, and opportunities for social and financial inclusion.
- Welsh Government should ensure that carers are caring for an individual in receipt of Continuing Health Care funding, and health care professionals, are aware of carers' rights under the Social Services and Well-being (Wales) Act 2014 and signposted to their local authority Information, Advice and Assistance service.
- Welsh Government and Local Authorities should support carers to prepare for their loved ones' life after the carer, with a focus around housing and support, when appropriate.
- Local Authorities should undertake a fundamental rethink in the design and delivery of respite services for carers. Carers and people living with dementia should be instrumental in the design of respite support services, in partnership with a range of sectors, including hospitality, the environment, sports, arts and leisure.
- Local Authorities should provide, or ensure the provision of, adequate flexible respite care options for older carers.
- Local authority Information, Advice and Assistance services should draw on the expertise of occupational therapists and physiotherapists to provide good quality information, advice and guidance about what assistive technology is available and how it can help.

Care of dying people and bereavement

There is no standard approach to quantifying the numbers of carers caring for dying people, but it is estimated that between 24,000 and 48,000 people are caring for dying people in Wales.⁷⁰ In the last three months of the decedent's life, carers of people with cancer contribute a median 69 hours 30 minutes of care-giving each week.⁷¹

Carers of dying people face unique challenges, including: difficulties coping with the increasingly complex and demanding needs of the person being cared for; having to co-ordinate care and professionals on a 24/7 basis; having conversations about resuscitation, artificial feeding and stopping treatment, and dealing with loss and grief in bereavement.

⁷⁰ Hospice UK and Hospices Cymru, , Health, social care and sport committee inquiry: impact of the Social Services and Wellbeing Act (2014) on carers: a Hospice UK and Hospices Cymru response, September 2018 <http://senedd.assembly.wales/documents/s79493/C%2016%20-%20Hospice%20UK.pdf>

⁷¹ Rowland, Christine; Hanratty, Barbara; Pilling, Mark; van den Berg, Bernard; Grande, Gunn: "The contributions of family care-giving at end-of-life: a national post-bereavement census survey of cancer carers' hours of care and expenditures", in: Palliative Medicine, vol 31,, no.4, 1 April 2017, pp 346-355.

Following bereavement, carers can experience a profound sense of isolation, loss of identity and loss of valued relationships with service providers. One in ten bereaved carers experience profound grief disorder (PGD) following the death of the person they cared for, which can have serious implications for their mental health.⁷²

It is therefore important to include bereavement support in the assessment of carers' needs, to identify whether an early intervention from a bereavement service, including pre-bereavement support, is required. The majority of carers of people with terminal and life-limiting conditions will come into contact with NHS services and hospices in the first instance. It is therefore vital that hospices and NHS services are able to identify and support carers, and refer them to the local authority for statutory support, where this is appropriate.

The majority of hospices offer support to families and carers as well as to the patient. However, a limited perception of hospice services means that local authority information, advice and assistance services may not inform carers of how their local hospice could support them as well as the cared-for person.

Those whose caring role ends, for whatever reason, can be a vulnerable group, especially those carers who have been providing significant care for a number of years, who are likely to have given up work, become socially isolated and may have developed health conditions themselves. It is essential that these carers receive appropriate information and advice about any benefit entitlements, reskilling, returning to work and developing social networks to help them move forward.

Public policy proposals

- Public policy should recognise carers' contribution, and ensure that they are supported to be able to live fulfilling lives whilst continuing in their caring role.
- The needs of carers of dying people should be included in Population Needs Assessments, and hospice care providers should play their part in collecting the relevant data.
- Local authorities should include bereavement support in the assessment of carers' needs.
- Hospices and NHS services should identify and support carers, and refer them to the local authority for statutory support, where appropriate.
- Hospices and local authorities should promote and raise awareness of the variety of services hospices offer carers.

Recognition

⁷² Marie Curie, *The Hidden Costs of Caring*, 2015

According to the Welsh Government's 2013 Strategy for Carers⁷³, carers should be:

- Listened to, treated with respect and achieve proper recognition;
- Be genuinely involved in all decisions that affect them and the people they care for, including decisions about the care they are willing and able to provide.

However, too often, carers still feel that they are struggling to have their role and contribution recognised by health and social care professionals⁷⁴. Whilst some professionals are very good at including carers in the process, others effectively ignore their contribution. More broadly, carers feel that their situation is ignored by society as a whole. 51% of respondents to a Carers Wales survey reported feeling that society does not care about them at all⁷⁵.

“A Healthier Wales”, Welsh Government's plan for health and social care, identifies the need to recognise and support unpaid carers and the need for greater parity of esteem between them and health and social care professionals.⁷⁶ We welcome the acknowledgement of the key role that carers play. Carers want to feel like a partner in decision-making and receive an acknowledgement not just of the contribution that they make in providing care, but also their knowledge of the person for whom they care. If implemented effectively, these provisions should help boost carers' self-esteem and increase their sense of connection with health professionals.

Public policy proposals:

- The contribution of the carer in looking after the person cared for should be adequately recognised by health and social care professionals, whilst acknowledging that their contribution should not be taken for granted by the professionals involved.
- Welsh Government, Local Authorities and Local Health Boards, should provide visible support to the annual Carer's Week (June) and Carer's Rights Day (November) to draw attention to the contribution that carers make to both the economy and society.
- Welsh Government should ensure that provisions establishing the rights of carers under the Social Services and Well-being (Wales) Act 2014 are not diluted or removed by any future legislative changes in this area.

⁷³ Welsh Government, 2013, WG 18868

⁷⁴ Carers Wales, State of Caring, 2014.

⁷⁵ Carers Wales, State of Caring, 2014.

⁷⁶ A Healthier Wales: our plan for health and social care, Welsh Government, 2018