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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Ymddiriedolaeth Gofalwyr Cymru

Response from: Carers Trust Wales

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# Priorities for the Health, Social Care and Sport Committee

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# Carers Trust

## About Carers Trust Wales

Carers Trust Wales is part of Carers Trust, a major charity for, with and about carers. We work to improve support, services and recognition for the 370,000 people in Wales living with the challenges of caring, **unpaid**, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

**Our Mission** is to identify, support and involve Wales' unpaid carers through the provision of action, help and advice.

Together with our locally-based network partners, we provide access to desperately-needed breaks, information and advice, education, training and employment opportunities – working with 20,000 carers a year in Wales. Our network partners benefit from the provision of grants, advice documents and reports to improve carers' services. We give carers and young carers opportunities to speak to someone and make their voices heard, offline via our carers' services and young carers' schemes, and via our online communities.

### Our Strategic aims are

1. Championing carers – ensuring their voices heard and carers have a high profile across Wales including in the media, government
2. Delivering services for carers in Wales – researching and promoting solutions for carers across Wales
3. Building partnerships and delivering change – working meaningfully across sectors to reach more carers in all spheres of life
4. A strong Carers Trust Wales network – working closely with our network partners to increase sustainability and impact across Wales

**Our Vision** is a Caring Wales – where unpaid carers are recognised and able to get the support they need

## Overview

1. Carers Trust Wales strongly believes that a priority for the Health and Social Care Committee in the coming year should be an inquiry into the needs of carers in Wales and the level of support required. We believe such an inquiry should include a focus on: the provision of replacement care and short breaks, support for carers of people with mental health problems, and support for young and young adult carers.
2. A carer is anyone caring, unpaid, for a friend or family member who without their support would not be able to cope.
3. Wales is a uniquely caring country with the highest proportion of carers in the UK. Carers in Wales are also, on average, caring for more hours a week than carers elsewhere in the UK.
4. Replacement care and short breaks are two of the most frequently raised issues by carers. Carers Trust Wales is calling for the introduction of a Carers Well-being Fund – a national fund to provide breaks and replacement care to carers in Wales. There is a clear moral and economic case for providing such a fund.
5. This fund could be modelled on the Scottish Short Breaks Fund, which has been in place since 2010, but take into account the lessons learned from it.
6. Carers of people with mental health problems, including dementia, face specific and significant barriers. These barriers include getting the information and advice they need, and being meaningfully involved in the treatment of the people they care for. We believe that exploring what can be done to tackle the barriers carers of people with dementia face should be a priority for the committee
7. We agree that loneliness and isolation amongst older people would be a worthwhile priority for the Health and Social Care Committee. Ideally any work on this issue would also explore the role of support services, including support services aimed exclusively at carers, in tackling loneliness and isolation amongst older people. Carers Trust Wales has

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a suite of good practice examples from across Wales on this particular issue.

8. Carers Trust Wales would welcome the opportunity to speak to the Health and Social Care Committee on the issues we have discussed in this response.

### 1. Response

- 1.1. Carers Trust Wales is calling on the Health, Social Care and Sport Committee to carry out an inquiry into the challenges facing carers in Wales, and the services available to support carers
- 1.2. A carer is anyone who cares, unpaid, for a friend or family member who would not cope without their support.
- 1.3. Wales is a uniquely caring country, according to the 2011 census we have the highest proportion of carers in the UK. The 2011 census also found that carers in Wales care for longer on average than carers anywhere else in the UK<sup>1</sup>.
- 1.4. Officially, 12% of the population of Wales provide unpaid care to a friend or family member who would not cope without their support. In reality, this figure is likely to be much higher.
- 1.5. Among young carers alone, of which there are officially around 12,000 in Wales, research suggests the true figure may be four times higher<sup>2</sup>.

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<http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/articles/2011censusanalysisunpaidcareinenglandandwales2011andcomparisonwith2001/2013-02-15>

<sup>2</sup> <http://www.bbc.co.uk/news/education-11757907>

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1.6. Carers contribute £8.1 billion worth of care in Wales every year, more than the entire Welsh NHS budget and the equivalent of £21,892 per carer every year<sup>3</sup>.

## 2. Replacement Care and Short Breaks

2.1. Replacement care and short breaks play a vital role in protecting the well-being of both carers and those they care for. Similarly, there is a large evidence base that supports the economic case for investing in support for carers – doing so reduces demand upon both health and social service<sup>4</sup>. For example:

2.1.1. One study found that when a person is readmitted to hospital, problems associated with the carer were the reason in 62% of cases<sup>5</sup>.

2.1.2. One report found that commissioning for carers could equate to a saving of £4 for every £1 spent<sup>6</sup>

2.1.3. 35% of carers without good support experienced ill health compared to 15% of those with good support

2.1.4. Fewer carers experience mental health problems if they have taken a break since beginning their caring role<sup>7</sup>

2.2. Despite this, services for carers and, in particular, breaks and replacement care have been under significant pressure. This is a direct result of the real terms reductions in local authority budgets. The Carers Trust Wales Network,

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<sup>3</sup> <http://www.sociology.leeds.ac.uk/assets/files/research/cuk-valuing-carers-2015-web.pdf>

<sup>4</sup> Much of the evidence is collated in our publication 'Investing in Carers, Investing to Save' (2016), [https://carers.org/sites/files/carerstrust/media/commissioning\\_wales\\_finallo.pdf](https://carers.org/sites/files/carerstrust/media/commissioning_wales_finallo.pdf)

<sup>5</sup> Williams, E, Fitton, F (1991) 'Survey of Carers of Elderly Patients Discharged from Hospital', British Journal of General Practice, 41, 105–108.

<sup>6</sup> Conochie, G (2011), Supporting Carers: The Case for Change (The Princess Royal Trust for Carers and Crossroads Care).

<sup>7</sup> Singleton, N, Maung, NA, Cowie, A, Sparks, J, Bumpstead, R, Meltzer, H (2002) Mental Health of Carers (Office of National Statistics, The Stationery Office).

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fifteen independently constituted charities across Wales delivering services to carers, have experienced this pressure first hand.

- 2.3. There have been reductions both in respite services and day centres offered by local authorities – the Welsh Government’s figures show a sizeable decline in individuals accessing both these services since 2012<sup>8</sup>.
- 2.4. In the past year, Carers Trust Wales has been calling for the introduction of a national Carer Well-being Fund. The purpose of the fund would be to increase the availability of breaks to carers across Wales, easing pressure on health and social services.
- 2.5. Such a fund would take into account the lessons of Scotland’s Short Breaks Fund which has delivered over £11 million worth of breaks to carers in Scotland since 2010<sup>9</sup>.
- 2.6. A modest annual investment of £1.4 million in Wales would deliver around 53,000 hours of care at home at the new National Living Wage or provide 31,000 days of care at day centres across Wales. Alternatively, the same fund would secure 2,040 weeks of respite. These calculations include the cost of administrating the fund<sup>10</sup>.
- 2.7. Carers Trust Wales believes that the availability of short breaks and replacement care for carers must play a part in the Health and Social Care Committee’s work going forward, and should form a key part of any inquiry into carers in Wales

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<sup>8</sup> <http://gov.wales/docs/statistics/2015/150902-assessments-social-services-adults-2014-15-en.pdf>

<sup>9</sup> <http://www.sharedcarescotland.org.uk/publications/short-breaks-fund-round-2-evaluation-report/>

<sup>10</sup> Full proposal is available upon request

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## 3. Young and Young Adult Carers

3.1. Young carers (those aged under 18) and young adult carers (those aged 16 to 25) face very specific challenges in maintaining their well-being and receiving the support they need

3.2. The challenges faced by young and young adult carers are varied. Our research with the University of Nottingham<sup>11</sup> found that:

3.2.1. Nearly half of young adult carers (45%) reported having mental health problems

3.2.2. One in four young adult carers said they had been bullied in school as a result of their caring role

3.2.3. young adult carers are four times more likely to drop out of college or university

3.2.4. are more likely to not be in education, employment or training

3.3. Many of the solutions that young and young adult carers need require meaningful coordination and cooperation between health, social care, education and housing. Reaching vulnerable young and young adult carers across Wales requires a joined up, innovative approach that takes into account the breadth of areas that impacts upon their lives.

3.4. Carers Trust Wales would ask that the Health and Social Care Committee ensures that young and young adult carers form a part of any work the committee carries out in regards to carers.

## 4. Carers of people with mental health problems (including dementia)

4.1. Through our work with services for carers and with carers themselves, we hear frequently that those who care for people with mental health problems experience considerable difficulties in undertaking their caring role. This is often the result of a lack of awareness among professionals and a lack of appropriate information and advice to the carer.

4.2. Research by Carers Trust found that over half of carers of people with dementia said they had not received information about managing medication

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<sup>11</sup> [www.ccwales.org.uk/edrms/157384/](http://www.ccwales.org.uk/edrms/157384/)



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and over half had not been given advice on legal issues<sup>12</sup>

- 4.3.** It is for this reason that Carers Trust developed the Triangle of Care model. The Triangle of Care is a tool that has been used in England to improve carer engagement in acute inpatient and home treatment services<sup>13</sup>.
- 4.4.** This model has been well-received in England and is being implemented in a number of hospitals and trusts across the country. There has been interest in implementing it in Wales but capacity has made taking the initial steps difficult. We are still exploring ways to deliver this model, which is evidenced to improve support for carers of people with mental health problems, in Wales.
- 4.5.** We call on the Health and Social Care Committee to explore the particular barriers faced by those caring for people with mental health problems, including:
- 4.5.1.** The lack of appropriate information, including on legal issues and medicine management
  - 4.5.2.** The difficulty of ensuring these carers are meaningfully involved in the treatment of the people for whom they care and models that could help tackle this difficulty.

## Contact

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<sup>12</sup> <http://eprints.whiterose.ac.uk/76737/1/DementiaCarers.pdf>

<sup>13</sup> <https://professionals.carers.org/working-mental-health-carers/triangle-care-mental-health>