

2nd All Wales Carers Assembly

18th November 2016

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



Introduction

Following on from the success of last year, the second All Wales Carers Assembly was held at the National Assembly for Wales on 18th November 2016. From across the length and breadth of Wales carers came together again to replicate the constituencies and regions of the 60 Assembly Members to have a voice and bring forward the issues that matter to them.

Carers save the Welsh economy the equivalent of 8.1 billion pounds each year in Wales if the care they provide had to be replaced by care from statutory agencies across Wales. Carers need to be listened to and recognised for the contribution they make. They need to have a voice and be involved as equal partners in developing services alongside practitioners, policy makers and commissioners.

The All Wales Carers Assembly was chaired by Roy Noble OBE, Broadcaster and sponsored by David Melding AM. We give our sincere thanks to both of them for their contribution.

This year's Assembly consisted of two sessions. In the first morning session we had an expert panel: Katrin Shaw – Assistant Director of Investigations and Legal Adviser – Ombudsman Wales; Steve Thomas CBE – Chief Executive – Welsh Local Government Association; David Francis – Assistant Chief Inspector – Care and Social Services Inspectorate Wales; Nesta Lloyd-Jones, Policy and Public Affairs Manager – Welsh NHS Confederation. Each were given five minutes to outline their organisations position on carers issues. Pre-submitted questions were then put forward to the panel for response.

The second part of the Assembly was themed for debate amongst carers themselves and the pre-submitted statements and questions for debate were based around the Social Services and Well-being (Wales) Act 2014.

The key themes were:

- Well-being and Prevention
- Information, Advice and Assistance
- Support Services for carers and Meeting carers needs
- Carer Assessments
- Emergency Provision and Respite Care
- Direct Payments
- Social Enterprises
- Carer Finances
- When caring come to an end

We would like to give our sincere thanks to the panel for making a positive contribution by taking part and answering questions. We would also like to thank Deryn Consulting and Huw John photographer for some of the photographs featured in this report. Finally, we would also like to thank all the carers who gave up their valuable time and travelled from across Wales to take part and share their experiences.



Keith Bowen
Director, Carers Wales



Roy Noble introduced the four panel members who outlined how their organisations were working to support carers and subsequently took questions from the floor.

Christine Kemp-Philp (Newport) asked about the amount of financial help the Welsh Government is giving to local authorities to implement the new Social Services and Well-being (Wales) Act. Steve Thomas said that there was around £3.5m available from various sources to fund the Act and said that “If you want to see a badly-funded social care system, look at England” he also went on to say that

“We’ve got to start thinking about what sort of model of social care we want in the UK. Are we talking about a bare bones safety net service or are we talking about a properly funded service which can actually deal with the needs of people within our communities... we have an Act in place which we want to make a success but we’re struggling and there’s no point pretending that we’re not”.



Steve Griffiths (Llanelli) asked whether it is possible to amend the Ombudsman service so that organisations can report an abuse of the law by local authorities? Katrin Shaw outlined the role of the Ombudsman and described new powers that the Ombudsman now has in respect of privately provided care, in addition to publicly funded care. She also confirmed that individual organisations cannot currently make direct complaints to the Ombudsman but it would be something they would consider, although this would need the Welsh Government to slightly amend their remit.

Ian Proudfoot (Aberavon) asked the panel to explain why assessments are not being offered to carers as a matter of good practice? David Francis said that a lot of effort was being put into training on the Social Care and Well-being Act and that it was difficult to deliver services with the speed that the Act has been implemented.

Jackie Askey (Cardiff West) challenged what she described as the appalling quality of care in the community. David Francis contested this and said that many people value some of the social care work that is undertaken.

All Wales Carers Assembly

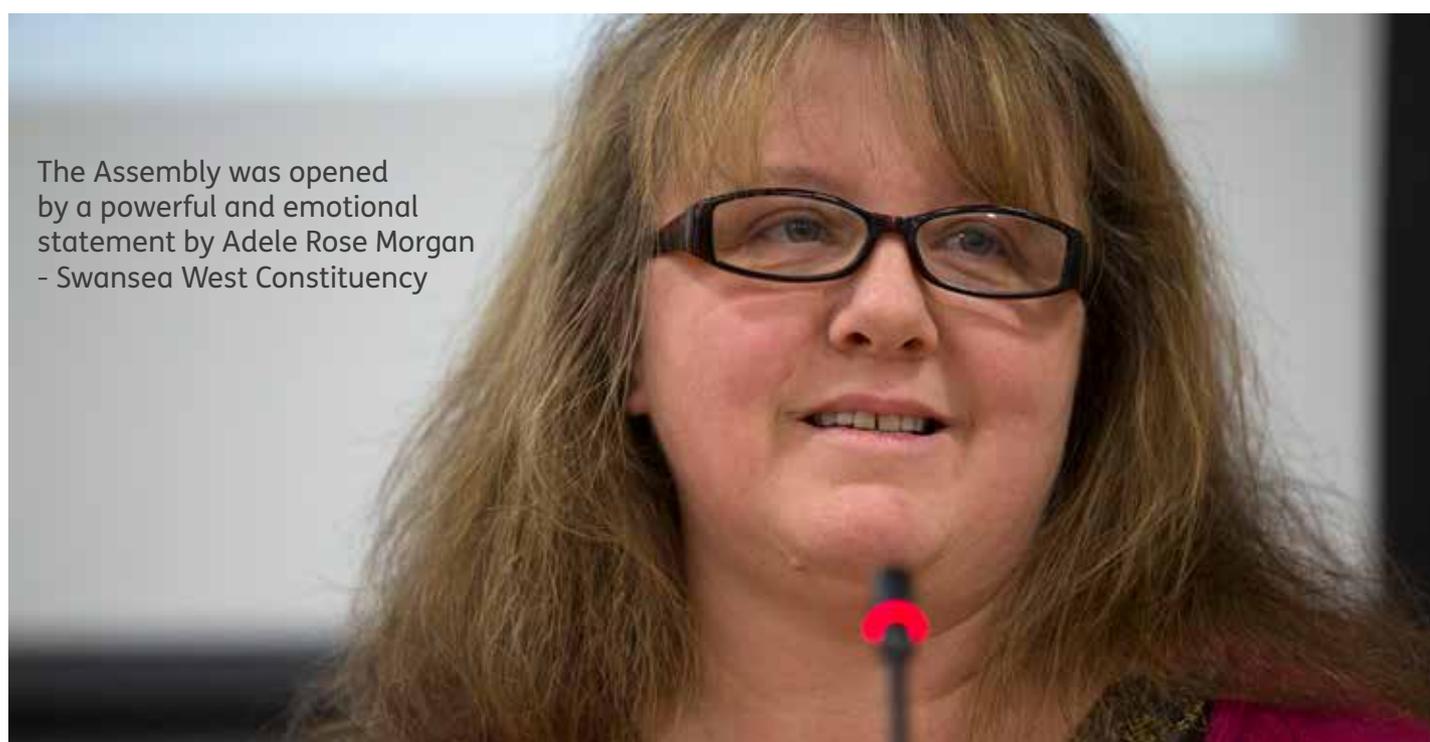
Roy Noble OBE, Chair set the scene for the Carers Assembly based around the principles contained within Social Services and Well-being (Wales) Act that came into force on the 6th April 2016. The Act includes new duties on local authorities to offer and undertake carer's needs assessments as well as meeting the needs of carers following an assessment.

Fundamental principles contained within the Act are:

- **Voice and control** – putting the individual and their needs, at the centre of their care, and giving them a voice in, and control over reaching the outcomes that help them achieve well-being.
- **Prevention and early intervention** – increasing preventative services within the community to minimise the escalation of critical need.
- **Well-being** – supporting people to achieve their own well-being and measuring the success of care and support.
- **Co-production** – encouraging individuals to become more involved in the design and delivery of services.

Adele gave details about her life as a carer for Rhys and the consequences that caring has had on her life. Adele also went on to say “there are some wonderful professionals and support out there. The ground level staff are wow, I’m really loving learning about new legislation and about children’s rights, I’m really enjoying all that. And the new Social Services and Wellbeing Act, albeit a massive undertaking and limited resources, I do have a sense I’ve actually got a voice now and I actually feel more confident to speak up about my experiences because it’s validated now. And Rhys, well everybody should have a Rhys.

The Assembly opened and a variety of themes were discussed. For the purposes of this report we have extracted a selection of important points and statements made by carers.



The Assembly was opened by a powerful and emotional statement by Adele Rose Morgan - Swansea West Constituency

Theme one

Well-being and Prevention

The Social Services and Well-being (Wales) Act requires that local authorities must provide or arrange the provision of a range and level of preventative services that contribute towards preventing or delaying people's needs for care and support, local authorities must also take into account people's well-being and the personal outcomes they wish to achieve in day to day life.

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My wife Joyce was diagnosed with Alzheimers in 2011. The 6 month reviews/follow ups have ceased due to lack of funds. My wife had a stroke on 10th March 2016, she was 4 months in a hospital and is now in a nursing home. She cannot speak and has lost the use of her legs and has other problems. She will never come home. I feel that if she had been to see the memory clinic regularly she may not have had the stroke or we may have been warned that she may have a stroke one day.”

David Suthers – Cardiff West constituency

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There are patches of very good service. My husband has advanced Parkinsons, dementia, he's blind, had a stroke and has vascular dementia. He is part of the Young Onset Dementia Team. They have been magnificent in supporting me and my husband, giving me respite and he is now in a unit for young onset dementia patients. So, there are patches of very, very good practice and very, very good people but it's sourcing those places. It was by chance that I got to know about it, by chance, my GP didn't know.”

Tania Walsh – Cardiff North Constituency



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Part of the problem is that very few people in health or social services understand what the Act means by well-being and prevention. In terms of prevention, whereas the Act was very good in terms of requiring local authorities and health boards to step in as early as possible to prevent degradation of peoples conditions, some local authorities are using the prevention agenda to tell disabled people and to tell carers that the Act is telling them that they have to provide less services and family has to step in and do more. The exact opposite of what the Act is actually saying. The Act has given carers the right to say, sorry folks, I just can't do this any longer, I'm stepping back. That's in the Act.”

Vin West – Arfon constituency

Theme two

Information, Advice and Assistance

The Social Services and Well-being (Wales) Act 2014 provides that local authorities must provide an information, advice and assistance service. This service must promote early intervention and should be considered to be a preventative service in its own right to ensure that people of all ages can be better supported at an earlier stage to explore their options for meeting their needs.



Our Track the Act survey found that 82% of carers had not seen any information published by their local authority that would help them in their caring role, although of those carers who had seen information, 62% found it useful or very useful.

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How do we get all the information to carers and why do we have to go through the same medical details if we need social services help.”

Sue Hadlow – Ogmore constituency

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How are social services going to manage the expectation of carers? It is the failure to meet expectations that is the most distressing and harmful.”

Pauline Jones – Pontypridd constituency

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Once carers reach over the age of 25 years there is not much supported transition and many carers do not feel ready to go it alone and there is no longer as much support available to them.”

Louise Gurl – Blaenau Gwent constituency

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I have a slightly positive example in that at the very last minute she was unable to attend a hospital appointment due to caring responsibilities and had to cancel. When she phoned to explain she was met with a response she had never had before. The person on the other end of the phone acknowledged her caring responsibilities and said that if she ever wanted to move an appointment again they would take it into account and she would not be penalised which some people do if they fail to turn up for appointments.”

Janet Williams – Cardiff North constituency

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As part of a Forum we have had successes in achieving some goals. As an individual everything continues to be a bit of a struggle. So maybe the answer is for carers to unite, form groups, attend meetings and lobby at a local level. This does require work and effort but when carers unite and have a strong voice changes can take place.”

Steven Griffiths – Llanelli constituency

Theme three

Support Services for Carers and Meeting Carers Needs

Our Track the Act survey has found that 16 out of the 22 local authorities in Wales were unable to tell us how many people they had referred on to other organisations. 82% of carers who responded to our Track the Act survey had not seen any information published by their local authority that would help them in their caring role but of those carers who had seen information produced by local authorities 62% found the information useful or very useful.

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In March, I asked for a carers assessment for the first time ever. The assessment began with the question ‘what matterstome?’ It also asked, ‘what can I do to help myself?’ My spirits rose, and my spirits fell. It’s good to know that ‘what matterstome’ is important; but I found it quite demoralising to be asked what I can do to help myself, when I’ve been doing more or less everything by myself for the last 27 years.”

Jennie Lewis – Arfon constituency



“Act has given carers the same rights as the person they care for. However as we’ve heard this morning from Steve, there is no new money, there are pockets of money to deliver the grant, but there’s no extra money to deliver the service to carers. We’re always being sold the idea that there’s going to be a lot more help than there is when you start asking for anything. I just wonder how social services and the Government are going to manage the expectations of carers because for me, it’s far more distressing and harmful to be told you’re going to get something to find out there’s nothing there.”

Pauline Jones - Pontypridd Constituency

Theme four

Carer assessments

Any carer, of any age has a legal right to a carer's needs assessment. The local authority must offer an assessment upon request or where it appears to the authority that a carer may have needs for support. The duty applies regardless of the authority's view of the level of support the carers may need or the financial resources they have or the financial resources of the person who needs the care. The assessment must include the extent to which the carer is able and willing to provide the care and the outcomes that the carer wishes to achieve in their day to day life.

Our Track the Act survey found that many carers are still not being offered or are requesting carers assessments. Of the people who had completed the survey 80% had not been offered a carers needs assessment. This is a stark finding given that those people who had completed the survey had already identified themselves as carers.

All the assessor is concerned with at the yearly review is how much care you are likely to need for the next year (and any way of reducing your package) not the fact that you have been doing it for 20 years and how you will cope with the next 20 years!!!! I don't know why but asking for help is one of the most difficult things in the world to do and yet it's probably the single most crucially important thing a carer needs to do. Please don't make it more difficult than it already is to get help.

What has worked extremely well for me is my daughter being able to access the Independent Living Fund. It has enabled me to continue working part-time and it has given my daughter the freedom to access community activities. Without this funding I would not be able to cope and the uncertainty around the replacement for ILF ie the 'Welsh Grant' is putting a huge pressure on me and other carers."

Pauline Jones – Pontypridd constituency

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How can we find out more about care and assistance for carers? Our daughter is autistic, and we have had 7 nights respite in over 2 years. I had a carer's assessment over a month ago and haven't heard anything yet. Who looks after the carers and all the stress we go through?"

Catherine Dyer – Gower constituency

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Why can't health and social services work more closely together when people are in hospital? Carers should be involved in the discharge planning process and be offered and given an assessment of their needs and any services put in place before the person they care for is discharged. I know of carers for people with dementia who have not been consulted with and are expected to just take their loved ones home without having an assessment and with inadequate or no services in place. This is not good for the carer or for the person they look after."

Rosie Tope – Cardiff Central constituency

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I attended a carer’s assessment and spent over an hour discussing my needs and those of my husband and children I care for. The only assistance I was really offered was I was told to inform my GP at my next appointment. I did this at my next visit and the GP (lead clinician at the practice) shrugged at me and said “so what?” I was horrified and a little humiliated.

I understand that improvements have been made and I am certain that some doctors are better at this than others and my experience may not be the experience of all but there is an urgent need for consistency so that not one more carer feels unimportant and humiliated.”

Susan Rodaway – Gower constituency

Many local authorities are relevantly commissioning local third sector organisations to undertake initial carer needs assessments eg. Neath Port Talbot, Bridgend, Powys and Pembrokeshire. This can be a positive way to undertake proportionate assessments and ensure that carers get the right information at the right time and are signposted on to relevant community support.



Theme five

Emergency provision and replacement care

When a carer has a carer's needs assessment or they are included in the disabled person's care plan and able and willing and are meeting some of that person's eligible needs the local authority must identify all the needs as if the carer was not meeting those needs.

This is so that the local authority is able to respond appropriately and quickly if the carer becomes unable or unwilling to meet some or all of the identified needs of the disabled person. At the point that the local authority are informed that a carer suddenly is unable to meet care and support needs a significant change of circumstances has taken place and the requirement for a re-assessment must not prevent the local authority from taking urgent and immediate action.



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Should social services be more efficient in the provision of emergency care when the carer becomes ill or has an accident?

Last year I had a bad accident, I ended up in a hospital in Newport many miles from my home. The morning after I was admitted I used the ward phone and called NPT social services, I was on the phone for an hour and half telling my tale of woe to an endless stream of different people, I explained my husband has dementia that he was on their books as he had had a care assessment, that he was forgetful and liable to fall. I was told this was Friday I was very pleased to be told this as I was as high as a kite on morphine but it seems that Friday is a very inconsiderate day to phone and I was told there was nothing that could be done. The following Thursday I received a call from the social worker who had done the assessment wanting to know what was wrong because she had seen my name on a piece of paper. I explained yet again and she managed to get someone to call in on my husband every day to make sure he was ok so why did it take nearly a week to get someone out to a person with dementia even when they are known to social services?”

Linda Jagers – Neath constituency

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A lot of effort is currently being made by my local authority to provide quality respite, for carers and cared-for, in more imaginative ways than in the past. As intimated in its document Carers Strategy 2016 – 2019 it is to be offered in the home and in community centres, in bite-size pieces, ranging from a couple of hours, to a single day, for carers and cared-for who want it. These opportunities are very much appreciated but there are waiting lists.

But these good efforts only go so far. What seem not to be adequately provided for, are the needs of those cared-for who require specialised nursing, or who suffer from dementia and need to be prevented from walking away. What I feel will be urgently needed, more and more as the population ages and lives longer, are more purpose-built residential buildings where these vulnerable people can be housed and well cared for, during short periods, in the absence of the carer while she or he has some essential relief. There are currently two such venues in my county (one excellent with a waiting list, one with 2 beds only, also providing other services). This is inadequate and in its Carers Strategy 2016 – 2019 there is no firm commitment for more of this kind of provision in the future.”

Glenys Wilks – Monmouthshire constituency

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With the implementation of the new Social Services and Well-being Act (Wales) 2014 the emphasis is for social workers to enable carers and promote the use of services in the wider community as opposed to social services providing packages of care. What financial help will be given to those people who have to work and care at the same time? How can you limit the impact on the cost of caring for the individual?

What has worked well is the family support received from sons and daughter. Because I work full time as a safeguarding coordinator for the local authority I often need support to care for my husband otherwise my career would be affected. The support from my children has been second to none and has helped to keep me caring.

I am a qualified Nurse, Teacher and more recently gained my Social Work Degree. The most positive thing in my life as a carer has to be, being able to maintain my identity and carry on studying and working. However, I am realistic in realising that it has been a struggle.

Another positive is having a dedicated doctor in the GP surgery who only deals with people with MS and although we don't see this Dr as routine we do get appointments every few months to discuss the different physical and mental problems this condition brings.

Another huge positive has been the lifeline installation. This service has been absolutely amazing especially when my husband became really ill and fell out of the bed and they stayed with me on the phone, they were not patronising they respected my decisions and stayed on the line while I managed to get my husband off the floor and arrange for hospital admission. This service I would give a gold star to.

In the initial stages of becoming a carer the Carers service in RCT was brilliant and helped me through the difficult times as my life changed so dramatically. The trips away from home were a lifeline which again helped me to be me it was another lifeline.”

Alyson May Williams – Pontypridd Constituency

Theme six

Direct payments

Direct payments are monetary amounts made available by local authorities to individuals, to enable them to meet their care and support needs or in the case of a carer, their support needs. Direct payments can enable people to exercise more choice and control to meet their needs and support them to achieve their personal outcomes. Direct payments must be made available where a person expresses a wish to receive one.

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As a wife and carer with a nursing background I manage a team of 3 other carers employed under the Direct Payment Scheme.

We are fortunate in that I am able to manage the team and do all the administrative work, however the question that my husband expresses repeatedly is ‘how could I do this without you?’ Sadly the truth is there is no administrative system currently in place that supports clients receiving Direct Payments. This means that when I die or indeed when I am old and/or disabled myself our perfect system of home care would end.

People deserve dignified care delivered by a limited number of people that they look forward to seeing coming through their front doors and in our experience the Direct Payment Scheme is the only system that provides this. The only missing element is administrative support.”

Wendy Pugh – Ynys Mon constituency



Theme seven

Social enterprises

Section 15 of the Social Services and Well-being (Wales) Act 2014 requires that local authorities must provide or arrange for the provision of a range and level of preventative services to achieve a number of purposes under the Act including contributing towards and preventing the development of people's needs for care and support and reducing the needs for care and support.

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I have a son with learning disabilities who completes a residential college course next year. He has gained many practical creative arts skills and developed significantly as an artist and also from a social perspective in his college placement. The next logical step is for him to continue his development by setting up as a practising artist and also maintaining social contact with an appropriate peer group via a Social Enterprise in which in which he can work in a studio alongside other young artists with learning disabilities to create artworks for exhibition and sale. Whilst this is an enterprise I would like to be involved in developing, it is not something I have the time or expertise to gain the funding for without significant help. Another Social enterprise would be required to provide him with the social life currently available in his college placement.

My worry is that the Social enterprise idea which has the potential to be extremely beneficial to adults with learning disabilities in terms of facilitating more independent living capability, if not fully supported by the Welsh government may be just another way of getting hard-pressed carers to put in unpaid time and their own resources to projects which will fall by the wayside when they run out of energy, at the same time relaxing the responsibility on the funded social services departments who one imagines should be providing such much needed initiatives.”

Yvonne Eckersely – Wrexham constituency



Theme eight

Carer finances

Issues relating to welfare benefits and taxation is non-devolved and is currently a matter for the Westminster Government.

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I retired from full time employment as a nurse in 2008 aged 55yrs and took out my NHS pension. I returned to work on a part time basis to work 2 days (15 hours a week). My part time salary + my NHS pension equate my previous full time salary and makes it possible for me to be at home more to care for my husband.

I anticipated that I would only need to work until the age of 60 yrs. However with changes made to state pensions I am unable to retire until age 64 yrs.

When I am not at work, I care for my husband 24/7 (153 hours per week). I also lead on the small team of carers that we employ through the Direct Payment Scheme. Within that role I manage the care package and participate as a carer on the 40 hour weekly care package the local authority has granted my husband. The care package is delivered during 4 care calls per day (total 3.5 hours per day). The carers that I employ are paid for that time but I am not.

There are many carers in this situation where they are unable to retire and can't afford not to work.

Please could the government consider 2 options that may make it better?

Option1: Assess and analyse individual needs when it comes to state pensions and instead of making it a 'one rule fits all' pension policy, consider the needs of carers that are already saving the government money and award them their state pension at the age of 60

Option 2: Allow carers (relatives) to be paid for the care they provide within care packages granted by local authorities.”

Wendy Pugh – Ynys Mon constituency

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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.

As well as caring for disabled spouses many elderly Carers also care for parents and siblings. When these distance carers are widowed the financial burden, which is already impacted by the travelling expenses they incur to provide care, is even greater.

Their cared for, the very aged and infirm, may also struggle financially and not many are able to assist them. Even if they have been employed in the past most carers have been in non-pensionable employment; yet many find that, when they are widowed, their entitlement to a portion of their spouse's pension takes them over the Income Tax threshold and their finances are decimated.

Now that the Welsh Assembly has been 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

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I claim Carers Allowance of £62 but my ESA is 'docked' by £52, so I am only £10 better off. If the money is supposed to help with the cost of caring, why are they giving with one hand and taking away with the other?”

Hilary Croughton – Dwyfor Meirionydd constituency

Conclusion

When the All Wales Carers Assembly took place the Social Services and Well-being (Wales) Act had been in force for around 8 months having come into force on 6th April 2016. This legislation aims to change the way that social care is delivered in Wales and places a new set of duties upon local authorities with carers very much at the heart of the Act.

The delivery of the Act is in its infancy and much work has already been done but a lot more work will need to follow to achieve the aspirations of the Act.

Carers Wales is monitoring the progress of local authorities in delivering their new duties to carers by making Freedom of Information requests to local authorities across Wales. We have also checked their websites and analysed statistics published by Welsh Government. Carers have been feeding back directly to us through our Track the Act survey.

Findings from the 6 month report

- 17 of the 22 local authorities were unable to provide any data on how many carers contacted them by phone, the internet or in person for information, advice or assistance. Although, of those carers that had seen information produced by local authorities, 62% found the information useful or very useful
- 16 of the 22 local authorities in Wales were unable to tell us how many people they had referred on to other organisations for community preventative support.
- Of the carers who completed the survey, 80% had not been offered a carer's needs assessment.
- There was a significant variation amongst local authorities in the number of carers receiving carer's needs assessments as well as those going on to receive support via a care plan following an assessment.



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