

Focus Group Report on

# ‘My Experiences of Caring for Someone with a Neurological Condition’

Conducted by

*West Berkshire*

*Neurological Alliance*

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Representing all people in Berkshire West affected by a neurological condition

**Report for Berkshire West Long Term Conditions Board.**

**Findings from a focus group held on Monday 16<sup>th</sup> May 2016**

**‘My Experiences of Caring for Someone with a Neurological Condition’**

**Purpose**

The purpose of the focus group was to identify real-life experiences of being a Carer looking after someone with a neurological condition and to identify recommendations to service providers to improve the experiences of those in such a role.

**Background**

The economic value of the contributions made by Carers is comparable to the NHS budget. **See Appendix 2.** Therefore it is important that NHS and Social Care Commissioners have up-to-date local information about the challenges and issues facing local Carers. The NHS Berkshire West CCG Federation Long Term Conditions Board is the focal point for reviewing and developing all NHS long term conditions services in the Western half of Berkshire, linking with the services of other providers, including of Carers’ services.

The Berkshire Carers Service was abolished from March 2016 and was replaced from 1<sup>st</sup> April with a variety of services in each local authority. Web searches on 25<sup>th</sup> May indicate there are new gaps in local provision for Carers, particularly regarding for those Carers needing personal support, which is currently not easy to access.

**Findings**

Those taking part in the focus group reported on a wide range of matters. These are summarised as:

- The caring role is something that arises unexpectedly and is to a varying extent an unwanted role.
- Carers and their cared-for do not always recognise that they are Carers, whereas third parties tend to use the ‘Carer’ tag more freely.
- The caring experience is usually a mix of challenging and often difficult times.
- Relationships can be affected in several ways, ranging from being ‘cut in half’ through to Carers needing to develop and deploy multiple mind-sets.
- The caring role can lead to a wide range of emotional experiences such as: resentment, receipt of abuse, lack of gratitude, loss of shared decision-making, guilt, irritability, loneliness, exhaustion, not coping, worry, low self-esteem or the need to retain identity.

- Carers appreciate variously being able to continue to work or continue to lead their own lives or have time for breaks or time for hobbies to help maintain dignity, self respect and good mental health.
- Carers generally reported the need for good planning skills and resilience, to manage and accommodate change and to keep on top of critical matters such as the cared-for's medications control, hospitalisation of the cared-for or looking after their own health, all in the context of likely increasing isolation and increasing workload and general lack of thanks or appreciation.
- Some Carers are uncertain as to their entitlements.
- Social Services and Carers Services are sometimes excellent but sometimes not. This applies to initial assessments, to follow-ups and to service provision. Carers report a tendency for Social Care to close cases that should remain open in most instances.
- Uneven or undependable quality of care provided by some care agencies is a general concern, requiring stronger monitoring from the authorities.
- Becoming a bereaved Carer potentially introduces a separate set of complex psychological challenges.

## **Recommendations**

1. Information about Carers Rights should be more widely available and be better targeted to all Carers.

2. Social Services in Reading, West Berkshire and Wokingham should work more effectively towards ensuring that:

- All assessments should be conducted more promptly, be followed up thoroughly and be actioned.
- Carers' assessments should be carried out early in the process.
- There should be better continuity of staff involved in delivery of Social Care.
- Carer training should be provided promptly where identified.
- Reassessments should be provided in a timely rather than 'annual' or other random manner.
- Cases should not be closed unless agreed with clients and Carers.
- The overall quality of output from care agencies should be improved through better monitoring and regulation by the relevant authorities.

3. Carers need the opportunity to see the cared-for's neuro consultant at a frequency relevant to the changing needs of the Carer, to ensure best development of what could/should be done in the caring role.

4. Carers should be offered higher levels of psychological support and physical help, including more breaks.

## **About the focus group attendees**

The event was publicised widely through the voluntary sector, but only six people responded and only five attended, despite grants being offered to attendees. It is well known that Carers find it difficult to make time to attend non-essential activities.

## **Format of the Focus Group**

A WBNA Trustee led the discussion. There were two note-takers.

Attendees were provided with a written agenda as below:

- When did you first realise that you were a Carer?
- How long was it before you first approached anyone for help?
- How long was it before you received any help?
- Along the way has your caring role remained the same, or has it changed?
- Have you been treated by everyone in the way you would expect?
- Did you get the information and explanations when you needed?
- How has all this impacted on you, physically, mentally or otherwise over time?
- What would you have liked to have happened differently?
- What recommendations do you have for clinicians, social services, the voluntary sector and other Carers?

Within that framework, attendees determined their own priorities for discussion. The meeting was conducted using minimal prompts.

A transcript of the discussion is shown in **Appendix 1**.

## **Limitations of this Focus Group.**

The experiences raised at a two-hour focus group with only five participants cannot cover comprehensively the experiences of Carers. The themes identified should not be taken to represent the full extent and nature of what it is like to have a Caring role. This report provides pointers for reflection and further work.

For further information please contact John Holt, Liaison Officer at:

*West Berkshire Neurological Alliance,*

2, Clayhill Crescent, Newbury RG14 2NP

Tel: 01635 33582 [johnmholtbsc@aol.com](mailto:johnmholtbsc@aol.com) [www.wbna.org.uk](http://www.wbna.org.uk)

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**Appendix 1**

**WBNA FOCUS GROUP ON EXPERIENCES OF CARING**

Held at the Holiday Inn on Monday 16<sup>th</sup> May, 2016

**Transcript of proceedings**

**Carer 1** cared for his wife with MS for over 40 years and the experience was a mix of mainly good but sometimes very difficult times.

**Carer 2** has cared for a husband with Alzheimer's for the past 5 months. He cannot contribute to a conversation anymore and so the relationship is cut in half.

**Carer 3** has been the Carer for his wife with Parkinson's Disease for the past 11 years. The support he needs to provide has increased very slowly as her decline has been slow and she might not even recognise that he is her Carer.

**Carer 4** has been Carer of her husband with MND for the past two and a half years. He was diagnosed in 2010 and given 2 years to live. She doesn't want to be a Carer but has no option, mainly for financial reasons. Her entire time is taken up with caring and worrying and becoming resentful. She does not find caring easy. He does not co-operate. He will drop things on the floor and expect her to pick them up.

**Carer 5** considers that she is not a Carer yet, but works with a lot of people who are Carers. Others present considered that she could be in the early stages of being a Carer.

**Carer 1** did have other options but chose to be a Carer. His wife was partly funded by a care package, but he worried about the unreliable care being given and over a 30-year period had to sack three agencies.

**Carer 3** does a defined minimum to encourage wife to do as much for herself as possible.

**Carer 4's** husband was always very active and now gets very frustrated that he can't be independent. Takes it out on his wife and is often very angry with her.

**Carer 2** has a similar problem. Her husband complains of being trapped as he no longer has a driving licence but he will not help himself.

**Carer 1** Always tried to involve his wife in shared decision-making but progressively had to take over things like shopping and cooking; everything. Shared decision making became progressively more difficult. He became aware that Social Services referred to him as a 'Carer', but that was an unfamiliar tag.

**Carer 2** became a Carer was very quickly and had to take over everything somewhat suddenly despite being not well herself. She feels guilty because she gets so irritable with him and feels put upon and lonely.

**Carer 3:** Having a break from caring is very important. You need people coming in, like a cleaner or friend to keep your wife company for a bit.

**Carer 1** agreed. It is very important to have time for yourself. In his case he had taken one specific night of the week off to pursue his hobby, which he regarded as sacrosanct to retain his dignity and sanity.

**Carer 1** said his wife had occasional crises which he dealt with in his own way. He said he lived 3 lives: 'my' life, 'her' life and 'our' life' and when she died he spent weeks trying to sort out multiple losses and gaps. In addition, he had developed a way of splitting his brain into two modes – 'husband' and 'Carer'. He knew he had to look after 'me' so that he could care for wife. This was the 'false' set of mechanism by which he survived.

**Carer 4** works part-time, which is both a relief and a necessity. She tries to take her husband out as often as possible but gets angry with him as he does not help himself. He is not keen on using a computer but is beginning to use one to be able to communicate. He used to have his own repairs business and was a very handy person, but now he can't use his hands – however, he can give advice, which helps his self-esteem! He likes collecting catalogues to give to people and doesn't understand that people work on line now – wife realises that she has to accommodate his whims.

**Carer 3** explained that in Parkinson's, medication is a big problem where a patient has 'on' and 'off' periods. Patterns of movement are so dependent on the medication being correctly administered and managing this well is a main concern to him.

**Carer 1** said his wife had recurring and seriously life-threatening problems as well as the MS, requiring contingency plans to get her into hospital very quickly and then plans to get her out fast because she was not well enough to stay long in hospital. He needed to do a lot of pre-planning and plan-changing.

**Carer 5** said that often after a prolonged period of intense caring up to the spouse's death, the bereaved Carer can experience considerable health problems like chronic fatigue syndrome, sometimes 6 months or so after the loss of the person cared for.

**Carer 2** said someone from Elderly Care came to see them for assessment but they have heard nothing since. She hasn't had a Carer's assessment and as far as she understands, their case is closed. Why?

**Carer 3** An Occupational Therapist came in to do an assessment and highlighted his wife's balance problems and then Social Services told them where to buy handles/new bed/grab rails etc. Nothing was supplied by Social Services.

**Carer 4** said Reading Borough Council have been very helpful and grab rails were supplied free of charge. The Occupational Therapist has been particularly good supplying a riser/recliner chair and hospital bed and she rings periodically to check that they can still cope.

**Carer 3's** experience has been very different in West Berkshire. 'To ensure your insurance is valid, something you need immediately, you have to get an OT assessment – but this took 6 months!'

**Carer 1** said that he and his wife were supposed to have an annual assessment, but timing was erratic and it was always a different assessor and the assessment form kept changing, so it was a poor system.

**Carer 3** asked 'what are we entitled to?' He has no idea.

**Carer 1** Everyone is entitled to an assessment and a Carer's assessment. However, at what point does something snap and become critical? If a Carer becomes ill, things became critical.

**Carer 2** feels her caring role has had an adverse impact both physically and mentally and is worried about what would happen if she became ill – 'who would feed the dog and cat?'

**Prompt:** *Has your caring role changed?*

**Carer 1's** role changed a lot over the decades. His wife was always calm which made things easier. He didn't look after himself physically and after his wife died he felt he had changed psychologically, partly for the better, partly otherwise.

**Carer 3** is critical of support from the National Office of PDUK. The specialist nurses at HQ are not helpful with specific questions and refer him to the local nurse specialist, but generally they are not available.

**Carer 4** is registered with Carers from Reading Council but hasn't had an assessment yet.

**Carer 4's** caring role leads to her becoming very tired because of all the physical help she needs to give. She does the PEG feeds, works 2 days a week and then has all the cleaning and other chores to do so is physically exhausted by the end of the day. She is becoming very concerned how she will continue to cope. She feels in limbo – 'when will the crisis come?' It is so difficult to plan and she is becoming psychologically badly affected. She also worries about her husband's quality of life.

**Carer 4** said that her husband went into Duchess of Kent House for four days to enable her to get away and it was 'an absolute blessing to have that break'.

**Prompt:** *What Recommendations would you make?*

**Carer 1** Care assistants from care agencies need to be better trained. This would remove numerous pressures from Carers.

**Carer 5** A person living with Motor Neurone Disease, living on her own and dependent on Care agencies says she has a 'permanent headache' with the worry of inconsistent Carers.

**Carer 3** needs to see a consultant more than once a year and there should be follow up especially where medications have been changed.

**Carer 3** would like to know what are his entitlements as a Carer.

**Carer 4** is very grateful for all the help received thus far from the NHS, Social Services and the MND Association but is very concerned about the future and consequently frequently suffers from a stress headache.

**Carer 4** had no complaints about the help she has received.

**Carer 4** is physically exhausted and feels guilty about thinking of his death.

**Carer 2** Her husband saw a psychologist at Beechcroft but there was no follow up appointment – why not? There is an Alzheimer's Course which is supposed to be good.

**Carer 5** would like people, in particular those with deteriorating neurological conditions, to have a consistent Occupational Therapist and Social Worker and their case should never be closed.



## WBNA FOCUS GROUP ON EXPERIENCES OF CARING

### Appendix 2

#### Valuing Carers 2015

***The rising value of Carers' support*** is the third in a series of research reports looking at the value to the UK economy of the support provided by unpaid Carers. The report is a collaboration between the University of Sheffield, University of Leeds and Carers UK.

Valuing Carers 2015 found that:

- The economic value of the contribution made by Carers in the UK is now £132 billion per year, almost double its value in 2001 (£68 billion).
- £132 billion is close to the total annual cost of health spending in the UK, which was £134.1 billion in the year 2014-2015.
- The value of Carers' contribution is growing, primarily because Carers are providing more hours of care and partly due to the increased hourly cost of paid home-care. Carers are providing more care because:
  - our ageing population means that more people in the UK are needing care for longer
  - support services are not keeping pace with the UK's increasing care needs, meaning that families are having to step in to fill the gap

The funding for this research report has been provided by Healthwatch West Berkshire's Community Engagement Programme (CEP) grant scheme. The CEP grants ranged from £500-£3000, and were specifically reserved for research relating to vulnerable, hard-to-reach groups or where there is a health or social care issue that is problematic, or not working as it should. The research had to be evidence based, with outcomes that can be used to highlight and develop suggestions for service improvement.

Carers are a priority area for Healthwatch West Berkshire\*. This report successfully highlights issues for carers of people with a neurological condition, who we would also consider to be in the category of 'seldom heard voices'. Though a small sample of carers, it highlights some specific issues that we hope both the Long Term Conditions Board and Adult Social Care Services will take on-board and aim to improve in the coming months in line with the Care Act (2014).

The Care Act (2014) increased the rights of carers so that their health is just as important as those they are caring for. The importance for carers' views and experiences to be heard and acted on is clear, in order to reduce health inequalities for people who provide unpaid care for people who couldn't manage without their help. This report highlights the need for carers' rights to be more widely available and for carers' assessments to be managed more effectively, as well as more specific issues relating to the members of the focus group used.

\*You can view Healthwatch West Berkshire's priorities and current workplan, which have been developed through our Champions board, local feedback and other local Clinical Commissioning Group (CCG), Local Authority and NHS priorities on our website:

<http://www.healthwatchwestberks.org.uk/publications/>

## *West Berkshire Neurological Alliance*

### **About West Berkshire Neurological Alliance**

The Alliance is an umbrella organisation for neurological voluntary groups, patients and carers covering the Local Authority areas of Reading, West Berkshire and Wokingham, an area also known as NHS Berkshire West. The Alliance conducts research using a range of methodologies into the experiences of local people living with or affected by neurological conditions. This is the Alliance's fifteenth Focus Group report.

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Tel: 01635 33582 [johnmholtbsc@aol.com](mailto:johnmholtbsc@aol.com) [www.wbna.org.uk](http://www.wbna.org.uk)

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