

THE FIRST REPORT  
WHICH GIVES AN  
INSIGHT INTO THE  
IMPACT &  
EXPERIENCES OF  
CARERS IN BRENT.

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IT HAS BEEN WELL  
EVIDENCED THAT  
CARERS SUPPORT  
PUBLIC SERVICES  
BY PROVIDING  
CARE WORTH £132  
BILLION EACH  
YEAR.

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SUPPORTING  
CARERS NOW AND  
IN THE FUTURE IS  
ESSENTIAL FOR  
NOT ONLY OUR  
ECONOMY BUT  
ALSO FOR THE  
WELL-BEING OF  
BOTH THE CARER  
AND THEIR  
DEPENDENT!

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CARERS UK'S  
STATE OF CARING  
SURVEY 2016  
FOUND THAT:

- In 3 carers 29% reported having an assessment in the past year had to wait six months or longer for it.
- Over 1/3 of carers 39% looking after someone at the end of their life had to wait six months or more for an assessment.
- Almost 1/4 of carers 22% had to request an assessment for themselves over the last year instead of being offered one.

Check it out: [carersuk.org/stateofcaring](http://carersuk.org/stateofcaring)



# The Brent State of Caring Report 2016



*“Respite - a proper break from caring remains the number one priority of need for unpaid carers”*

*Carers in Brent save the economy perhaps the same value as the cost of running Northwick Park Hospital!*

*The impact of caring has a major impact on the health & well-being of carers’, this is understandable as approx. 90% of carers’ care full time (min of 39hrs & more weekly) for over 10 years!*

## Introduction

Brent Carer’s Centre have been supporting carers for over 20 years in the borough. During this time we have seen many changes in the landscape of carers and the support available, but one thing has remained constant and that is the regular numbers of new carers being registered year on year.

Carers UK is one of two major campaigning charities at the forefront of the carers movement, working hard to bring carers together to have a voice and deliver change. A key aspect of their work is their ground-breaking research on the reality of carers experiences, ensuring their voices reach decision makers at the highest level to influence change.

‘The State of Caring Report’ undertaken annually by Carers UK, presents a national picture based on real experiences of what

life is like for carers. Whilst this data is extremely useful, through my networking and outreach with other Carer Centre’s facilitated by Carers Trust, it became apparent that each borough or region may differ in the range of support services being delivered to carers.

This made me reflect on whether the national report reflected the real experiences of Carers in Brent. I also felt it would be a useful exercise for key stakeholders to have some useful local data and feedback on carers, which previously has not been available in the borough.

Brent Carer’s Centre ran this localised survey for approx. 9 months during 2015. 163 carers responded.

**Anne-Marie Morris, CEO  
Brent Carers Centre**

## Summary of Findings

- 11% reported that they had never had any break from caring.
- Approx. 53% have been caring for someone for over 10 years.
- 67% of respondents who answered stated their health was worse as a result of caring.
- More people caring for someone with a mental health condition over 36%
- 43% of carers are caring for someone over the age of 75.
- 49% of carers cared for a son or daughter, with near 35% caring for a parent, with a further 19% caring for their partner.
- 69% of carers felt more stress, with 63% finding it difficult to get a good night’s sleep.
- Nearly 75% lived in the same house of the person they cared for.

## Summary of Findings cont'd

- Only 15% of carers work full time with a further 13% working part-time. *“Health Checks undertaken resulted in nearly 70% of those carers receiving medical treatment & helpful advice”*
- 32% of carers have had to give up work, 13% were able to reduce their hours, with 9% retiring much earlier than they would have wished to.
- Over 48% of carers are struggling to make ends meet.
- 64% of carers did not receive a flu jab. Of those who did, only 22% were offered a jab because they were a carer, with 28% requesting a flu jab.
- Pharmacist were ranked the highest as being carer friendly in Brent with GP’s following in second place with an 8 percentile points difference between the two.

## Recommendations

- Improve partnership working with Adult & Children Social Services, Health Services, Schools and voluntary & community services to increase awareness and appropriate response in meeting carers needs and signposting to support available.
- To develop a Carers’ Strategic Partnership Board to improve joint working, communication and commissioning of carer support and services across the borough.
- To redraft and update the Brent Carers 2014 Strategy, to be reviewed annually by the Carers’ Strategic Partnership Board.
- GP’s need to improve on identifying patients who are carers to offer them flu jabs and health checks annually, this is an important tool in maintaining their well-being, as well as signposting them to support available.
- Improve mechanisms whereby complaints are used to improve services, rather than services being declined or withdrawn from a carer.
- Brent Carers Centre to build on the greater role that pharmacies can play in disseminating & displaying carer information in the community.
- The implementation of robust quality assurance in the provision of social care.
- Explorative research on the different kinds of help & care proven to reduce hospital admissions.
- Working collaboratively towards building a more carer friendly London Borough of Brent.

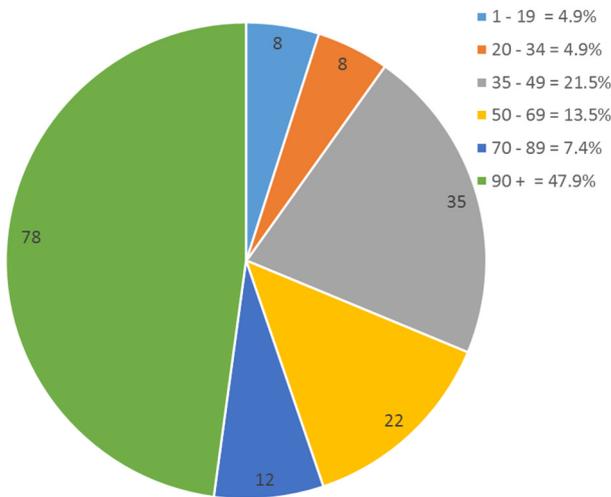


## Length of Time Caring

Most carers have been caring for many years, over half for more than 10 years, with a further 31% for more than 15.

**Most carers’ provide unpaid care for many years!**

# Hours Caring per Week



For almost a half of carers 48% it is in effect more than a full time role, since they provide 90 hours or more of care per week; a further two fifths 42% provide the equivalent of a heavy full-time job, that is between 39 and 89 hours. This clearly has implications for the health, well-being and finances of the carers. For only 10% of the respondents, did caring responsibilities take up less than 34 hours a week.

# Relationships

Caring is overwhelmingly a family affair; less than 2% looked after a person to whom they were not related.

The largest age group being cared for were those over 75 (43%) followed by the young (23% under 18 and 12% aged 18 to 24) This is reflected in the fact that three quarters live in the same house as their carers. A quarter live in their own homes and a few, less than 10%, elsewhere.

# Health Conditions of the Cared For

Those in need of care suffered from a wide range of conditions of which the largest groups were those categorised as having mental health issues (36%), followed by those with a physical disability (31%) and Long Term Health Condition (29%).

**CARERS COMMENTS:**

*“Mum needs assistance and support with every aspect of daily life, up to and including constant prompts to eat, drink, swallow.”*

Medical Condition	Percentage	Count
Physical disability	30.67%	50
Mental health	36.20%	59
Learning disability	20.86%	34
Autism	21.47%	35
Needs that arise from being older	21.47%	35
Dementia	19.02%	31
Neurological	7.98%	13
Sensory impairment	8.59%	14
Long term health condition	28.83%	47
Cancer	5.52%	9
Substance misuse	6.13%	10
Complex Health Conditions	20.25%	33
Palliative or end of life care	0.61%	1
Other	9.20%	15

# Type of Support Carers Provide

Most carers provided more than one kind of care and support. Almost all, 86% gave practical support, 75% provided emotional support of some nature; 73% were involved in arranging or co-ordinating support, appointments, etc.; two thirds helped with medication, from making sure that pills were taken to changing dressings or giving injections; more than half, 58% gave personal care.

**CARERS COMMENTS:**

*“Preparation of special diet meals and working out how to get nutrition & fluid intake right. Monitor and replace bowel prolapse. Given the very individual nature of Parkinson's, thinking up strategies, games, exercises and tricks to maintain mobility and get around physical problems. Compiling meds and supervising carers, who administer most of the medication during the day.”*

**CARERS COMMENTS:**

*“I have asked on two occasions, but nothing has happened”*

*“I have filled in a few, but never hear back.”*

*“I did phone social services once, but was told quite firmly that help was unlikely and I could phone back for a telephone assessment”*

## Carers Assessments

A carers assessment is recognised as an important tool in identifying carers in need of support, with the proviso of providing support and respite to maintain their physical, mental health and emotional wellbeing as well as any interests they may have in pursuing work, education, training or recreational activities. It was therefore surprising to learn how little help and support that carers reported receiving. Just over 36% of respondents had had a carers assessment, over half had not - 55%. Some 29% had never requested one but of those who had, 10% had been refused. 50% of those carers who stated they had been refused stated so, on the basis that nothing had come of their request.

## Care Support

Over half of practical support came through the provision of equipment 32% or technology 21%. Just over a fifth had a care worker coming in to help and this was almost matched by the assistance received from family and friends. 34%, however, reported that they received no help at all. In only 11% of cases did the cared for have access to a day care centre. 43% of carers stated that the amount of care or support arranged by social services was reduced; 17% of carers stated that support had increased because their needs had increase, Only 11% of carers had received a break from their caring role.



**Only 20% of carers receive care support, however 33.55% reported they receive no support at all.**

## Social Services

Almost half of the carers (47%) had no experience with social care services. Of those who had, the largest group (17%) described it as of a mixed quality, 17% thought it was good or excellent and 13% that it was bad or terrible. 14% had stopped or refused a service because of concerns over quality. Comments made suggest that the other 86% were not necessarily satisfied; some simply did not use them; others were considering refusing them while others were too desperate to take this course of action. Surprise was expressed that Brent Social Services, when they were drawn to their attention, did not respond to the reports of poor care, neglect and lack of time-keeping on the part of staff that they were paying for. 70% of carers reported that there had been no change in the amount of care or support that they or the cared for were receiving but comments revealed a concern that the quality was reduced.

**CARERS  
COMMENTS:**  
"We have had bad carers, but also good ones & this affects us emotionally"

### CARERS

#### COMMENTS:

*"Perhaps the illness couldn't have been prevented, but I do wonder whether I had got so tired I hadn't noticed that she was becoming ill. If so, earlier treatment might have prevented a crisis and hospital admission."*

## Health Services

Carers have frequent contact with medical authorities. Their main recourse is to GPs in normal hours or walk in centres (73%), district nurses and out of hours GPs (55%) in addition 21% used the 111 telephone service 8% used the NHS website. 30% went to see their pharmacist with over half having used either hospital A&E (34%) or the 999 emergency telephone services (24%). 52% of those being cared for had been admitted to emergency hospital services in the last three years and of these, 56% were in the last year.

It would appear that there is still much to do on the part of the various authorities to ameliorate not only the lives of patients and their carers but also these authorities themselves. For example, while 40% of the respondents thought that these emergency admissions were unavoidable, 60% believed that, with more or different kinds of help and care, these could have been avoided.

## Carer Friendly Services

It was disappointing to learn how few places are considered very user friendly by carers, though the figures are improved if the 'quite user friendly' is included. Thus GP surgeries are rated 26% and 33% respectively and hospitals 19% and 34%. The Social Services came out worst with 18% and 29% with almost a fifth considering them to be either not very or not at all user friendly. Pharmacists with 34% and 33% are the most highly rated. They are also widely used for ordering, collecting and delivering prescriptions and for advice on medication. These figures are borne out by the later responses about the least user friendly services and organisations where care and support services (18%) vied closely with GP (17%) and the workplace (17%).

## Carers Health & Wealth-Being

Half reported that their health had made it more difficult for them to carry out their caring role, 44% stated that caring had had a negative impact on their physical or mental health, 25% on their relationships with family & friends or caused them financial loss.

The responses to questions on health and well-being confirm what is known about the negative impact on carers. Over two thirds 67%, reported that their health was worse and 29% that it made no difference. 69% felt more stress, 63% found it difficult to get a good night's sleep, 60% felt more anxious, 33% suffered from depression. 36% reported that they neglected themselves, finding it difficult to maintain a balanced diet with 45% getting less exercise. 29% had experienced an injury or their personal health has suffered.

Where medical help is available, carers may not necessarily access it. For example 64% had not had the flu jab. Of those who had, 44% did so at the suggestion of their GP, with approx. half because they were carer and half for other health reasons. 29% asked for it themselves. 27% of carers did not know that they were entitled to one. Over a third 67% had not had an NHS health check. Although 74% said that they were likely or very likely to accept if invited to have one, 23% had not taken up the offer for reasons related to their caring roles, either of time or cost or of work.

*Of those carers' who did receive a health check, 68% reported that it had resulted in further medical treatment and/or useful advice.*

## Work & Employment

Carers confirmed what is already known of the negative impact on their work and careers. Only 15% work full time and 13% part time. 11% are looking for work while 37% are full time carers and 11% retired.

Only 4% reported that there had been no impact on their capacity to work. 32% had to give up work, 13% reduced their hours, 9% retired earlier than they would have wished, 5% had taken a less qualified job or turned down promotion, 15% continued to work the same hours but were affected by stress, tiredness and lateness. The reasons given for the above varied, but by far the most important (42%) was the stress of juggling caring responsibilities with work. The remainder came down to a lack of flexibility on the part of others, mainly the medical services and employers and the expense of lack of replacement care.

## Money & Finance

Inevitably leaving work has caused financial problems, even hardship for many carers. Almost half are struggling to make ends meet (48%), 39% cannot afford their bills, 37% cannot afford utility bills or mortgage payments, 20% are or have been in debt. To deal with this carers have cut back not only on luxuries 53%, but also leisure activities 40% and seeing family and friends 29%. They have also cut back on essentials such as food and heating 26%, 16% fell into arrears with housing and utility bills, 32.38% made use of overdrafts and credit cards, 19.42% borrowed from friends and family or taken out a loan 2.16%. As a result 45.39% report that their financial circumstances have affected their health.

Only 10% had no worries for the year ahead. Of the rest 61% worried about the impact of their caring on their health, 51% on their finances, 46% on their relations with their family and friends, 44% on the relationship with the cared for, 53% about cuts to the care and support services, 41% about cuts to social security and benefits and 23% about their ability to both care and remain in work.

## **CARERS COMMENTS - Re: Impact of Caring on Health & Wellbeing:**

*"Having to sleep on my mum's sofa; not right at my age. Waiting for two bedroom property. Hope this will be soon as this is affecting my health."*

*"My role as a carer has had big impact on my life. Sleepless nights, no holidays."*

*"I feel guilty for wanting time for myself, and to myself. I do get support from a sibling, but they are now working."*

*"If I were to find gainful employment in the near future, what would become of my parent? Although in an extra-care facility, they would not get the care they should. Especially if staff are in short supply for whatever reason. I feel guilty for wanting time for myself, and to myself. I do get support from a sibling, but they are now working."*

*"If I were to find gainful employment in the near future, what would become of my parent? Although in an extra-care facility, they would not get the care they should. Especially if staff are in short supply for whatever reason."*

*"Impact on my social life- can't get out as I would choose."*

*"relationship breakdown with my partner & other siblings"*

*"mobility problem: because caring responsibilities are the years entailed a lot of physical carrying and tiring. My discs in the back collapsed and I had emergency Cauda Equina Surgery done with high and imminent risk of being permanently paralysed if I did not. (very rare to be done at my age)"*

*"sleep/anxiety & depression problems"*

*"physical problems - panic attacks, sweats"*

*"I now have diabetes, high blood pressure, high cholesterol, aches and pains. I know this will get only worse as sign of old age. That is life, it happens to all of us!"*

*"I have drunk more alcohol"*

*"That all sounds very negative - my mental health in particular has suffered and I rarely get more than a couple of hours sleep. But, this is more due to the attitude of service providers than caring itself. "Caring" has allowed me to learn a range of new skills and to value my paid job - yes I am facing constructive dismissal - but I actually feel more empowered, confident and motivated to work than ever before ... I feel it's made me a better manager."*

