

**Consultation response from Parkinson's UK Cymru**

**National Assembly for Wales' Environment and Sustainability Committee Consultation on the General Principles of the Well-being of Future Generations (Wales) Bill**

**Carers and the Wellbeing of Future Generations (Wales) Bill**

1. Parkinson's UK Cymru, as an active member of the Wales Carers Alliance, fully endorses the consultation response submitted to the Environment and Sustainability Committee by the Wales Carers Alliance.
2. As noted therein, the Wellbeing of Future Generations (Wales) Bill is the third piece of Welsh legislation to cover strategic planning for carers since Welsh Government introduced The Carers Strategies (Wales) Measure in 2010. The Measure came into effect in 2012 and placed a duty on Local Authorities, Local Health Boards and NHS Trusts to prepare, publish and implement a strategy for carers, with Local Health Boards (LHBs) as the lead agency. Regulation required the strategies to include detail pertaining to; identification of carers, the provision of information, training of front-line staff, engagement with GPs and consultation with carers.
3. The publication, in 2013, of the Social Services and Wellbeing (Wales) Bill repealed the Carers Strategies (Wales) Measure 2010. In January 2014 Welsh Government introduced an amendment to the Bill so as to address concerns expressed regarding the repeal of the Measure. Section 14.3 of the Social Services and Wellbeing (Wales) Act 2014 therefore places a duty on LHBs to report to Welsh Ministers on any sections of the local health and wellbeing strategies relating to carers (via the Single Integrated Plans.)
4. The Wellbeing of Future Generations (Wales) Bill tabled in July 2014 subsequently repeals section 14.3 of the Social Services and Wellbeing (Wales) Act 2014.
5. Section 36 of the Bill does refer once to carers but only in relation to the needs assessments under section 14 of the Social Services and Wellbeing (Wales) Act 2014. There is no replication of the detail previously provided in the Carers

Strategies (Wales) Measure 2010 in terms of strategic planning for carers. Further, as the content of the local wellbeing plans is not specified in section 37, there is no obligation upon Public Service Boards to include carers in the plans. Indeed, it is evident from current published Single Integrated Plans that strategic planning for carers varies widely – from links to the existing current local LHB carers strategies in some to minimal or no mention at all in others.

6. Parkinson's UK Cymru is concerned about the way in which the legal status of strategic planning for carers in Wales has been diminished by the legislative process in the two years since the Measure came into force in 2012. In particular we are anxious that the specific duty that was placed on LHBs and NHS Trusts, as the lead agency responsible for carers strategies as well as the detail to be contained in these strategies, provided for by regulations under the Carers Measure, has now been lost.
7. For carers of people with Parkinson's, the primary means of contact with statutory agencies is via health professionals. Parkinson's UK Cymru therefore calls for the Wellbeing of Future Generations Bill to:
  - a. Maintain LHBs and NHS Trusts as the lead agencies for carers;
  - b. Ensure that the detail of the current local carers strategies is not lost (as described in paragraph 2 above.)

## About Parkinson's

Parkinson's is a progressive neurological disorder for which there is currently no cure. It is associated with the death of nerve cells in the mid-brain which results in the loss of the chemical messenger dopamine. This affects learned voluntary movements such as walking, talking, writing and swallowing.

As the condition progresses it impacts on all aspects of the person's life and the lives of those around them.

## About Parkinson's UK Cymru

Every hour, someone in the UK is told they have Parkinson's. Because we're here, no one has to face Parkinson's alone.

We bring people with Parkinson's, their carers and families together through our network of local support groups, our website and our free confidential helpline.

Our Parkinson's specialist nurses, our supporters and our trained staff work together to provide information and training on every aspect of Parkinson's.

As the UK's largest support and research charity for Parkinson's, we're leading the work to find a cure, and we're closer than ever.

We also campaign to change attitudes and demand better services.

For more information please contact :

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