



Cost of caring for an ageing population

Carers Trust Wales exists to improve support, services and recognition for unpaid carers in Wales. With our Network Partners – local services that deliver support to carers – we work to ensure that information, advice and practical support is available to carers across the country.

Carers Trust Wales delivers practical support and information to carers and to those who work with them including: schools, social workers, nurses, pharmacists and physiotherapists. We also seek to influence decision-makers, the media and the public to promote, protect and recognise the contribution carers make, and the support they deserve.

We welcome the opportunity to contribute to the Finance Committee's inquiry into the cost of caring for an ageing population.

Whilst we are not best placed to comment on all aspects of the inquiry's terms of reference in detail, we believe that the below evidence falls within the scope of the inquiry, providing a broad insight into the challenges facing un-paid carers in Wales.

Key recommendations:

- Develop mechanisms to support uptake of Carers Allowance so it is actively encouraged and promoted in Wales and consider the potential benefits of seeking to devolve relevant legislative tools to Wales (including Carers Allowance)
- Introduce a national Carer Well-being Fund to provide for greater flexible 'respite' and breaks for carers across Wales, coordinated by the third sector and delivered in partnership with local authorities and local health boards.
- Press the Welsh Government on the capacity and ability of local authorities and health boards to deliver the duties outlined for carers in the Social Services and Wellbeing (Wales) Act
- A significant shift in funding to support local authorities deliver preventative services and long-term consideration of the role of the third sector in planning to support older carers over the next 30 years

To examine patterns in demand for social care services for those of pension age and the related costs of delivery of residential and non-residential care, taking account of the role of informal carers who provide unpaid services to those requiring care;

To consider future social care needs and related costs, including the projected increase in the proportion of the population of Wales of pension age;

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To assess the fiscal levers available to the Welsh Government to reform the arrangements for funding social care. This will include the consideration of alternative models, including international examples, for the funding of social care to ensure a good quality, fair and sustainable service in a time of increasing demands on the health and social care systems;

Scale of the contribution made by carers

1. 3 in 5 of us will become a carer at some point in our lives. There are millions of unpaid carers providing support across the UK with the last census showing that there are at least 370,000 in Wales: the highest proportion of carers in the UK.¹
2. In almost every category, Wales has the highest proportion of carers in the UK – including the highest proportion of older carers and the highest proportion of carers providing over 50 hours of care a week.
3. One in five people aged 50–64 are carers in the UK. 65% of older carers (aged 60–94) have long-term health problems or a disability themselves. 68.8% of older carers say that being a carer has an adverse effect on their mental health. One third of older carers say they have cancelled treatment or an operation for themselves because of their caring responsibilities.²
4. Unpaid carers contribute £8.1 billion to the Welsh economy each year (this is calculated at the cost of an hour of unpaid care being paid at the minimum wage) and it is important that this valuable contribution is recognised and appreciated.³

Support currently available

5. Whilst Welsh Government has made great progress towards better supporting carers through innovative policy and legislative change, recognition and implementation has been slow and inconsistent. Too often, there has been a failure to understand the complex relationship that exists between carers and services and the importance of developing systems and structures that recognise, support and empower carers both to deliver good care and to prioritise their own wellbeing and life goals.
6. Strong legal rights, for example those delivered through the Social Services and Wellbeing (Wales) Act, have yet to be consistently delivered to the spirit and letter of the law at the point of implementation. For example, Carers Trust Wales and our local Network Partners, have been made aware of waiting lists for carers needs assessments, low levels of awareness amongst carers of their entitlement to an assessment or a clear understanding of when an assessment has been

¹ <https://carers.org/key-facts-about-carers-and-people-they-care>

² <https://carers.org/key-facts-about-carers-and-people-they-care>

³ <https://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015>

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undertaken. In some cases, “what matters” conversations are being held instead of formal needs assessments and carers have reported being steered away from a needs assessment because services would not be available to meet support needs should they be formally identified.

7. Carers Wales’ Track the Act briefing provides clear evidence to support our concerns regarding the extent to which the Social Services and Wellbeing (Wales) Act is ensuring that Carers’ needs are being identified and met in all Local Authorities across Wales.⁴

Why supporting carers is a good investment

8. Carers are unpaid. Carers are not, however, “cost-free”. They require care and support in their own right to enable them to care without risking their work, health and wellbeing. It is important, when considering the cost of caring for an ageing population, that meeting the associated needs of unpaid carers is expressly factored in.
9. Carers’ own health and wellbeing needs are often exacerbated or caused because of their caring role.⁵ If carers’ health continues to deteriorate it will have a negative impact on their own wellbeing, and also the wellbeing of the person or people they care for. It may also have an impact on the health and social care services as they may be required to provide unplanned, emergency care to the people with care and support needs.
10. The un-paid work of carers props up the health and social care system in Wales⁶. If we do not move quickly to get the right support, to the right people, at the right time, significant additional pressures will inevitably be placed on health and social services as more and more carers feel forced to give up their unsustainable caring roles.
11. Supporting carers appropriately delivers benefits for carers and the people they care for. For example:
 - supporting carers by providing breaks and emotional support helps to prevent burnout and keep carers caring for longer;
 - working to encourage carers into or to continue in education improves their emotional well-being and personal fulfilment as well as widening their options for future employment, education or training;
 - involving carers in hospital treatment and clinical decisions improves communication and planning which results in better outcomes for both patient and carer.

⁴ <https://www.carersuk.org/files/section/5763/track-the-act-briefing-2-final-draft-year-1.pdf>

⁵ <http://static.carers.org/files/in-poor-health-carers-uk-report-1674.pdf>

⁶ <http://www.wales.nhs.uk/carers>

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However, too often carers are not supported in any of these ways.

12. The roles undertaken by carers are of clear benefit to the Welsh economy and contribute to easing pressure on local authorities and NHS Wales in a challenging financial climate. To maintain their caring role, and their own health and wellbeing, different carers need different kinds of support.
13. The specific support individual carers need to thrive will be as diverse as their circumstances. In our experience, this can range from requiring better information on managing medicines to having access to reliable services to provide a much-needed break from caring.⁷ However, the first step in delivering appropriate support will always stem from individuals and professionals being equipped with the information and tools they need to identify carers and to understand the barriers they face.
14. Failing to address the pressures currently facing carers will undoubtedly have economic consequences. Additionally, failure to change will risk the health, wellbeing, financial security and life chances of a whole generation of carers. Carers provide 96% of care in the communities of Wales and too often their own needs are not acknowledged or met⁸.
15. We believe that in order for vital health and social care services to survive carers and the services they rely on must be placed on a sustainable footing and given the tools to thrive.
16. In England, the Royal College of General Practitioners has worked with Baker Tilly to identify the social return on investment which can be made when CCGs invest in services which support carers. The study shows that this could equate to a saving of almost £4 for every £1 invested.⁹
17. Additionally, an Impact Assessment published by the Department of Health in England in October 2014 makes an estimate of the “monetised health benefits” of additional support for carers. This estimates that an anticipated extra spend on carers for England of £293 million would save councils £429 million in replacement care costs and result in “monetised health benefits” of £2.3 bn. This suggests, as a ratio, that each pound spent on supporting carers could save councils £1.47 on replacement care costs and benefit the wider health system by £7.88.¹⁰
18. The services carers receive and require are diverse and include a wide range of

⁷ https://carers.org/sites/files/carerstrust/related_documents/carerstrustwalesmanifesto.pdf

⁸ <http://gov.wales/about/cabinet/cabinetstatements/2017/carersfriendlywales/?lang=en>

⁹ <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/carers-support.aspx>

¹⁰ Department of Health (2014) Impact Assessment (Carers)
http://www.legislation.gov.uk/ukia/2014/407/pdfs/ukia_20140407_en.pdf

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local and national services. Services include:

- information, advice and support
- short breaks
- replacement care
- palliative care
- employment support
- training
- benefit support.

The preventative value of these services, both in securing the well-being of individuals, and in avoiding additional costs to local authorities and local health boards, is well-established. For example:

A longitudinal study of 100 people with dementia found a 20-fold protective effect of having a co-resident carer when it comes to preventing or delaying residential care admissions¹¹

Carers providing more than 50 hours of care per week are twice as likely to report ill health as those not providing care. Wales has the highest proportion of carers providing more than 50 hours of care per week in the UK.¹²

19. One study found that problems associated with the carer contributed to readmission in 62% of cases¹³

20. Additionally, many carers are unaware of the extra financial support they are entitled to. In 2010, a working paper by the Department for Work and Pensions estimated that uptake of Carer's Allowance across the UK was around 65%.¹⁴

21. Out of carers surveyed, 9% had missed out on Carer's Allowance for 3–5 years, 10% for 5–10 years and 14% for over ten years, because they did not realise they were entitled to it.¹⁵

Prioritising and funding respite care

22. We know that carers value flexible breaks and respite care. Breaks can help to ensure that the carer remains well and is able to continue to provide care. The Social Services and Well-being (Wales) Act places carers on the same legal

¹¹ Banerjee, S, Murray, J, Foley, B, Atkins, L, Schneider, J, Mann, A (2003) Predictors of institutionalisation in people with dementia, *Journal of Neurology, Neurosurgery & Psychiatry* 2003, 74,1315–1316.

¹² <http://static.carers.org/files/in-poor-health-carers-uk-report-1674.pdf>

¹³ Williams, E, Fitton, F (1991) Survey of Carers of elderly patients discharged from hospital, *British Journal of General Practice*, 41, 105 –108.

¹⁴ https://carers.org/sites/files/carerstrust/related_documents/carerstrustwalesmanifesto.pdf

¹⁵ <https://carers.org/key-facts-about-carers-and-people-they-care>

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footing as those they care for, and places a duty on local authorities to promote and provide preventative services.

23. Despite this, services across Wales that provide quality breaks and respite for carers have been squeezed, and commissioning has focused increasingly on price rather than quality. We have also seen a significant decrease in individuals accessing day services or respite care since 2012.¹⁶
24. We believe that there would be value in introducing a national Carer Well-being Fund to provide additional breaks for carers across Wales, coordinated by the third sector and delivered in partnership with local authorities and local health boards.
25. Introducing a modest fund of approximately £1.4million a year would be able to generate over 53,000 hours of additional breaks for carers in Wales. This relatively small investment would also provide a powerful base upon which third sector preventative services could build and develop. Such a fund would have the long-term benefit of helping mitigate against additional or unsustainable demand on local health and social care services.

To examine the financial pressures on the social care system, such as increases in wages, automatic pension enrolment and staff recruitment and retention difficulties, including the related financial impacts arising from the UK leaving the European Union;

26. We know that many unpaid carers could not manage without the high-quality support of paid care support workers. The government must ensure that enough paid staff are available to support carers – wherever these workers come from in the world.
27. Planning for the different scenarios possible after the UK leaves the European Union in March 2019 must be considered. Plans must be put in place to ensure that there is no rapid or sudden decrease in numbers of paid care support workers, as they help many carers get the break from caring that they need, or provide the reassurance to carers that the person they care for is having their needs met. It is vital for the health and wellbeing of unpaid carers to get a break from, or support with, their caring role. It is important that after Brexit, carers still have access to this support from paid care support workers.

To consider the financial impact of current Welsh Government policies - including recent social services legislation and reforms to social care funding - on local authorities, care providers and service users;

¹⁶ https://carers.org/sites/files/carerstrust/related_documents/carerstrustwalesmanifesto.pdf

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28. Funding for Carers services is insufficient, and narrowly restricted to the implementation of the Social Services and Wellbeing Act. It is also short term in nature and lacking in transparency at the point of allocation.
29. Consideration needs to be given to the cost benefit of properly mapping, commissioning and resourcing appropriate services throughout Wales. In particular, as highlighted above, it is important to more sustainably fund respite care and breaks.
30. Further funding is needed for respite and short breaks. This must be ring fenced to Local Authorities, and part of a long-term funding stream. We have been funded by Welsh Government to undertake a Wales wide study to investigate the ways in which flexible support (including emergency support and short breaks) could best be provided longer term. It is important that these report findings are used to deliver a step-change in the funding and commissioning of appropriate respite services for carers across Wales.
31. The challenges facing unpaid carers in Wales today are significant and have growing potential to impact on our public services if they are not robustly addressed. The demand on health and social care services is growing and projected to grow further still. If just a small percentage of carers stopped caring, health and social care services could easily become unsustainable. Supporting our unpaid carers is the definition of a preventative integrated health and social care service.
32. At a national level, in particular within Welsh Government, unpaid carers are largely considered within the parameters of the Social Services and Integration department. Current thinking, and policy development within other departments fails to be fully cognisant of the fact that public services, particularly our NHS, are increasingly being challenged by carer-related issues and will be challenged further still if carer relationships breakdown as a result of lacking support.
33. It is important to address the wider issues facing carers in a way that is mindful of the significant impact failing to support carers could have on the wider economy, health and social care services. There are significant social and economic advantages to supporting carers to live health and fulfilling lives. It is important that policy, legislation and practice work together effectively to deliver a truly carer friendly Wales.
34. We believe that a new Carers Act for Wales could be a key piece of legislation that could usefully bring together many of the unconnected strands of carer support and deliver some much-needed funding. Crucially, legislation would give Wales the opportunity to address some challenges in a clear and definitive way including:

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- delivering carers needs assessments
- informing carers about support
- supporting carers in education
- supporting carers in employment
- recognising carers as partners in the care of the person they care for in medical settings

35. Such legislation would build on the legislative progress already made by Welsh Government in social care by delivering more focus and funding to the carers elements of the Social Services and Wellbeing (Wales) Act.

A similar Act in Scotland is at pre-implementation stage but is already ensuring that the issues are being addressed jointly by different departments across Scottish Government.

It also includes elements designed to address many of the structural barriers to supporting carers in the longer term which we also face in Wales, such as:

- a lack of data collection for carers.
- a lack of identification of carers of all ages in a variety of contexts (including schools and healthcare settings).
- a lack of self-identification.
- a lack of information and support.

A Carers Act for Wales could help to deliver collaboration, joined up thinking and appropriate funding for many of the practical day to day requirements for local authorities in particular: how to fund, train and support delivery and promotion of carers needs assessments.

A Wales Carers Act would be an opportunity to address the issues in detail for the long term. Delivered properly, it would not only save public services huge sums of money, it would send out an important statement that Welsh Government is addressing and acting on a critical issue for the nation's future.

Additional information

Groups of carers with specific needs

36. It is important that the committee is mindful of some of the specific challenges facing older carers and carers of people with dementia when considering evidence in relation to this inquiry.

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Key Issues for Carers of People with Dementia

37. Carers Trust's research into the experiences and needs of carers of people with dementia, demonstrates clearly what the issues faced by this group of carers experience. A Road Less Rocky¹⁷, sets ten key crisis points when carers of people with dementia need specific, information, advice and support in their own right to prepare for and cope with their caring journey. These are:

- When dementia is diagnosed,
- When the carer takes on an "active" caring role,
- When the capacity of the person with dementia declines,
- When the carer needs emotional support and/or a break from caring,
- When the person with dementia loses their mobility,
- When the person with dementia has other health problems,
- When the carer has to cope with behavioural problems,
- When the carer's own circumstances change,
- When the person with dementia becomes incontinent,
- When decisions about residential care and end of life care have to be made

38. Carers are still going unidentified at an early enough point whereby they reach crisis point at one of these later points 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.

39. Carers of people with dementia experience particular challenges that are in addition to the wider issues experienced by all carers. Often due to their age, the nature and complexity of dementia and their own health needs they are a particularly vulnerable group who need attention in their own right.

40. It is important that all hospitals in Wales develop their carer awareness to ensure that carers are included throughout the care pathway which would reduce poor discharge practices.

41. Additionally, Commissioners must ensure carers of people with dementia are included in commissioning decisions including ensuring their own needs (as identified in the Road Less Rocky) are taken into account when commissioning services.

Older carers

42. The numbers of older carers is growing all the time, those aged 85 and over grew by 128% in the last decade (Carers UK and Age UK, 2015).

¹⁷ Newbronner. L, Chamberlain. R et al, A Road Less Rocky – Supporting Carers of People with Dementia, Carers Trust, 2013

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43. Older carers have their own specific needs and have tended to be a forgotten group, often going unidentified because they do not recognise themselves as a carer or are not recognised by services. With an aging population and the increase in the life expectancy of people with learning disabilities which is to be celebrated; people are caring for longer and later in their lives¹⁸.

44. 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 for caring in later life, especially so for carers who have been caring for children with long term conditions whose life expectancy meant they were unlikely to reach old age but increasing numbers now are.
- Older carers have a strong sense of “duty to care”, this can be reinforced by health and social care professionals which means they may feel they have no choice or continue to do so longer than they are able.
- Lack of information on financial planning, including information on lasting powers of attorney are not provided at an early enough point.

It is also worth referring to a number of reports produced by Carers Trust which support this¹⁹²⁰:

To support older carers it is important that:

45. Primary and secondary care services identify older carers as early as possible and ensure they are referred for a carers need assessment.

46. Planning for caring in later life should be considered as a public health priority and the public supported to plan for their own care needs and the potential for becoming a carer in later life.

47. Health and social care systems must be aligned and integrated to ensure older carers are not required to navigate the complex systems for both their own and the person they care for’s health needs. This presents particular challenges when discharging an unpaid carer from hospital.

¹⁸ Marks. L, Retirement on Hold, Carers Trust, 2016 (due to be published January 2017)

¹⁹ Fraser. M, Always on Call, Always Concerned, Carers Trust, 2011

²⁰ Caring about Older Carers: Providing Support for People Caring in Later Life, Carers Trust, 2015

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48. There must be improved information and guidance on financial planning including information on Lasting Powers of Attorney to ensure carers are prepared for the future and are not required to address these issues too late in their caring journey.
49. Public, community and hospital transport must be improved to address issues of isolation and loneliness which are particularly acute issues for older carers.
50. Clearer support and guidance to help carers navigate a complex health and care system.