

Carers Assembly

20 November 2015

Old Debating Chamber, National Assembly for Wales,
Ty Hywel, Cardiff



Introduction

To mark Carers Rights Day 2015, Carers Wales held its first ever Carers Assembly. From across the length and breadth of Wales, carers replicating the constituencies and regions of Assembly Members of the National Assembly, gathered to debate and have their voices heard.

Carers save the state the equivalent of £8.1 billion in Wales each year.¹ Carers need to be listened to, supported and recognised by politicians, policy makers and service commissioners.

The Carers Assembly started with opening remarks by David Melding AM Deputy Presiding Officer, before the panel of politicians were asked to outline their Party positions on carers' issues.

The Chairman then invited a number of carers from across Wales to read out their pre-submitted questions and statements. The panel were later given the opportunity to respond having listened to carers' comments.

The key themes were:

- Rights and assessments
- Provision of Information
- Respite care and cuts
- Work and Finances
- The role of Co-operatives and third sector

Our thanks go to David Rees AM (Labour), Altaf Hussain AM (Conservative) and Ian Johnson (Plaid Cymru) for taking part in the panel, listening to carers and contributing positively to the day. We also give our sincere thanks to David Melding AM,

Deputy Presiding Officer at the National Assembly for Wales for sponsoring the Carers Assembly and Roy Noble OBE for chairing the event.

We would also like to thank all the carers who gave up their valuable time and travelled from the four corners of Wales to take part.



Keith Bowen
Director, Carers Wales



David Melding AM Sponsor



Left to right: Altaf Hussain (AM Conservative), Beth Evans (Carers Wales), Roy Noble OBE (Chairperson), Ian Johnson (Plaid Cymru), David Rees (AM Labour)

¹ Carers UK (2015) *Valuing Carers 2015 – the rising value of carers' support*. Available at carersuk.org/valuingcarers

Theme one

Rights and assessment

New rights for carers come into force in 2016 when the Social Services and Wellbeing (Wales) Act 2014 is enacted, including new duties on local authorities to undertake carers' assessments and meet the needs of carers following an assessment. However, 48% of carers in Wales currently report never having had a carer's assessment with 75% concerned about the impact of caring on their own health.



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How is it possible that one of the most common complaints from identified carers is that they were not informed by their case worker that they are entitled to request a carer's assessment and seek Direct Payments?

What possible excuse can justify such blatant disregard for these omissions to inform carers of the most fundamental of their rights?

Steven Griffiths – Mid and West Wales regional

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How can carers and service providers work more closely together? I was recently very unwell and needed time to recover. I had time away from the person I care for. Despite repeated requests to social services for help for her, nobody visited or called her. I had a carer's assessment, which at the time seemed helpful, and heard nothing more. Apart from being unwell, I am finding it increasingly difficult to provide care in the way in which I have been doing. The physical demands, as well as having no life of my own or the energy to enjoy life, is making it difficult to provide care on a full time 24/7 basis.

Jane Rose – representing Carmarthen and East Dinefwr constituency



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There is an issue around Continuing Health Care and families being offered re-assessment through health funding if they care for someone with complex needs. Carers need to know that if they accept this, there are sizeable inequalities, since you cannot get Direct Payments if you are funded through health and your rights are severely compromised.

Pauline Young – Cardiff West constituency

All statistics in this report are from the Carers Wales State of Caring 2015 report.

Download at carersuk.org/wales/stateofcaring

Theme two

Provision of information

Every year in Wales 123,000 people will become carers. The consequences of not getting the right information at the right time can mean that carers miss out on entitlements to benefits as well as practical support.



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There is a definite need to have more information readily available at the point of becoming a carer. In some areas carers packs are available when requested, but this falls short as many do not request them. It can take years to get all the relevant information on benefits and assistance. A campaign to identify carers is needed with some carefully thought out strategies. Often literature asks “do you care for someone?” – most would answer no as they see it as just what they do for someone. Is there a plan for any such campaign?

Cheryl Bulman – Ceredigion constituency

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Why is the communication between GPs, secondary care, social workers, district nurses etc so inadequate?

Jan Davies – South Wales East regional



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How are we going to ensure that carers are being reached and supported in the community? Without proper systems in place to support carers many are left isolated and alone. From the moment we became carers we had to fight and seek everything, nothing was in place to support us.

Carers should be offered information as soon as they start caring, from hospitals, GPs and social workers. They should be aware of their options and rights, to them to enable them to continue to care for their loved ones at home.

Jill Thomas – North Wales regional



Theme three

Respite care and cuts

51% of carers in Wales say that they are worried about the impact of cuts to care and support services over the next year, with 43% reporting that the amount of care and support arranged by social services has been reduced. Practical support is essential for many carers, yet many struggle to access appropriate replacement care.



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I am a full time carer for my husband and my 83 year old mother who lives with us.

My mother has many complex health issues which need continuous daily monitoring, including Vascular Dementia, cardiac problems, chronic kidney disease and insulin-dependent diabetes.

I am able to care for her at home because of my years of nursing experience. But when we need respite care difficulties arise as there are no funded respite beds for those needing 24 hour nursing care in my area or, as I understand it, in the whole of Wales.

Caroline Thomas – Clwyd West constituency

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As a sandwich carer for my older father (who has dementia, spinal injuries, cancer and is deaf/blind). He lived with us and our young children, one of whom was also registered disabled. It was often very difficult to predict the year ahead – hospital visits, illness, or indeed if my father was ill and not able to access the respite care, meaning it had to be cancelled, and the whole process had to be started again. This is still very much a problem in Gwynedd having talked recently with carers who have the same problem of shortage of respite beds. Our own experience in Gwynedd over a period of 13 years of having to book respite care a year in advance, often not in the ‘care home’ of preferred choice.

Jill Thomas – North Wales regional

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Respite and replacement care – both are major issues for carers especially since services are being cut back and budgets slashed. Planned respite/ replacement care isn’t always available when the carer would like it for it to be beneficial.

Emergency services are virtually non-existent. What can be done to improve these services and safeguard them against any cutbacks?

Sylvia Prankard – Wrexham constituency

Theme four

Work and finances

Many carers leave work all together when they feel that they can no longer continue juggling work and caring. Many more reduce their hours, turn down promotion or take lower paid, flexible work. This means that caring will often have a considerable impact on a carer's income, with 58% of carers in Wales reporting being worried about their finances.



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The Social Services and Well-being (Wales) act that comes into force next April has unfortunately left open the option for local authorities to charge carers. The warning to ‘consider impact’ of charging on carers will be ignored by some local authorities, especially while they are trying to operate with insufficient funding.

It would be appreciated if all parties would reach an informal agreement that charging carers for social support would be frowned on.

Vin West – North Wales

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In the Gilbert and Sullivan comic opera “Iolanthe”, her son Strephon is made a Member of Parliament, carries every bill he chooses. To his measures all assent, showing that fairies have their uses. Well, whilst I would indeed like to sit in the Assembly Chamber and raise important issues, it is the distance from where I live in Ceredigion and Cardiff Bay that would make that a problem. Therefore I would hope that when “your houses do assemble” to quote “Iolanthe” once again, you will petition Parliament that the Assembly is given the powers to look after the carers of this nation. So that we can both continue looking after those we care for, saving the Welsh Government millions of pounds in social care costs, and still have the chance to be able to do things that we might want to, be it going out for trips or standing for election.

Harry Hayfield – Mid and West Wales

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Caring is expensive at any age: 54% of all carers in the UK say they worry about their financial security, while 48% already struggle to make ends meet. Carer's Allowance stops when State Pension begins. When elderly carers are widowed the financial burden is even greater, the family income is decimated, yet many find that their entitlement to a portion of their spouse's pension takes them over the Income Tax threshold.

Should the Welsh Assembly be given Income Tax raising powers by the Westminster Government, would you consider introducing a Carers' addition to the Income Tax threshold?

Jean Humphreys – Bridgend constituency

Theme five

Co-operatives and third sector

The Social Services and Wellbeing Act (Wales) 2014 will introduce a new duty on local authorities to promote social enterprises, co-operatives and the third sector in the running of local preventative services. Carers and those they look after will be encouraged to take control of their own user-led services and activities.



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How does Welsh Government intend to support carers under the Social Services and Well-being Act? Will carers organisations, local authorities and health be supported financially to do this?

Nigel Hardaker – Ogmore constituency

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Care workers are generally low paid considering the duties they need to perform to look after disabled people. What can be done locally and nationally to reward care workers with better wages?

Jeffrey Morris – South Wales Central constituency

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I believe you have figures showing that some 98% of social support is provided free of charge by unpaid family carers, leaving just 2% that local authorities treat as an unbearable, unaffordable burden. It should follow from this fact that, instead of carers seeking to talk to local authorities, local authorities should be trying to talk to us to work out how we are going to sustainably meet the support requirements of the current and future population. Local authorities and Welsh Government should be urgently setting up co-production groups all over Wales begging carers, disabled and older people to join them to share their experience and expertise to try and find a way forward to start treating social support in a civilised manner.

Vin West – North Wales regional

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I am a single mother of four children. One of my children has severe and complex additional needs. I have relied heavily on my local Swansea Carers Centre in times of crisis, isolation and financial hardship. Swansea Carers Centre has provided a lifeline for both myself and my children, I have accessed many of their services on many occasions. Recently they have provided training for me to become a peer advocate to support other parent-carers. One of the hardest things for parent-carers on top of the obvious difficulties of caring for a child with disabilities is not having their own identity or meeting their own needs. We always come bottom of the list. Carers support services meet these needs.

Carers save the UK the equivalent cost of another NHS and a half, carers centres and carer support services enable us to sustain our caring roles. How would other carers here be affected if their local carers support services failed to secure funding and ceased to exist?

Karenza Cassidy – Swansea West constituency

Photos and feedback from the day





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I just wanted to say many congratulations on delivering a wonderful event on Friday. It was absolutely spot on and ticked every box for me.

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I really enjoyed the event and look forward to next year, it seemed to go very quickly and maybe next time a more lengthy event might be possible so as to hear all the points discussed at length. We only just touched on the tip of the iceberg.

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I thought it was very moving and powerful hearing the collective voices.

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I wanted to say a very big thank you for allowing me to attend what I hope will become the first of many annual Carers Assembly events. Not only was it a great opportunity to share some of the experiences of carers with Assembly Members and prospective candidates, it was also a great opportunity to meet up with carers from across Wales, and to know that we all share in similar concerns.

Conclusion

2016 will be an important year for carers in Wales with the Social Services and Wellbeing Act (Wales) 2014 coming in to force in April, followed by elections for the National Assembly for Wales in May.

Reflecting many of the themes highlighted at the Carers Assembly, the Carers Wales Manifesto outlines the key issues carers would like politicians and policy makers to address over the life of the next Assembly:

Health & care

- Good quality, reliable and affordable care services which enable them to have a life, alongside caring.
- Health and social care services that identify carers and recognise carers as expert partners in care.
- An amendment to the Social Services and Wellbeing (Wales) Act 2014 to introduce a formal appeals process for carers and those they care for
- A health service which recognises that carers have their own health needs and that provides flexible support which proactively seeks to reduce carer ill-health.

Recognition, information and advice

- For their role to be recognised and respected as a crucial part of society.
- For advice, information and support to be easily accessible wherever carers are, rather than them having to seek it out.
- Health and social care professionals, workplaces and community settings should work to identify carers and guide them to support.

Employment and training

- To have access to good quality, reliable and affordable replacement care services so they can have confidence in the care being provided whilst they are at work.
- Flexible, understanding employers who recognise the value of supporting carers to combine work and caring.
- The costs of the failure to support working carers is high. In addition to the long term personal costs to families, the Welsh economy is paying the price too.
- Rights at work which recognise and value caring as much as other family responsibilities and allow carers time off to care.
- Support to return to work when caring comes to an end.
- A benefits system which supports carers to work or study alongside caring, rather than makes it harder.

Download the Carers Wales Manifesto at carersuk.org/wales/manifesto



Photo: Chris Steele-Perkins / Magnum



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