

Carers Evidence Pack for Kensington and Chelsea

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 Borough Action Plan gives priority to the areas chosen.

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 £135 million a year in Kensington and Chelsea.

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. 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. 474 carers responded to the 2009/10 survey. 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 take-up 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. Currently a Carers Forum exists in Kensington and Chelsea which meets quarterly.

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 be also 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 Kensington and Chelsea. 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 11,100 Kensington and Chelsea residents providing unpaid care, or 1 in 14 of the total population. This was the 5th lowest proportion in the country. The 2011 Census, released in early 2013, will give an updated picture on changes over the last decade; recent population figures suggest it may be slightly higher. 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.

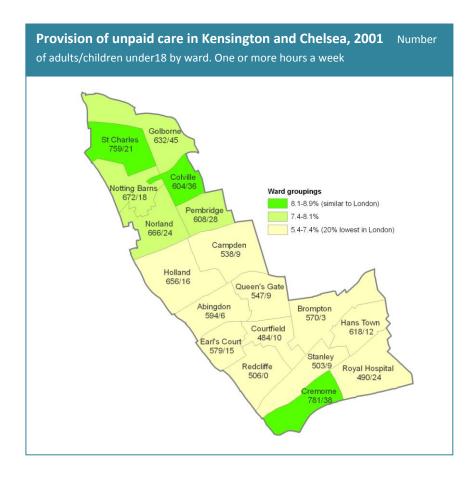
The low number of carers locally may be influenced by the large working age population, many of whom were born outside the country, and the high proportion of residents living alone - it is likely that family members may not live as nearby to each other as in other areas and the high cost of housing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

Nearly 9% of those living in St Charles and Cremorne 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+	8,202	1,082	1,496	10,780
All ages	8,454	1,121	1,508	11,083
% of all residents	5.4%	0.7%	1.0%	7.1%

^{*}Does not include communal establishments



Level of provision of care

Three quarters of those providing care provided 19 hours or less per week, with a quarter providing 20+ hours. Half of these (1,500 people, or 1 in 100) provided 50+ hours, the lowest proportion of anywhere in the country. Those in contact with councils tend to have higher levels of intensity, with three quarters providing 20 or more hours a week, and well over a third providing 50+ hours a week (from Carers Survey).

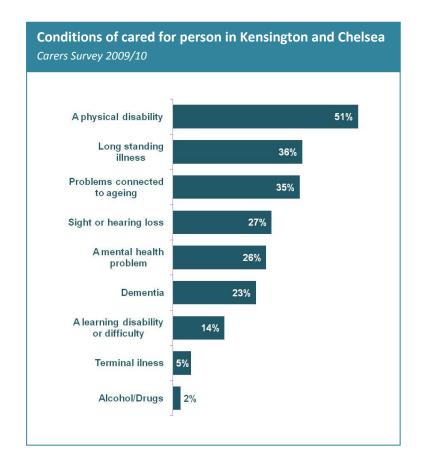
Characteristics of carers

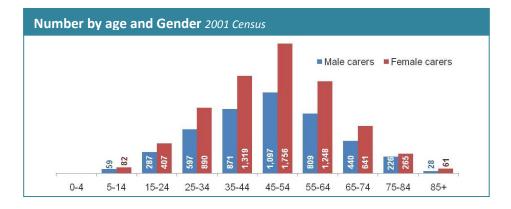
There were 4,414 male and 6,669 female carers identified in the 2001 Census, with women almost one and a half times as likely to be a carer as men in the borough. Caring was most common for those aged 45-54, although intensity of caring increases with age. A local survey identified half of carers providing 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. Higher than average to friends/ relatives (17%)
- Over half of people cared for are female (55%) and half (53%) are aged 75+
- Four out of ten responding (42%) said they were retired, with just 15% full time
- Two thirds of carers surveyed were from White ethnic groups (64%) and one third (36%) are from BME groups: 8% Asian, 12% Black, 17% other BME
- 70% of carers live with those they care for and 30% live somewhere else
- Six out of ten (62%) 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				
Other practical help	92%	Help - paperwork/ finances	74%	
Keeping an eye to see if all right	91%	Taking him/her out	72%	
Giving emotional support	82%	Giving medicines	69%	
Keeping him/her company	82%	Personal care	61%	
Help with care services/benefits	78%	Physical help	59%	

Carers known to social services

Data suggests that services are only being delivered to a minority of carers in the borough, with 1,595 adult carers in the borough offered a carers assessment or review. This represents around 15% of all likely adult carers in the borough in 2001. Recent data suggests numbers are rising again.

However, comparisons with 2001 Census data suggest the number offered assessment/review is still high compared to London and England averages and has grown substantially over time, albeit with a drop in number in 2010/11.

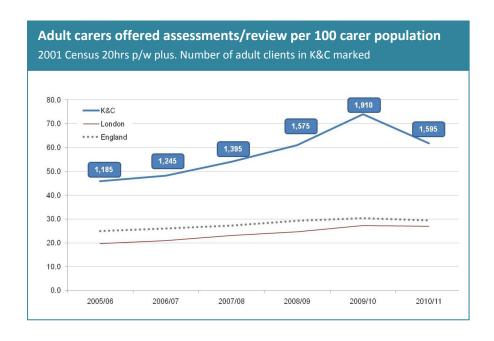
National data suggests that 37% of the caring population started caring during the year, and similar proportions also cease caring. The turnover rises to 44% for those providing 20 hours a week or more. This reinforces the need for services to continually identify new carers.

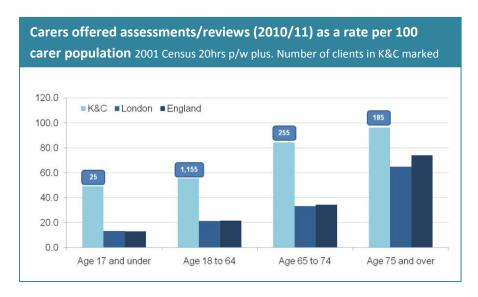
Groups identified by social services

There has been particular success in reaching all age groups but particularly under 75s and young carers, groups that tend to be less likely to be in contact with services than older groups.

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 physical disability compared to elsewhere, with 245 clients in contact over 2010/11, twice the expected London rate. Assessment and service use of adult mental health clients (145) and learning disability (95) clients was also higher than average.





Carers known to NHS GPs

One in five (22%) of responders to the 2009/10 carers survey said the GP they see does not know they are a carer. One published ad-hoc 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 in RBKC 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-reporting 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 26% increase in people aged 75+ locally.

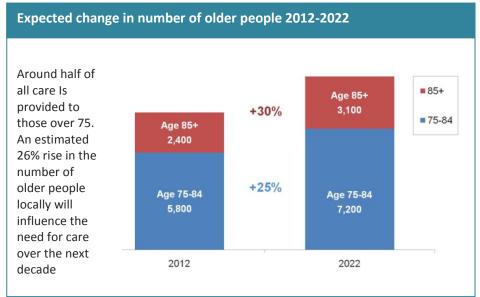
Pressure to provide care will be heightened by the trend towards maintaining independence at home for as long as possible, and changes to thresholds of statutory social care.

Carers known to other services

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

- Carers Kensington and Chelsea
- Age UK (formerly Age Concern)
- Full of Life
- Equal People
- Kensington and Chelsea Mental Health Carers Association
- Carers Network Westminster
- Open Age
- Portobello Green Fitness Centre
- CLCH (Carer's Counselling Service)
- Citizens Advice

Support, advice and information was provided by voluntary sector organisations to 242 carers in 2010/11, rising to 492 in 2011/12.



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 11% 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 projections	in burden of disease 2012-2022 Based on population
Physical disability or frailty	Expected rise of 11% 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 20% 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 in numbers of carers known to the council in 2010/11 needs to be addressed (although recent data shows a rise).
- 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, and two thirds don't have enough or any space or time to be themselves. These proportions are common to carers all around the country and illustrate the challenges involved in caring.

The local carers survey also highlighted that 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, 85% of those offered a carer's assessment had one, with 47% having a separate assessment and 38% having a joint assessment with the person they cared for. The proportion of carers having a separate assessment is similar to London (47%) but the proportion declining has consistently been higher than London and England.

The number offered and taking up carers assessments or reviews dropped in 2010/11. Nevertheless, the rate of assessment/ review and subsequent service use is still higher in Kensington and Chelsea than 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	74%	77%
Don't have enough/ any space or time to be myself	69%	73%
Don't have enough control/ have no control over daily life	65%	68%
Don't feel I have enough/have no encouragement and support	53%	52%
Don't have enough/have no social contact with people	52%	55%
Can't look after myself well enough/ neglecting myself	44%	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	25%	22%
Would like some training/ need some training	18%	14%
Have some worries/ extreme worries about personal safety	15%	15%

Number of adults offered and taking up carer's assessments or reviews over time in Kensington and Chelsea



Information and advice

In 2010/11, 930 adult carers in the borough received a carer-specific service as a result of their assessment and 375 received information.

The proportion receiving a carer-specific service (71%) is high compared to London and England (50%) and the rate of carers receiving services per 2001 Census carers population is twice as high as London and England. However, the number has dropped from a high of 1,230 in 2008/09 after consistently rising previously in the decade.

Local discussions with carers in Kensington and Chelsea 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.

During 2010/11, 360 carers received direct payments from the local authority, which was almost three times as many as would be expected, given the national average. Uptake was particularly high for adults aged 18-64 (285 clients) and young carers (10 clients).

Local research by Carers UK found people were most likely to spend their personal budget on taking a break (less than 24 hours, or longer e.g. a holiday), purchasing practical things such as a cooker or computer, costs to support life outside caring e.g. fees or travel expenses for education or leisure activity, and emotional support or relaxation.

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

•	78% of carers said they found it very/fairly				
	easy to find information and advice about				
	support, services or benefits				

Better than average

 91% said they found the information or advice very/ quite helpful Similar to average

 67% said they found it very/ quite easy to get the support or services they need as a carer Slightly lower than average

 77% said they always/ usually felt consulted in discussions about support or services provided Similar to 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 higher in the borough than nationally, in the 2009/10 carers survey, but with significant scope for improvement:

	Always involved in discussions in hospital	53%
•	Always involved in discussions in GP surgery	64%
•	Always treated with respect in hospital	59%
•	Always treated with respect in GP surgery	67%

Key points:

- Although the numbers taking up carers' assessments and receiving direct payments are high compared to elsewhere, there is scope to improve them further, given levels of vulnerability and need.
- The drop in numbers receiving information and advice compared to previous years may need to be addressed.
- 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 slightly better in the borough than 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

Carers UK found that 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, one quarter of responders to the Carers survey stated they were not in paid employment because of caring. Over half (54%) had experienced financial difficulties to some extent or a lot in the previous 12 months, the 4th highest proportion of surveyed areas nationally.

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

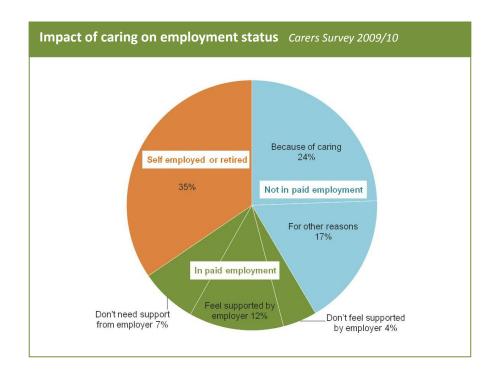
"There aren't enough suitable job opportunities locally" (63%) "I am not sure I would be able to work regularly" (40%)

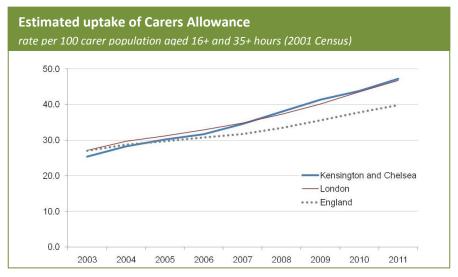
"I cannot work because of my caring responsibilities" 37%)

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, 970 clients received Carer's Allowance in Kensington and Chelsea, up from 650 five years previously. Comparisons with 2001 Census figures on likely number of carers suggests local take-up is similar to London and slightly better than England.





Employment, training and finance services provided

All newly identified carers in the borough receive a benefits and council tax discount check and employment support, as part of a larger package from Carers Kensington and Chelsea (CKC). Other services provided in the borough to support carers with employment, training and finance include the following:

- Income Maximisation Service provided by Citizen's Advice Bureau
- Jobcentre Plus work-focused support scheme for carers to access training and support, find job vacancies and apply for jobs. Advisers are also able to give carers information about finding and paying for replacement care, as well as benefits advice.
- NOVA and Open Age (for 50 plus) offer support tailored to carers preparing them for entering or re-entering the job market
- RBKC Worklessness Network offers a broad range of training providers and local colleges to link with
- Tailored support for carers seeking training and employment opportunities

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 a lack of capacity within carer funding 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.
- Further promotion of carers' exemption to council tax could be carried out
- 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.

Supporting carers to remain mentally and physically well

The evidence around caring and health

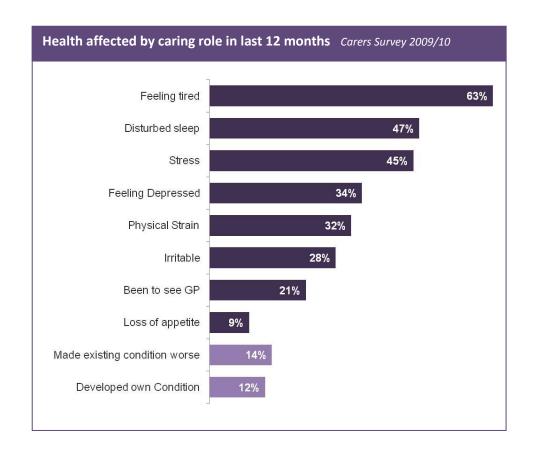
Research has found that those providing care are more likely to be in poor health than those not providing care. Emotional and mental health problems tend to be more often associated with care giving than physical health problems: nationally, carers providing substantial levels of care are twice as likely 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 lower burden of ill-health locally among carers than nationally. However, the survey identifies 1 in 5 with a long-standing illness, 1 in 7 with a physical impairment or disability, a similar number with sight or hearing loss, and 1 in 20 with a mental health problem. One in six (17%) of local carers rated their quality of life as bad/very bad/so bad it could not be worse and only half (56%) said they looked after themselves.

Local carers reported similar key health impacts of caring as national responders – feeling tired, sleep disturbance and stress – but report them at slightly lower levels.

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 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.

There are limited numbers of 'enhanced' services for carers in general practice, such as carer health checks, anxiety and disease screening, priority flu jabs, priority and double appointments, and signposting to support.

Carer's breaks

In 2009/10, 1 in 5 responders to the local Carers Survey (21%) said they had used services or support to take a break from caring for more than 24 hours. This was the 6th lowest in the country (28% average). A slightly higher than average number of responders stated that the service/ support was not suitable for them. There were also lower levels of satisfaction with the support or services.

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 low levels of satisfaction with services or support around rests from caring, with 49% very or extremely satisfied, compared to 65% nationally, and 1 in 8 dissatisfied.

Health checks and health improvement

A minority of GP practices in the borough are providing health checks specifically to carers, as part of the Enhanced Carers Service. Numbers tend to be low in London as a whole.

Gym membership is provided for free to 75 carers at the Portobello Gym in the north of the borough. At present, no membership is available in the south of the borough.

Service gaps

The local carers survey found higher levels of support from GPs to carers in their caring role. However, 1 in 5 responders (22%) 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 730 referrals where there were concerns about the possible occurrence of abuse. In about one in ten cases (10%) the alleged perpetrator was the 'main family carer', and also one in ten where 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.
- There is scope to increase numbers and monitoring of carers attending health checks, and free gym access in the south

Young carers

Number of young carers locally

Locally, the 2001 Census identified around 300 Kensington and Chelsea residents providing unpaid care, or 1 in 89 of the total population under 18.

Providing unpaid care, by number of hours, 2001 Census

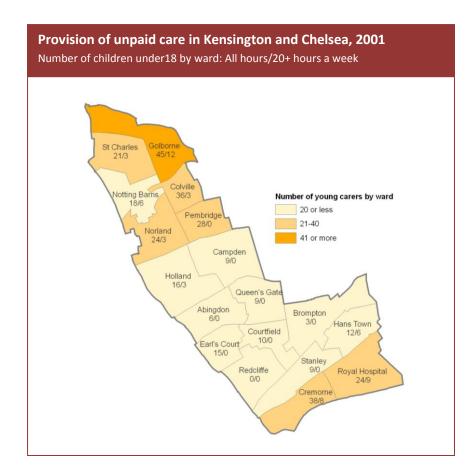
	1-19	20-49	50+	TOTAL
Children <18 providing care	252	39	12	303
% of all <18 population	0.9%	0.1%	<0.1%	1.1%

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 Young Carers Project, Family Action, receive ten or more referrals per quarter, with substantial turnover due to carers reaching the age of 18. In 2012, there were 153 young carers known to Family Action.

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. Local action plans focus on raising the profile of young carers with services to encourage referral to the Young Carers Project.



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.

Services available for young carers from Family Action include: weekly activity sessions, special trips out (e.g. short holidays), 1:1 counselling, and a family support service. Support schemes for young carers include: fun and fitness programmes, the Young Carers Personal Budgets project, Young Carers Photography project, Young Carers Homework Project.

The main identified gap in services is for young carers aged 18 or over, who are too old for the Young Carers Service and too young for many of the adult services, where the carers are usually middle aged or older.

Key points:

- Although the borough is relatively successful at identifying young carers compared to elsewhere, 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.
- There is a recognised 'gap' for carers who have reached the age of 18, and are therefore too old for the young carers service, but too young for the range of services offered to predominantly older adult carers.

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