

Policy Statement

Carers

November 2016

Summary

According to recent figures there are more than 384 000 carers¹ living in Wales, representing 12.1% of the Welsh population (the average across England and Wales combined is 10.3% of the population)². Currently more than 6.5 million people across the UK provide care for family members or friends³, with estimates from Carers UK suggesting that a further 3.5 million carers will be needed by 2037 based on current demographic projections⁴.

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”⁵.

Carers can be involved in a whole range of practical, physical, personal and administrative tasks. Examples could include: cooking; housework; lifting, washing and dressing the person cared for; helping with toileting needs; administering medication; and providing emotional support.

It is these carers, rather than the health and social care systems, who provide the bulk of care to those who need it. Without them, the health and social care systems would be swamped – there are twice as many carers as paid staff working in the combined health and social care systems⁶.

¹ 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.

² S Yeandle & L Buckner (2015): *Valuing Carers 2015 – the rising value of carers’ support* (Carers UK): p5

³ Carers Wales (2014): *State of Caring 2014*: p3

⁴ House of Lords Select Committee on Public Service and Demographic Change (14 March 2013): *Ready for Ageing?* (HL Paper 140): p82

⁵ Welsh Government (2013): *The Carers Strategy for Wales 2013*, WG 18868

⁶ House of Lords Select Committee, 14 March 2013

Increasing numbers of those providing care are older people. The peak age for caring in the UK is estimated to be between 50 and 59⁷ and the number of those aged 65 or over providing care is increasing more rapidly than the increase among the general population.

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.

Too often in these financially difficult times, carers are increasingly relied upon to fill gaps in provision. 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.

Carers play a vital role, both economically and socially. 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 billion⁸ to £132 billion⁹ annually.

Providing care has a significant impact upon the person providing care. This impact takes multiple forms: health, both physical and mental; finances (including working life), especially future financial security; emotional strain; and inadequate support.

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. 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 the future. 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.

⁷ L Buckner & S Yeandle (undated): *We Care. Do you?* (Centre for Social Inclusion, Sheffield Hallam University)

⁸ C McNeil and J Hunter (2014): [The Generation Strain](#) (IPPR, London): p3

⁹ S Yeandle & L Buckner, 2015: p5

There is a growing dependence on older carers, people for whom enjoying their retirement may no longer be an option. 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 2017.¹⁰ Without adequate support for carers, pressures on the National Health Service and the social care system can only continue to grow.

Summary of Public Policy proposals

- 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 flexible forms of 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.
- 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.
- 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 state pension age before 2010.
- The UK Government should ensure that the Carer's Allowance is pegged to increases in the National Living Wage (for those aged 25 and over) to ensure that working for 16 hours a week on the National Living Wage never exceeds the eligibility threshold for Carer's Allowance¹¹.
- 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 benefits available.

¹⁰ McNeil and Hunter, 2014

¹¹ To be eligible for Carer's Allowance, you must earn no more than £110 per week after allowable deductions. With the National Living Wage set at £7.20 for those 25 and over (April 2016) figures, working 16 hours a week earns £115.20.

- Employers should be required to introduce carer-friendly employment conditions, unless it can be explicitly demonstrated to contradict job specification requirements.
- 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.
- 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 wellbeing, and opportunities for social and financial inclusion.
- Local Authorities should provide, or ensure the provision of, adequate flexible respite care options for older carers.
- The Welsh Government must ensure that the implementation of the Social Services and Well-being (Wales) Act 2014 and the supporting Code of Practice guarantees 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. A carer should not feel under pressure to meet needs where they do not feel willing or able to do so. To that end, provision should be made to for any discussion on willingness and capacity to take place confidentially with the carer.
- 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.

Carers

This policy statement covers:

- The health impact of caring
- The financial impact of caring
- Support and respite care
- 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.

It has been estimated that at least two-thirds of older carers already have long-term health problems or a disability themselves¹². On top of existing health issues, 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.

Carers often suffer from higher levels of arthritis, high blood pressure, long-term back problems or mobility problems¹³, all of which can create difficulties in carrying out care tasks as well as being aggravated by the physical process of caring. Lifting is a particular area of concern with large numbers of carers receiving no training in how to perform this task in the recommended way¹⁴.

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, 87% of respondents felt more stressed as a result of their caring roles and 79% of respondents also reported

¹² The Princess Royal Trust for Carers (2011): [Always on Call, Always Concerned](#)

¹³ Carers UK (September 2014): [Carers at Breaking Point](#)

¹⁴ The Princess Royal Trust for Carers, 2011

feeling more anxious¹⁵. 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 health¹⁶.

Carers must not be expected to sacrifice their health in the process of caring for a family member or friend. Under the Social Services and Well-being (Wales) Act 2014, all carers are entitled to an independent carer's assessment, regardless of whether the person they care for is having their needs assessed or not.

Public policy proposals:

- 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 flexible forms of 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.

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.

Many of those who are working when they become carers end up either quitting their jobs or reducing their hours. 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 years¹⁷. In a Carers Wales survey, 51% of adult

¹⁵ Carers Wales (2015): [State of Caring 2015](#). NB, both of these figures have increased from the 2014 survey.

¹⁶ The Princess Royal Trust for Carers, 2011.

¹⁷ D Ben-Galim & A Salim (2013): [The Sandwich Generation](#) (IPPR, London)

respondents (of all ages) had given up work to care and 18% had reduced their working hours. 23% of working carers were worried about their ability to remain in work¹⁸.

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 marked¹⁹. 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 create 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 financial resources, whilst at the same time they may be facing the additional costs highlighted above. However, there is also the psychological and emotional impact and carers may feel they have lost a part of their identity, lose confidence and feel more lonely or isolated than previously²⁰.

Leaving work to care also has significant implications for the financial future of the individual. 36% of respondents to a survey of carers who had left work reported that they would no longer be able to save for a pension as a result, with 49% also reporting that they would be unable to save up to meet their own future care needs²¹.

As a consequence, many individuals 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.

It is widely acknowledged that many of the issues discussed here also 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

¹⁸ Carers Wales, 2016

¹⁹ Carers UK & Age UK (2016): [*Walking the Tightrope. The challenges of combining work and care in later life.*](#)

²⁰ *ibid*: p30

²¹ Carers UK, September 2014

situation is particularly acute for older women who are or were in receipt of a lower income²².

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, 50-64, is often when workers are at their most skilled and experienced²³.

There is evidence to suggest that business can benefit from implementing policies that help employees to balance work with other family responsibilities²⁴. Potential benefits include productivity gains, cost savings, reduced sick leave and lower staff turnover.

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.

A survey carried out by Carers Wales reported that 53% of respondents were struggling to make ends meet, with 36% of those respondents having cut back on essentials such as food and heating. 32% of respondents were using up their savings in order to get by²⁵. 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.

The Carer's Allowance, currently paid at £62.10 a week, is available to those who provide care for at least 35 hours a week, earn less than £110 a week after deductions and look after a person who gets a qualifying disability benefit. With the National Living Wage set at £7.20 for those 25 and over (April 2016) figures, working 16 hours a week earns £115.20.

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

²² Ben-Galim and Salim, 2013.

²³ Carers UK (July 2014): [Care Leave: Impact on Business Research Report](#)

²⁴ 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)

²⁵ Carers Wales, 2016.

negatively impact upon the benefits received by the person cared for. The complexity of such a system is an additional frustration for many.

However, once an individual claims their State Pension, they can no longer receive the full amount of Carer's Allowance even though they continue to care and still face the additional costs created by providing care, as these are classed as overlapping benefits. If your State Pension is less than the Carer's Allowance, the difference between the two can be made up in Carer's Allowance. If your State Pension is more than the Carer's Allowance, you cannot be paid Carer's Allowance but if you claim, you can still receive the underlying entitlement that could increase other means-tested benefits. However, this change upon drawing State Pension can create a sense of injustice for those who feel they no longer receive recognition for the contribution they make.

Applying for entitlements is also viewed as problematic. 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, or 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.

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, as highlighted above, carers are already facing a loss of income and higher household bills²⁶. The cost of respite care is seen as a particular problem.

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.
- 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.
- 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

²⁶ Current changes being undertaken to the welfare system may further disadvantage many carers and the people they care for financially.

Welsh Governments working together to raise awareness of the support available.

- Employers should be required to introduce carer-friendly employment conditions unless it can be explicitly demonstrated to contradict job specification requirements.

Support and respite care

Many carers feel that they do not receive the support they require in order to care effectively²⁷. 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.

Caring roles can also cause isolation from family and friends. This can have implications for the health and wellbeing of the carer, especially if they are caring for someone whose condition causes difficult behaviour or whose condition is difficult for people to understand. This isolation can lead to carers feeling as though they have lost their identity to some degree²⁸.

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 means²⁹. A carer can receive this assessment whether or not the person for whom they care has an assessment.

Assumptions can be made about the extent to which people are willing and able to provide care. 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. 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. Both of these attitudes can have implications for the provision of support.

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.

²⁷ Carers UK (2016): State of Caring 2016

²⁸ Age UK (2010): *Invisible but Invaluable*

²⁹ Carers Wales (2016): [Assessments. A guide to getting an assessment in Wales from 2016](#)

Many are reluctant to discuss the pressures that they face and their feelings. As financial pressures within the social care system have grown, fewer and fewer people are receiving social care from the state. As a consequence, carers often feel as though they are in a fight to receive the support that they, and the individual that they care for, require³⁰. Too often, carers feel that the situation has to reach crisis point before an intervention takes place.

Even where eligibility for support has been established, the services provided are often described as inadequate, unreliable or being of poor quality³¹. As a result, many carers are reluctant to use care services for broader support or specifically for respite care as they do not have a sufficient degree of trust in the quality of the care provided. Worrying about the standard of care provided can lead to refusal of care to the detriment of the carer's own wellbeing.

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. 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 circumstances³². Dealing with challenging behaviour is particularly tiring and frustrating because of the need for constant vigilance.

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.

Reaching crisis point can also 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.

Public policy proposals

³⁰ Carers UK, 2016

³¹ *ibid*

³² Older People's Commissioner for Wales (2016): [*More than just memory loss. The experience of those affected by dementia in Wales.*](#)

- 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.
- 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.
- Local Authorities should provide, or ensure the provision of, adequate and flexible forms of respite care for older carers.
- The Welsh Government must ensure that the implementation of the Social Services and Well-being (Wales) Act 2014 and the supporting Code of Practice guarantees 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. A carer should not feel under pressure to meet needs where they do not feel willing or able to do so. To that end, provision should be made to for any discussion on willingness and capacity to take place confidentially with the carer.

Recognition

According to the Welsh Government's 2013 Strategy for Carers³³, 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.

Too often, carers feel that they are struggling to have their role and contribution recognised by health and social care professionals³⁴. Whilst some professionals are very good at including carers in the process, others effectively ignore their contribution. 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.

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 all³⁵. Carers play a vital role, filling a space in service provision that the health and social care systems are simply unable to cover.

³³ Welsh Government, 2013, WG 18868

³⁴ Carers Wales, 2014.

³⁵ *Ibid*

Carers often do not identify themselves as carers, as they view themselves simply as doing what is necessary for the individual they are helping. This lack of identification means that they may lose out on the support that is available to them. Encouraging this step, combined with greater awareness of their own rights as a carer, may help to provide essential support where it is needed most.

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.