

Carers Evidence Pack for Westminster

Joint Strategic Needs Assessment (JSNA) Report 2012

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Background

This report

This evidence pack is designed to provide the analytical underpinning that justifies why the Westminster Carers Strategy Action Plan gives priority to the areas chosen and informs our commissioning intentions.

It uses data and evidence from a range of national and local sources. In some cases, available data is relatively old. Early in 2013, new data will be made available from the 2011 Census and National Carers Survey, which will add to the existing knowledge base around carers' needs and inform future action plans.

What is a carer?

The Department of Health defines a carer as "a person who spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, disabled or has mental health or substance misuse problems".

In addition to adults, some children under the age of 18 may be helping to care for a parent or sibling, such as those with a mental health problem, learning disability or long-term physical illness. They are likely to be assuming a level of responsibility usually taken by an adult.

Many carers do not recognise themselves as carers – as many as 65% in the first year of providing care. This makes identification of carers by services challenging.

The value of unpaid care

The health, social and economic value of informal care is huge. In 2000, around two thirds (65%) of the value of long-term care support was provided via unpaid care, with a quarter (25%) from the state and 10% funded privately.

If carers' support had to be replaced with provision from statutory services, it would cost the NHS, social services and other statutory bodies around £34 billion a year nationally, or around £150 million a year in Westminster.

The challenges faced by carers

Carers can often suffer social deprivation, isolation and ill health. They may have fewer opportunities to do the things other people may take for granted, such as having access to paid employment or education, or having time to themselves or with friends. For young carers, it can often mean life chances are severely limited.

Support for carers

Carers require a range of support in order for them to continue in their caring role. They need help maintaining good mental and physical health and independence, and support in accessing the range of opportunities more easily available to others, such as maintaining good health, education and employment. Carers often provide care at significant cost to themselves and neglect their own health needs due to the demands of their caring role. Financial support is also key, as those caring on a regular or substantial basis are often on low income.

Changing legislation

The draft Care and Support Bill (2012) seeks to simplify, clarify and improve social care legislation, so that carers will find it easier to understand what they are entitled to and can access the support they need.

Information on carers' needs

Local understanding of carers' needs is built from a range of key sources:

- The 2001 Census provides information on numbers in the borough providing care locally. This details hours provided, age, gender, and geographical location of carer. Issues around the accuracy of the 2001 Census for Westminster mean numbers may be a significant undercount. Results from the 2011 Census will be made available at the end of the year and will refresh understanding around levels of provision.
- The 2009/10 National Carers Survey provides a rich insight into local provision of care and satisfaction with services, benchmarked against national findings. 275 carers responded to the 2009/10 survey, a response rate of 34%. Results from a refreshed survey will be available in Spring 2013.
- Service data from adult social care provides vital information on how many carers are known to the council, by age, time period and service type. Service data can also tell us about carers' assessments and takeup of direct payments.
- Carers Allowance benefit data illustrates benefit take-up of carers locally.
- National evidence around carers, including published evidence, is very often the most specific information available around needs, given gaps locally.
- Local voice is important in helping to understand motivations and perceptions of carers, and to help plan services. Carers Action is a carer-led forum, co-ordinated by Carers Network Westminster

Gaps in understanding

The biggest gap in understanding carers and their needs is the timeliness of the Census and Survey data. However, new data will be available at the end of this year, which will help shape future action plans.

Another gap is the lack of good quality research studies to help identify what interventions work for carers, and their value for money. Evidence for what to do tends to be based on what carers say they want.

Little is known about the overlaps between carers on different carers databases, and there is little knowledge currently of the numbers on GP systems. Carers locally have talked about having to undergo repeat assessments from a number of agencies. There is therefore currently a gap in the overall understanding of provision locally.

Key points:

- The way information is recorded (e.g. on databases) could be improved and standardised, and collection of GP data could also be developed
- Information sharing across organisations could also be explored (with the carer's permission). This would avoid duplication of assessment of carers' needs and therefore help support them more effectively
- New data from the 2011 Census and National Carers Survey could alter understanding of the pattern of caring locally, once published in 2013. This should be assimilated into future action plans

Identification and recognition of carers

Number of carers locally

Nationally, studies have shown that 3 in 5 people will be a carer at some point in their lives, and that 600,000 people become carers each year, which would be roughly 1,000-1,500 per year in Westminster. Carers are often hard to identify because they do not recognise themselves as carers (particularly in the early stages), may see it as fulfilment of family duties, or may be reluctant to make their needs known.

Locally, the 2001 Census identified around 12,400 Westminster residents providing unpaid care, or 1 in 14 of the total population. This was the 4th lowest proportion in the country. The 2011 Census, released in early 2013, will give an updated picture on changes over the last decade; Census population figures suggest it may be as high as 15,000. Non-residents providing care to someone living in the borough are not captured in these statistics, some of whom will be known to statutory services.

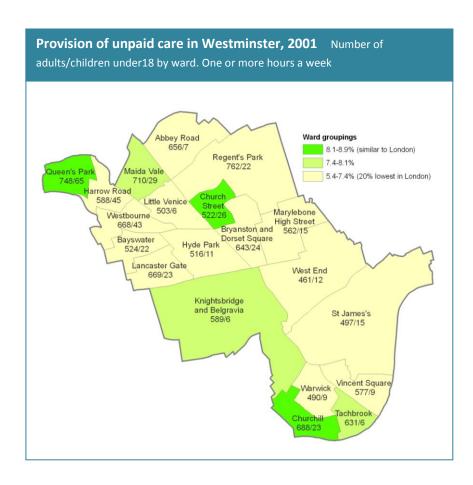
The low number of carers locally may be influenced by the large working age population, many of whom were born outside the country, and the high proportion of residents living alone - it is likely that family members may not live as nearby to each other as in other areas and the high cost of housing which can result in family members moving to less expensive areas.

Between 8-9% of those living in Queen's Park, Church St and Churchill wards provide unpaid care, similar to the London average. These areas have a greater number of families, more social housing, and a higher burden of disease compared to the rest of the borough. The number of young carers is also much higher in these areas.

Providing unpaid care, by number of hours, 2001 Census*

	1-19	20-49	50+	TOTAL
Adults 18+	8,465	1,398	2,123	11,986
All ages	8,786	1,458	2,152	12,396**
% of all residents	5.0%	0.8%	1.2%	7.1%

^{*}Does not include communal establishments. **2011 total estimated to be closer to 15,000 carers



Level of provision of care

Nearly three quarters of those providing care provided 19 hours or less per week, with a quarter providing 20+ hours. Around 2,150 (or 1 in 80) residents provided 50+ hours, the 8th lowest proportion of anywhere in the country. Those in contact with councils tend to have higher levels of intensity, with over four fifths providing 20 or more hours a week, and half providing 50+ hours a week (from Carers Survey).

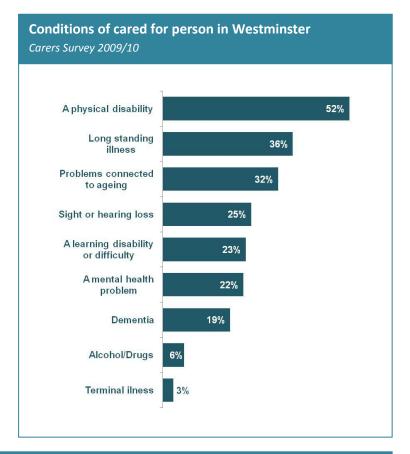
Characteristics of carers

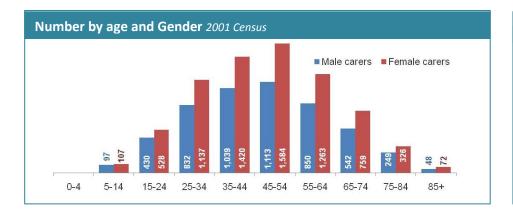
There were 5,200 male and 7,196 female carers identified in the 2001 Census, with women a third more likely to be a carer compared to men in the borough. Caring was most common for those aged 35-54, although intensity of caring increases with age. A local survey identified half of carers providing physical help and personal care, and the majority providing practical help, emotional support and companionship.

What we know about local carers

From the 2009/10 local carers survey of those known to the council

- Nine out of ten local carers care for one person. One third to parents, one third to spouse/partner, and 13% to friends/ relatives
- Half of people cared for are female (49%) and half (48%) are aged 75+
- Half responding (50%) said they were retired, with just 11% in full time work
- Over half of carers surveyed were from White ethnic groups (54%), and the remainder from BME groups: 9% Asian, 11% Black, 16% other BME
- 72% of carers live with those they care for and 28% live somewhere else
- Seven out of ten (69%) had been looking after someone for five years or more
- A half cite a physical disability as the most common reason for care and a quarter cite a mental health problem (higher than nationally)





Tasks carried out by carer in last 12 months Carers survey				
Keeping an eye to see if all right	87%	Help - paperwork/ finances	74%	
Other practical help	84%	Taking him/her out	74%	
Help with care services/benefits	82%	Giving medicines	73%	
Giving emotional support	80%	Personal care	64%	
Keeping him/her company	78%	Physical help	57%	

Carers known to social services

Data suggests that services are only being delivered to a minority of carers in the borough, with 1,110 adult carers in the borough offered a carers assessment or review. This represents around 9% of all likely adult carers in the borough in 2001.

However, comparisons with 2001 Census data suggest the number offered assessment/review has been high compared to London and England averages in the past few years but had dropped to a similar rate to London and England by 2010/11.

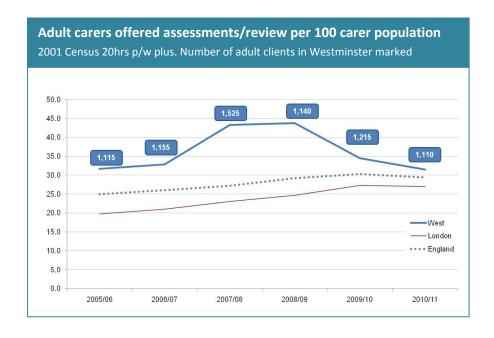
National data suggests that 37% of the caring population started caring during the year, and similar proportions also cease caring. The turnover rises to 44% for those providing 20 hours a week or more. This reinforces the need for services to continually identify new carers.

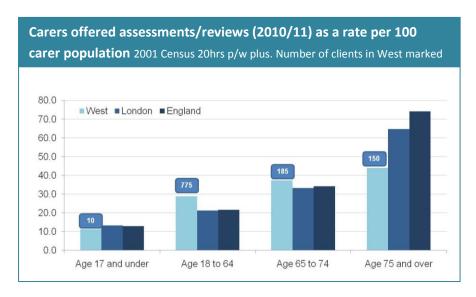
Groups identified by social services

There appears to have been greater success in reaching under 75s than those aged 75 or over – the rate for over 75s was two thirds the national rate in 2010/11.

Carers survey data suggests women are more likely to be known to council services than men, as is the case nationally. Black and minority ethnic groups are more likely to be known than White groups, perhaps due to the lower levels of income and higher levels of poor health in these groups.

There appears to have been good levels of service use and assessment of carers of 18-64 year olds with a mental health condition (190 clients over 2010/11), one and a half times the London rate. The rate for 18-64 year olds with learning disabilities and physical disability was similar to London (with 120 and 130 clients respectively).





Carers known to NHS GPs

One in five (21%) of responders to the 2009/10 carers survey said the GP they see does not know they are a carer. One published adhoc survey among GPs in another region found that less than half of GPs surveyed were confident in identifying carers. Lack of recognition of a person's caring role by health professionals may be hindering efforts to support the health needs of carers and those they care for.

GP practices are required to state whether they have a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment. All but two stated they had one in place in 2012. Whilst carers are coded by GPs on practice systems, there is currently no routine method of extracting numbers of carers known to local GPs, making levels of under-diagnosis unknown.

An increasing need for care

Nationally, it has been estimated that, between 2002 and 2037, there could be a 60% rise in the number of people with a condition usually considered to require care. This is due to increasing numbers of older people and burden of disease.

Better survival rates from advances in healthcare and standards of living, coupled with the ageing of the post war 'baby boom' generation is already resulting in an increasing number of older people and hence a need for care. Current estimates suggest a 14% increase in people aged 75+ locally.

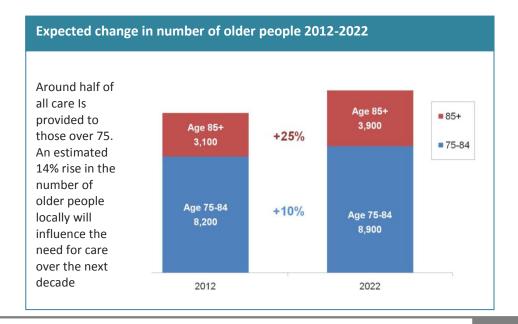
Pressure to provide care will be heightened by the trend towards maintaining independence at home for as long as possible, and changes to thresholds of statutory social care.

Carers known to other services

There are a range of organisations that provide support to carers locally, including:

- Carers Network Westminster
- Westminster Carers Service, providing support and breaks
- Time for me project, Open Age, for carers aged 50+ years
- Six Steps Forward project for carers of people with dementia
- Carers Injury Prevention Service, Central London Community Healthcare
- Stroke Support Service, Central London Community Healthcare
- Westminster Society for People with Learning Disabilities, Family Services Team

In 2011-12, Carers Network Westminster were in contact with over 2,000 carers, providing support, information and advice and administering a carers' breaks scheme.



Estimating the local need for caring is challenging, given the migratory nature of the local population. Using current population projections, it appears likely that demographic change alone may account for an 9% increase in need between 2012 and 2022 (before any service changes are considered).

If caring does not rise to meet this expected need, there may be a shortfall of 1,000 carers locally, with the number of people available to provide care not sufficient to meet the needs of those who requiring care. This may have significant cost implications.

Other factors influencing provision

There are a number of changes to the welfare system which may impact on the need for unpaid care locally and the ability to provide it. For example, Disability Living Allowance is being replaced by a new benefit, with the overall budget reduced.

Expected change	in burden of disease 2012-2022 Based on population
Physical disability or frailty	Expected rise of 9% over next decade due to better survival and baby boom
Sight/hearing loss	Impact among older age groups in particular
Dementia	Expected to rise by 23% over the next decade due to greater number of 85+ year olds. Caring needs for those with dementia are substantial
Mental health	No dramatic change expected
Learning disability	Increasing prevalence and better survival rates into adulthood mean estimated 10-15% rise in adults with profound and multiple learning disability in next decade
Alcohol/ drug dependency	No clear indication. May be influenced by economic downturn

Key points:

- There may be a need to work closely and in a coordinated way
 with a wide range of stakeholders to improve identification of
 carers, particularly new carers. These groups could be voluntary
 groups, the council/councillors, GPs, pharmacies, and hospitals.
- Local community schemes could be considered to identify 'hidden' carers by using local residents.
- The drop over time in numbers of carers offered assessments by the council needs to be understood and, if possible, reversed.
- There is a need to ensure that GP practice staff are aware of the number and needs of carers that may on their practice list.
- The expected rise in those needing care may result in more carers and hence more support needed for them in their caring role. There may be a need to 'mainstream' carer support services to ensure their sustainability into the future.

Personalised support available for carers

Personal support for carers

Three quarters of carers locally stated in the carer's survey that they don't do enough or any of the things they value or enjoy. This proportion is common to carers all around the country and illustrates the challenges involved in caring.

The local carers survey also highlighted that over a quarter of carers aren't able to get the basic services they need, with some feeling it was even a risk to their health (these services could include GPs, dentists, and libraries, for example).

Carers' assessments

Carers' assessments and reviews are an opportunity for carers to discuss their needs with social services, who can then decide what help what services to provide.

In 2010/11, almost everyone offered a carer's assessment had one (99%), with 50% having a separate assessment and 48% having a joint assessment with the person they cared for. The proportion of carers having a separate assessment is slightly higher than that for London (47%) and the proportion declining has consistently been much smaller than London and England.

The number offered and taking up carers assessments or reviews has been dropping since 2008/09, due in part to a change in the eligibility criteria for social care rather than any change in refusal rate. The rate of assessment/ review and subsequent service use is similar in Westminster to London and England, per caring population.

Carers' needs identified in local Carers Survey 2009/10:

	Borough	National
Don't do enough/ any of the things I value or enjoy with my time	75%	77%
Don't have enough/ any space or time to be myself	-	73%
Don't have enough control/ have no control over daily life	66%	68%
Don't have enough/have no social contact with people	59%	55%
Don't feel I have enough/have no encouragement and support	53%	52%
Can't look after myself well enough/ neglecting myself	47%	38%
Can't always get basic services I need (GP, dentist, library etc)/ can't get services and think there is a risk to my health	29%	22%
Have some worries/ extreme worries about personal safety	26%	15%
Would like some training/ need some training	19%	14%

Numbers offering and taking up carer's assessments or reviews over time in Westminster



Information and advice

In 2010/11, 410 adult carers in the borough received a carer-specific service as a result of their assessment and 330 received information.

The proportion receiving a carer-specific service (55%) is similar to London and England (50%) but the rate of carers receiving services per 2001 Census carers population is slightly lower than London and England, due to the drop in numbers known to social services.

Local discussions with carers in Westminster have identified that a range of different approaches should be taken in providing information and advice to carers, in a range of venues, such as pharmacies, supermarkets, and local cafes.

Personal budgets

Personal Budgets, or direct payments, provided by local authorities, can be used by carers to purchase services needed to support carers in their caring role, such as for their health improvement.

In 2011, Westminster City Council and INWL PCT jointly funded a personal budgets scheme for carers, initially on a pilot basis. Under the scheme carers with eligible needs received a one-off payment which they use to purchase services and and support to help them to continue in their caring role and maintain their own health (such as a break, gym membership, driving lessons, or white goods).

At the end of April 2012 over 100 carers had received a personal budget. The findings from the evaulation of the scheme will be available in December 2012 and will provide important evidence on the extent to which it improves outcomes for carers.

Satisfaction with support and services provided *Carers Survey 2009/10*

•	71% of carers said they found it very/fairly	9
	easy to find information and advice about	á
	support, services or benefits	

Similar to average

 88% said they found the information or advice very/ guite helpful Similar to average

 65% said they found it very/ quite easy to get the support or services they need as a carer Slightly lower than average

 73% said they always/ usually felt consulted in discussions about support or services provided Slightly lower than average

Involvement in decisions about care

Carers sometimes feel they are not sufficiently involved in decisions about the person they care for. This is particularly apparent in health settings, such as around hospital discharge planning. Levels of satisfaction were similar in the borough to nationally, in the 2009/10 carers survey, so with significant scope for improvement:

•	Always involved in discussions in hospital	56%
•	Always involved in discussions in GP surgery	61%
•	Always treated with respect in hospital	52 %
•	Always treated with respect in GP surgery	64%

Key points:

- The number taking up carer specific services is now lower than London and England and there is scope to improve uptake, by increasing numbers offered an assessment.
- There is scope to provide more information and advice not only in a range of formats but also a range of settings, including GP practices (e.g. electronic notice boards), pharmacies, libraries and job centres.
- Involvement of carers in decisions about care appears to be similar to nationally, but with scope for further improvement, particularly in hospital settings (e.g. through link workers and hospital discharge planning)
- Improving the provision of information, signposting, and guidance around personal budgets may help publicise the benefits of the scheme.

Employment, training and finance opportunities for carers

Employment & financial challenges faced

Nationally, three quarters of carers (72%) are worse off financially as a result of caring. More than half (54%) of all carers have given up work to care and one in five (21%) have had to reduce the hours they work as a result. Only a quarter of carers who worked were aware of the right to request flexible working.

Locally, over one fifth of responders to the Carers survey stated they were not in paid employment because of caring. Half (50%) had experienced financial difficulties to some extent or a lot in the previous 12 months, the 11th highest proportion of surveyed areas nationally.

National responses to potential barriers to employment: National Carers Survey 2009/10

National Carers Survey 2005, 10

"There aren't enough suitable job opportunities locally" (63%)

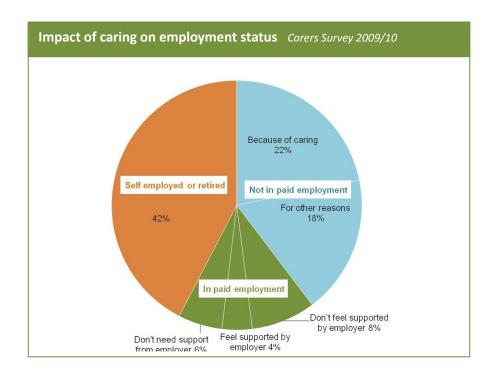
"I am not sure I would be able to work regularly" (40%)

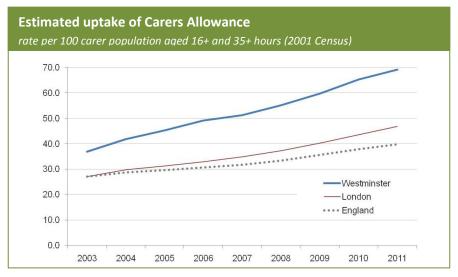
"I cannot work because of my caring responsibilities" 37%)

Carer's Allowance

National analysis in 2009 has identified that only 23% of those providing 35 or more hours a week were receiving Carer's Allowance, suggesting not all carers are claiming the benefits they are entitled to.

In November 2012, 1,970 clients received Carer's Allowance in Westminster, up from 1,400 five years previously. Comparisons with 2001 Census figures on likely number of carers suggests local take-up is much higher than London and England and improving faster over time. Given some uncertainties over carer population size in Westminster, the rate compared to London and England may be a slight over-estimate.





Employment, training and finance services provided

As part of the assessment process, carers and the person they care for both receive benefits checks to ensure that they are receiving all the benefits to which they are entitled. The assessment should also take into account the carer's wishes regarding work and training.

Carers Network Westminster and Job Centre Plus are the main organisations in Westminster that provide work-related support to carers.

In 2009-10 a national initiative, Work Focused Support for Carers (run by Job Centre Plus) was promoted widely in Westminster but there was little take-up with only six carers making inquiries about it and only three attending for an appointment with an adviser.

Gaps in service provision and satisfaction

There may be scope in the future to work with local health and social care organisations and commercial and social enterprises to understand how many carers are employed locally, and encourage greater participation in the workforce. However, there is not enough respite provision at present to enable large numbers of carers to be in full time employment, and the emotional impact of caring has an adverse effect on the confidence of carers to enter the job market.

It may also be beneficial to establish if carers locally are being offered flexible working conditions, in line with the Work and Families Act 2006.

Key points:

- There is a good rationale for continuing with schemes that improve income maximisation and deliver training, given the high turnover of carers, and the challenges they experience. Building strong links between information & advice services and the voluntary sector organisations will ensure good access.
- There may be scope for ex-young carers to access employment opportunities e.g. through volunteering options.
- Improving the provision and signposting of information and guidance on work/training opportunities may help publicise local schemes offered.
- Promotions of concessions to carers could be carried out more
- There is a lack of information on the employment and training aspirations of carers of working age not in paid employment. (could be addressed in Carers Survey, Autumn 2012)
- Promote the rights that carers (and others) in paid work have to flexible working, for example as part of Carers Rights Day

Supporting carers to remain mentally and physically well

The evidence around caring and health

Research has found that those providing care are more likely to be in poor health than those not providing care. Emotional and mental health problems tend to be more often associated with care giving than physical health problems: nationally, carers providing substantial levels of care are twice as likely to have mental health problems as those providing a lower level of care (27% against 13%).

The local carers survey and the 2001 Census both point towards a slightly higher burden of ill-health locally among carers than nationally. The survey identifies 1 in 4 with a long-standing illness, 1 in 5 with a physical impairment or disability, 1 in 6 with sight or hearing loss, and 1 in 11 with a mental health problem. One in five (20%) of local carers rated their quality of life as bad/very bad/so bad it could not be worse and only half (53%) said they looked after themselves.

Local carers reported similar key health impacts of caring as national responders – feeling tired, sleep disturbance and stress.

Health affected by caring role in last 12 months Carers Survey 2009/10 Feeling tired 66% Disturbed sleep 49% 45% Stress Feeling Depressed 35% Physical Strain 34% 32% Irritable Been to see GP 23% Loss of appetite 19% Developed own Condition 15% Made existing condition worse

Evidence around tackling poor health

There is currently a lack of high quality research into what interventions could effectively help improve carers' lives and their mental and physical health. Group-style and family interventions and 1:1 psychological interventions (such as CBT) have been examined with varying outcomes of effectiveness and cost-effectiveness. However, carers tend to demonstrate high levels of personal satisfaction with interventions such as respite care, or 'carer's breaks', and fitness club membership to improve health. This tends to guide what services are provided.

Services provided locally

Carers may require a range of support in maintaining good mental and physical health in order for them to continue in their caring role. The council offers carers breaks of 24 hours or more and rests for shorter periods of time.

Carer specific services in Westminster include: carers personal budgets; carers breaks scheme run by Carers Network Westminster; The carers injury prevention service; carer support groups; carer training sessions; and the carers emergency card scheme.

Carer's breaks

In 2009/10, 1 in 5 responders to the local Carers Survey (22%) said they had used services or support to take a break from caring for more than 24 hours. This was the 12th lowest in the country (28% average). A higher than average number of responders stated that no support or services were available for them. However, there appeared to be higher levels of satisfaction with the support or services than nationally.

A slightly lower proportion of responders (28% compared to 34% nationally) also stated they had regularly used support or services for rests from caring of 1-24 hours, with the perception that services were not available or suitable.

There were similar levels of satisfaction with services or support around rests from caring, with 61% very or extremely satisfied, compared to 65% nationally.

Health checks and health improvement

A number of initiatives have been undertaken over the last two years to raise awareness of the role and needs of carers among mainstream health services. These include: encouraging GP practices to maintain a carer register (all but two practices now do so); encouraging GPs to refer carers to Carers Network Westminster as part of a GP link scheme; and encouraging community pharmacies to include information about Carers Network Westminster when dispensing prescriptions.

Service gaps

The local carers survey found similar levels of support from GPs to carers in their caring role to nationally. However, 1 in 5 responders (21%) said the GP they see does not know they are a carer. National data from Carers UK suggests that 10% of patients on practice lists are carers. Lack of recognition from health professionals may be hindering efforts to support the health needs of carers and those they care for.

Safeguarding

Sometimes carers can cause harm to the person they care for. They can also experience harm from the cared for person. In 2011/12 there were 322 referrals where there were concerns about the possible occurrence of abuse. In about one in ten cases (8%) the alleged perpetrator was the 'main family carer', and in about one in five the alleged perpetrator lived with the victim.

Key points:

- A range of interventions that help reinforce and build well-being may tackle issues of low well-being and low life satisfaction reported among some carers locally.
- There is a need to identify and support carers via GP practices.
- This should involve making the carer register an effective tool, improving information flows, and providing carer awareness training among health professionals.
- The Royal Society for GPs and PRTC have already produced a guide for health professionals that will help facilitate this.
- There needs to be increased awareness of the factors that increase the risk of carers being involved in harm.

Young carers

Number of young carers locally

Locally, the 2001 Census identified around 400 Westminster residents providing unpaid care, or 1 in 66 of the total population under 18.

Providing unpaid care, by number of hours, 2001 Census

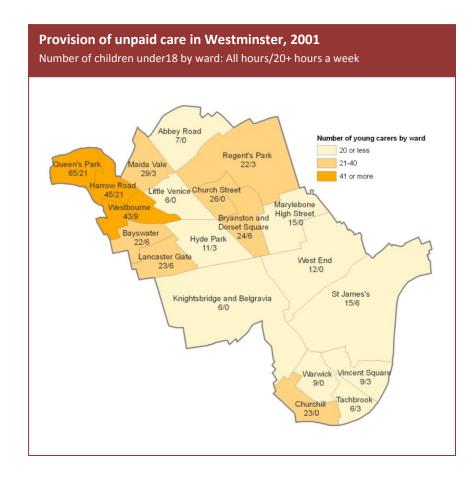
	1-19	20-49	50+	TOTAL
Children <18 providing care	321	60	29	410
% of all <18 population	1.2%	0.2%	0.1%	1.5%

Identification and recognition

Identification of carers is challenging, as young carers don't always identify with the label and often see it as a private matter. There is likely to be significant under-identification of young carers locally.

The Westminster Young Carers Service currently works with about 100 young carers. A feature for Westminster is the high number of young carers from the Bangladeshi community. This is partly a reflection of the make-up of the local population.

To improve identification of 'hidden' young carers, Ofsted (2009) recommends training within a school environment, such as awareness raising days and training of professionals and school governors, as well as data analysis of persistent absenteeism to understand whether this is being caused by having a caring role.



Supporting young carers

Young carers are usually unable to access mainstream activities, due to the demanding and restrictive nature of their caring role. Many support parents who have mental health, substance use and/or physical disabilities needs.

The approach taken by Westminster Council to move towards more joint working between adult and children's services has been encouraged nationally and is likely to result in a broader and more appropriate picture of families needs.

Key points:

- The borough has similar levels of success at identifying young carers as London and England, so there is still likely to be significant unmet need.
- A number of approaches could be introduced to help levels of identification, such as working with schools in identify young carers, and creating a young carers register in General Practice, with healthcare professionals encouraged to ask "is there someone under 18 who helps you at home".
- Healthcare staff may also require information advising them of where and how to refer young carers on to appropriate support services.
- Joint work across agencies and sharing assessments and information will help give a fuller picture of family needs and help the coordination of support

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