



***'IN SICKNESS AND IN HEALTH'***

**A HERTFORDSHIRE SNAPSHOT**

**Taken June 2012 for Carers Week**

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## INTRODUCTION

Carers Week is when we ask everyone to recognise and celebrate the contribution made by unpaid carers to the people they care for and their communities.

The theme of Carers Week 2012, was “In Sickness and in Health”, words familiar to many from the wedding vows, but this is caring far beyond that.

Especially for Carers Week, *Carers in Hertfordshire* undertook a short survey of 377 local carers. Their responses provide a closer snapshot of how caring affects the health and wellbeing of carers in our county. The findings of the local survey are reported here and set in the context of the findings from a national survey of carers<sup>1</sup>, reported during Carers Week.

In Hertfordshire, it is proposed that carers will be a priority group of residents to benefit from the county’s Health and Wellbeing Strategy. If there is question about that, then the evidence of Carers Week is clear: caring adversely affects many people’s health. If we don’t support carers there will be two patients instead of one and more cost, in every sense, to everyone.

### **We can act together in Hertfordshire to improve support to carers.**

At the culmination of Carers Week 2012, in a “construction exercise”, *Carers in Hertfordshire* invited 60 carers to demolish barriers that prevent supported caring and to construct a wall of carers support. The suggestions carers have made will be used by *Carers in Hertfordshire* to inform the project development later this year of “carer friendly community and hospital” and to inform and encourage everyone to take appropriate action to improve support for carers.

## SNAPSHOT SURVEY

*Carers in Hertfordshire* emailed 2000 carers to enquire if caring had affected their health and to tell us about the impact caring has. We asked carers if their GP knew they were a carer. We also asked carers to tell us their use of social service support and of any changes to the level and cost (to the carer) during the past twelve months. Finally, we wanted to know if carers experienced actual physical harm/assault or the threat of it.

We received 377 responses; a response rate of 19%. (323 responses by email; 54 by post)

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<sup>1</sup> In Sickness and in Health, 2012 Carers Week (<http://carersweek.org/about-carers/in-sickness-and-in-health>)

## FINDINGS

### Snapshot Survey 2012



TOTAL: 377 Carers

- Stress and anxiety: 88%
- Disturbed sleep: 63%
- Depression: 47%
- Back/joint damage: 46%
- Weight/eating disorder: 36%
- **63% reported 3 or more health factors: “vulnerable carers”.**
- **14% reported actual/risk of physical harm.**



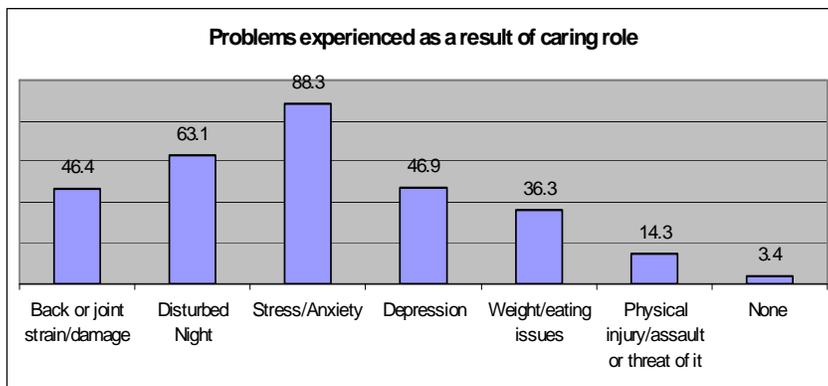
Almost two thirds of the carers in our survey reported that caring had affected their health adversely in three or more ways. Throughout this report these carers will be referred to as “vulnerable carers” because their own health is suffering significantly as an impact of caring.

The prevalence of problems experienced as a result of the caring role is shown in the graph below, expressed as percentages of the total number of respondents.

### Q1: Do you experience any of the following problems as a result of your caring role?

#### Carers Health Issues

(as % of the total responses: 377)



## Q2: Are you registered with your GP as a carer?

If **yes**, what benefits does that bring?

### Nothing registered, nothing gained? GPs



- Registered as a carer with their GP: 63%.
- Just under half (47%) of those registered as a carer reported that there was no benefit to them.
- Of the half that did report some benefit, the majority reported “flu jab”, but just under a quarter of carers said “flexible appointments” as well.

#### The “vulnerable carers”:

- Two thirds of vulnerable carers were registered with their GP as a carer.



We know from Hertfordshire NHS Primary Care Trust audit reports that almost all GP surgeries in Hertfordshire have established carer registers. Two surgeries in Hertfordshire have won national awards for carer support in recent years. Yet 47% of respondents registered with their GP as carers, reported that they received no benefit from that. In contrast, 21% of carers in our survey reported that they experienced two or more specified benefits from their surgeries (annual health check; quicker to get appointments or an annual flu jab).

#### Snapshot study

*67 year old woman caring for her husband, who has Lewy Body Dementia, Parkinson's disease and COPD (Chronic Obstructive Pulmonary Disease). She also cares for her neighbour who has cancer and Parkinson's disease.*

She described the health impacts of caring as: back/joint damage and disturbed sleep. She is registered with her GP as a carer and naming her doctor, described that the GP had given her “lots of support” as well as ensuring she has a flu jab. She is supported by *Carers in Hertfordshire*; Age UK and Crossroads.

However twice as many carers reported no benefit from being registered as a carer with their GP (47%). It appears that some surgeries are able to utilise the information they have that a patient is a carer to better support the individual; whereas others fail to do so. There is clearly inconsistency amongst GP surgeries in their response to carers and scope for improvement if we wish to improve support and prevent carers' ill-health.

### Q3: Do you or the person you care for use social care service/s?

#### Use of social services



- 50:50 used or did not use social care services.
- Level of service in the past twelve months: quarter had an increased level of service and 19% had reduced level of service.
- 49% paid more for their service and only 8% had charges reduced.

#### The “vulnerable carers”:

- Slightly more than half of vulnerable carers used social services.
- 22% of the vulnerable carers had a reduced care package in the past 12 months.
- Around a quarter of vulnerable carers using social services were not registered as a carer with their GP.



We asked those carers who used social services whether or not their care package had changed in the past twelve months and also about the costs.

#### **22% of the “vulnerable carers” reported a reduced package in the past twelve months.**

What we cannot say from this analysis is whether there is a link between increased service costs and reduced care packages, but anecdotal evidence from carers would suggest that it would be worth further enquiry.

#### **Snapshot study**

*Female carer of her husband who has Motor Neurone disease.*

She described the impact of caring on her health as: back/joint damage; stress and anxiety; disturbed sleep and depression.

She doesn't know if she is registered as a carer with her GP. Level of social service support reduced during the past twelve months and payment reduced to zero.

#### **Snapshot study**

*40 year old parent of a child with Prader-Willi syndrome - severe physical and learning disabilities from birth.*

She described the health impacts of caring as: disturbed sleep; stress and anxiety; physical harm/threat.

She uses direct payments, “but I never hear of any follow-up”. There had been no change in her social care support in the past twelve months. She is registered with her GP as a carer but felt she received no benefit from that.

## Snapshot study

83 year old carer of husband who has had a stroke and has vascular dementia.

She described the health impacts of caring as: disturbed sleep; stress and anxiety; back/joint damage.

She is registered as a carer with her GP surgery, which responds quickly to provide her with appointments. She uses social care services and the level of support has increased in the past twelve months. She is currently waiting for a financial assessment to facilitate her husband's attendance at a daycentre to give her a break.

## At risk of harm as a result of caring

**At risk of harm**



14% of carers reported that the impact of caring was that they experienced, or risked, actual physical injury/assault

- A worrying number, as traditionally under-reported.
- Risks arise from a number of factors.
- 61.1% are using social services.



This figure is worrying, particularly as respondents are often unwilling to report their vulnerability because of the stigma associated with being subjected to harm, from another person.

Physical harm may or may not be intentional. For example, one respondent described that he had suffered actual physical injury from his wife “crashing” upon him during epileptic seizures.

The carers research literature suggests that harm can be experienced as a carer, as a result of a number of different factors, e.g.

- Carers managing aggressive behaviour.
  - Carers not knowing how best to manage someone with bizarre behaviour.
  - Accidental harm as a result of the lack of physical control in the person receiving care.
- And it can also be as a result of abuse in the caring situation.

Earlier this year, *Carers in Hertfordshire*, with our partners, designed and delivered the first Safeguarding course, targeted specifically to family carers. The snapshot survey suggests that there is need for such a course. Two thirds of the 58 respondents who experience or are at risk of harm were also receiving support from social services, which provides an opportunity to consider and review risk to carers in the carer assessment process.

We did not extend the analysis to find out if respondents experiencing actual or risk of harm were known to their GPs as carers, but, generally it is important that GPs and primary health workers are aware of the risk and can respond appropriately.

The findings of the national survey: *In Sickness and in Health*, conducted on behalf of the eight partners in the Carers Week Alliance place our Hertfordshire snapshot in a wider context.

## The national picture



Survey of 3,400 carers.

- Caring had a negative impact on physical health: 83%
- Caring had a negative impact on mental health: 87%

*“I have had many stressful jobs in my working life, but I have never experienced such stress as caring for somebody with dementia. No matter how rewarding some times are and how much you love the person you care for, there are moments when you wonder why you started and why you continue.”*



The figures in the box below provide some direct comparisons between local carer findings and the national findings. In the comparison, Hertfordshire carers were significantly less likely to be registered with their GP as a carer; but the same percentage were offered a health check.

## More of the national picture



- 52% are sleeping less (Herts:63%)
- 34% are exercising a lot less as a result of caring
- 39% put off medical treatment because of caring
- 84% known to their GP (Herts:63%)
- 23% offered a health check (Herts:21%)

*“As an ill carer I find it hard to fit in rest – I worry constantly about finances – and reducing spending. Worried that there is never anyone to contact if I’m unable to care. I’ve worried the whole time I’ve been a carer - 29 years. What of the future? I dread to think.”*



## What makes a difference?



- More regular breaks (61%)
- More advice and information (43%)
- More financial and practical support (52%)

Increased understanding and support from GPs and healthcare staff, including regular health checks (36%).

Increased support in the workplace:

Flexible working (49%); Knowing your rights (45%);

Access to emotional support (44%); a champion and signposting to advice (40%)



The information in the box above is also taken from the national findings.

## CONCLUSIONS – A Call for Action

- 1 Caring has an adverse impact on the health of many carers. Further action is required to prevent carers' ill health and enable them to continue to care.
- 2 *Carers in Hertfordshire* must increase the uptake of core services that benefit carers' health and wellbeing.
  - a) Information and Carer Planning Service.
  - b) Safeguarding and Caring with Confidence courses for carers.
- 3 Hertfordshire NHS and primary care services must:
  - a) increase primary health service awareness of carers and their responsibilities to support them, particularly to reduce the risk of harm;
  - b) address the inconsistency in GP/primary service response to carers and ensure all surgeries use carer registers to provide benefit to carers;
  - c) use the Make a Difference for Carers Service <sup>2</sup> and carers' breaks services to reduce risk of care anxiety, stress and depression.
- 4 Hertfordshire County Council must ensure that social care providers with responsibility for undertaking assessment of carers are:
  - a) aware of the risk of harm;
  - b) are knowledgeable about support available to carers and ensure carers have a regular break from caring and the option to develop "Back up Plans" to reduce anxiety.

<sup>2</sup> Make a Difference for Carers Brokerage Service, *Carers in Hertfordshire*  
Hertfordshire Snapshot Report June 2012, prepared by *Carers in Hertfordshire*

Conclusions continued

- 5 Further work is required to address the problems resulting in carers' sleep disturbance in order to ensure support is available to address the impact of lack of sleep on carers' health, wellbeing and resilience.
- 6 The "whole system approach" identified in the Hertfordshire Commitment to Carers<sup>3</sup> must be implemented to provide a holistic response to carers and to ensure integrated services to support carers.

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<sup>3</sup> Hertfordshire County Council  
Hertfordshire Snapshot Report June 2012, prepared by *Carers in Hertfordshire*

**The Carer Paradox:**

*-- they (Carers) feel obliged to care but not to be cared for. Everyone needs a break, don't they: but who takes over care for the carer when the carer's not there?*

***Lady (Jill) Pitkeathley***

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