JSNA 2016 Carers

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1. Introduction

1.1. Caring is something that increasingly affects us all at some point in our lives. Caring without enough support in place can have a huge impact and it is taking its toll on millions of families throughout the UK. Whether caring is full-time, or it is part of a stressful mix of work and other family responsibilities, many carers find they don't have the time or energy to maintain relationships, stay in work, or look after their own health and wellbeing[1].

1.2. The National Carers' Strategy defined a carer as someone 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, frail, disabled or has mental health or substance misuse problems[2].

1.3. The causes of someone taking on caring responsibilities are varied but can include[3]:

- Serious physical illness
- Long-term physical disability
- Long-term neurological conditions
- Mental health problems
- Dementia
- Addiction
- Learning disabilities
- Autism
- Alcohol/substance misuse

1.4. Just as the reasons why someone becomes a carer vary greatly, the variety of tasks that a carer fulfils is diverse. They can include the following duties:

- **Practical household tasks:** such as cooking, cleaning, washing up, ironing, paying bills and financial management.
- **Personal care:** such as bathing, dressing, lifting, helping someone to eat, administering medication and collecting prescriptions.
- **Emotional support:** such as listening, offering advice and friendship.

1.5. Although the distinction is often made between a full-time or part-time carer, there is not a minimum time requirement or age restriction that "qualifies" someone as being more or less of a carer.

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[1] Carers UK. State of Caring 2015. https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2015 (accessed May 2016)

[2] HM Government. Carers at the heart of 21st-century families and communities. 2008. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136492/carers_at_the_heart_of_21_century_families.pdf (accessed May 2016)

[3] Carers Trust. http://www.carerstrusttw.org.uk/about/carers/ (accessed May 2016)

1.6. The 2011 Census shows there are approximately 5.8 million people providing unpaid care in England and Wales, representing just over one tenth of the population. There are around 28,773 unpaid carers in Ealing.

1.7. The number of people caring around-the-clock is also growing rapidly; there has been a 25% increase in the number of carers providing 50 or more hours a week of unpaid care in just 10 years. The largest growth was in those people who provide fifty or more hours unpaid care per week (the highest category of unpaid care analysed)[4].

1.8. Carers are estimated to save the UK economy £119 billion per year in care costs. This is equivalent to £18,473 per year for every carer in the UK[5].

1.9. National research has found that one in five carers report that their health suffers as a direct result of caring, as personal health needs are often neglected when faced with the priority of caring for somebody else[6].

1.10. Carers often end up as patients themselves or requiring care and support. There are many problems associated with caring responsibilities including mental and physical health problems, social isolation, and increased mortality as a result of mental or emotional distress, especially in older carers. The Government White Paper 'Healthy lives, healthy people' highlights carers as a group who experience health inequalities[7].

1.11. 2011 census information shows that carers who provide high levels of unpaid care (more than 50 hours per week) for sick or disabled relatives and friends, are more than twice as likely to suffer from poor health compared to people without caring responsibilities. (iii)

1.12. Commonly reported conditions amongst carers are arthritis and joint problems, back problems, heart disease, cancer and depression. One third of older carers have reported having to cancel their own treatment or an operation because of their caring responsibilities[8].

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[4] Office for National Statistics. 2011 census unpaid care snapshot http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/guide-method/census/2011/carers-week/index.html (accessed May 2016)

[5] Local Government. Economic case for local investment in carers support. http://www.local.gov.uk/documents/10180/5756320/The+Economic+Case+for+Investment+in+Carers/a39c3526-c8a4-4a18-9aa4-b5d8061df8a2 (accessed May 2016)

[6] Carers UK. http://www.carersuk.org/professionals/resources/research-library/item/496-carers-in-crisis (accessed May 2016)

[7] Department of Health. Healthy lives healthy people. https://www.gov.uk/government/publications/healthy-lives-healthy-people-our-strategy-for-public-health-in-england (accessed May 2016)

[8] The Princes Royal Trust for Carers. Always on call, always concerned. https://www.carers.org/sites/default/files/always_on_call_always_concerned.pdf (accessed May 2016)

1.13. Our rapidly ageing population and longer life expectancy mean that the number of older people in need of care and support is estimated to outstrip the number of working age family members able to provide it as early as 2017. More of those born with disabilities are surviving into adulthood and later life and many are surviving serious illness like cancer or stroke and the number of us living with long-term conditions is increasing creating new demands for our health and care service.

2. National Policy & Legislation

2.1. Carers at the heart of 21st Century Families and Communities', Department of Health, 2008[9]

The revised National Carers Strategy (2010)[10] set out priorities for carers and identified the actions required to ensure the best possible outcomes for carers and those they support, including:-

- supporting those with caring responsibilities to identify themselves as carers at an early stage
- recognising the value of their contribution
- involving them from the outset both in designing local care provision and in planning individual care packages
- enabling those with caring responsibilities to fulfil their educational and employment potential
- personalising support for carers and those they support, enabling them to have a family and community life
- supporting carers to remain mentally and physically well.

2.2. Our NHS care objectives: a draft mandate to the NHS Commissioning Board, Department of Health, 2012[11]

This document highlights carers, focusing on early identification of carers, positive experience of caring, working collaboratively, enhancing quality of life for carers of people with long term conditions, improved co-ordination, opportunities, information and support to take an active role in decisions about care and treatment, etc.

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[9] HM Government. Carers at the heart of 21st-century families and communities https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136492/carers_at_the_heart_of_21_century_families.pdf (accessed May 2016)

[10] HM Government. Recognised, valued and supported. Next steps for the Carers Strategy. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213804/dh_122393.pdf (accessed May 2016)

[11] NHS England. Health and high quality care for all, now and for future generations. https://www.england.nhs.uk/2012/07/care-objectives-draft-mandate/ (accessed May 2016)

2.3. Care Act 2014[12]

The Care Act places new duties and responsibilities on local authorities as well as extending existing responsibilities. The Act represents opportunities for significant improvement and changes in adult social care and transforms the way the current adult social care system operates. The Act creates the requirement for a single, consistent route to determining people's entitlement to care and support and extends the same entitlement to carers. As part of the Care Act carers are also entitled to an assessment in line with current practice. The aim of the assessment is to determine whether the carer has support needs and what those needs may be. The new duty does not require (as the previous provision did) that the carer must be providing "substantial care on a regular basis".

The Care Act 2014 emphasised:

- 'Parity of esteem' for carers & cared-for
- Principles of well-being & personalisation
- Universal rights to information & advice
- Right to carer's assessment & support plan

From 1 April 2015, care and support has changed to be more consistent across England.

Care and support is the help some adults need to live as well as possible with any illness or disability they may have. It can include help with things like:

- washing
- dressing
- eating
- getting out and about
- keeping in touch with friends or family

This opened up a new opportunity to provide much needed support to people providing lower levels of support.

2.4. Children and Families Act 2014

The Children and Families Act 2014 clarifies the law relating to young carers and addresses the whole council (applying to both adults and children services). From 1st April 2015 under the Act, Young Carers under the age of 18 are entitled to an assessment of need of their own regardless of who they care for, what type of care they provide or how often they provide it[13]. Local Authorities must identify young carers and assess young carers where they may have support needs.

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[12] Legislation UK. Care act 2014. http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm (accessed May 2015)

[13] The Young Carers (Needs Assessments) Regulations 2015 No. 527 CHILDREN AND YOUNG PERSONS, ENGLAND http://legislation.data.gov.uk/uksi/2015/527/made/data.html (accessed May 2016)

The Act spells out links between Adults and Children legislation to enable local authorities to align the assessment of a young carers with an assessment of adult they care for.

The Act also stipulates that local authorities have a duty to provide a parent carer needs assessment to carers of disabled child aged under 18 if it appears that the parent carer has needs, or the parent carer requests an assessment.

3. Local Strategies in Ealing

3.1. Ealing Council and Ealing Clinical Commissioning Group (CCG) Joint Carers' Strategy 2012-18

The Ealing Strategy built on the national policy direction as well as local issues and was centred on delivering the following outcomes:

- Being respected and supported - a whole family approach to care
- Balancing caring with a life apart from caring
- Improving access and involvement
- Development of local services to meet need
- Children and Young People to be protected from inappropriate caring and have the support they need to learn, develop and thrive to enjoy positive childhoods
- Provision of support to parent carers

The strategy identified a number of areas for development;

- Better identification of carers through primary care
- Improved access to and experience of the carer assessment process
- Continued improvement and access to information
- Advice support and training for carers
- Ensuring appropriate access to services in the context of the personalisation agenda
- Better involvement of carers in some specific service developments, in particular the Out of Hospital Strategy
- End of life care
- Support to young carers.

The areas identified as a priority in the strategy were:

- Finance and economic well-being
- Carer Identification
- Training to support carers in skills to care and increase confidence
- Information and support
- Support carers in employment, education or leisure
- Engagement in service development
- Develop pathways with primary care
- To improve choice and flexibility in support services available
- To promote carer involvement as expert carer

- Young Carers identification and support
- Parent carers support

3.2. Ealing Joint Carers Strategy and Progress since 2012

Ealing Council and ECCG recognised the significant level of unpaid care provided by parent carers, young people who care for a family member and adults who care for a family member.

The strategy aimed to ensure that services are commissioned in an effective, efficient manner taking into account the expressed wish of service users and their carer, enabling resources to be used to maximum impact.

Carers, NHS and Local Authority front line staff and the voluntary sector played a large part in developing shared priorities and strategies across social care, the NHS and public health.

3.3. During the period 2012 to 2015 Ealing has achieved the following:

Carer Identification

This is being progressed by the Carers' Centre employing a co-ordinator to help promote carers agenda within primary care GP practices, raising awareness and setting up systems to identify and signpost carers to support.

Developed pathways with primary care

Protocol and model for delivery of carer health assessment are in place, currently being further advertised and promoted as part of the GP primary care project by the carer centre worker

Care coordinators rolled out across Ealing GP networks helping to advise and support the most vulnerable patients and their carer.

GP surgeries have introduced registers identifying carers, including young carers, and use e-learning resources available from the RCGP.

Training to support carers in skills to care and increase confidence

Training opportunities with Ealing Council continue to be advertised to carers.

On line training options advertised by Ealing Council to carers

Alzheimer's Society providing additional specific training course for carers of people with dementia

WLMHT specific training course for carers of people with mental health issues

Online training available on KIDS TRAINING for parent carers

CTPLD continue to work with carers of people with learning disabilities to offer more support, particularly for carers of young people transitioning from children's to adult services

Special parenting classes continue for parents of children with Autism

ECCG have funded the Carers’ Centre to provide carers’ training to GP surgeries to raise awareness of carers issues

E-learning course is available for level 1 in dementia

Carers’ engagement in service development has continued with consultations with different carers groups

Promoted carer involvement as expert carer

Work undertaken between children’s services and adult’s substance misuse services to try to identify more effectively the needs of children of substance misusing parents some of whom will be young carers

Raising carers confidence though ECCG development of the self-care agenda.

Carer representatives have been involved in a variety of ECCG events to improve community services

Information and support has been increased through:

New health and social care funding for information service included support to carers for benefit advice to include form filling

Information and Advice Network increasing the ways for carers to access information

New Health and Social Care Grant funding for Being Part of the Community Includes befriending support to both vulnerable adults and isolated people which can include carers

Expanded the handyperson service to 6 visits per year to allow three visits for vulnerable adults and further three visits for the carer

Care coordinators rolled out across Ealing GP networks helping to advice and support the most vulnerable patients and carers

Emergency Cards now routinely offered after social work assessment

7% increase in Adult carers respite spend in 2014/15compared to previous year

Established the Carers Information Page www.ealing.gov.uk/Carers

Supporting carers in employment, education or leisure

Leisure pass has been extended to carers to encourage increased take up of physical exercise

Health and social care grant funding for being part of the community extends leisure and support opportunities for carers across the borough increasing options for choice of respite, voluntary sector support, peer support and social activities

Ealing Council has continued to benefit from two separate dementia café events for carers, cared for and family on a regular monthly basis. These are held at both the Michael Flanders Day Centre and Ealing Town Hall. In addition to people with dementia who visit, these events have been attended by an average of 30 carers per session (based on monthly attendance in the year up to September 2016).

Improved choice and flexibility

Market position statement undertaken in 2015 will inform areas to be developed in Adults service from 2016 onwards.

The reconfiguration of Health and Social care Grant in 2015 maintained respite provision as a priority for funding and increased opportunities for other social activities by increasing carers in the being part of the community grant funding .

Improved service to Young Carers

A memorandum of understanding “No Wrong Door” for young carers has been agreed between children and adult social services including WLMHT and Adult substance misuse

Young carers in schools award being rolled out and promoted in all schools encouraging schools to take an active role in identifying and supporting young carers from September 2016

Information for young carers and stakeholder organisations being developed

The young carer support service was re-commissioned from 1 October 2015, with the service being provided by Brentford Football Trust. In the year April 2015 to March 2016 a total of 176 young carers received direct support.

Improved Service to Parent Carers

Parents involved in the design of services offered locally. The Parents Forum played an active role in planning for Children and Families Act implementation

The Local Offer website has been modernised

The Impartial information and Support and Guidance service continues to be provided by a voluntary organisation under the local name of ISAID. It works with parent/carers and young people (0 to 25). The service provides advice etc. in relation to education, health and care plans and disability more broadly in schools

A voluntary organisation KIDS is commissioned by Ealing Council to provide mediation (an essential part of the pre Tribunal process)

Short breaks in the community have continued with plans being developed for recommissioning the service. In the nine months to September 2016, 66 families have benefitted from short breaks.

Ealing council has continued to fund the Parents Forum, a self-organised group, and are reviewing options to develop an advocacy service.

SEN Disability reforms

A new OFSTED/CQC inspection, it is whole area place based inspection, rather than an individual service

Ealing CCG and the Council have used a self-evaluation tool to assess implementation of the SEND reforms locally.

Improved Finance and Economic Wellbeing:

Carers' assessments are carried out in line with the Care Act; 1,851 carers were assessed in the twelve month period from April 2015 to March 2016.

Carers' grant continues to be available for carers not entitled to carer's assessment

Direct payments are increasingly used by carers; at August 2016 there were 25 carers in receipt of a direct payment and a further 12 carers awaiting allocation. In addition to this, around 225 one off carer direct payments are expected to be made during 2016/17.

Health and Social Care Grant funding for information services includes requirement to provide information on benefits, debt counselling, and training and employment options for carers.

Carers have been involved in various projects and events which benefit Carers including:

The Ealing Early Start Service is an integrated approach to service delivery brings together professionals into three integrated teams. Each of the locality teams will deliver home, Children Centre and community based services for prospective parents and parents of young children.

Public Health Grant Funding: for projects to support the delivery of the Ageing Well action plan including an exercise programme to prevent falls in older people, projects to improve outcomes for socially isolated older people (funded together with adults and social care). Additional funding was also provided to support people with dementia and their carer.

Integrating Health and Adult Social Care through use of the Better Care Fund: includes a number of schemes designed to support a reduction in hospital or care home admissions and, when hospital admission does occur, to enable patients to return home as quickly as possible.

Implementation of the Care Act: The general ethos of this new legislation is reflected throughout this Strategy, including the focus on promoting Wellbeing and enhancing cooperation between and within partners.

Like Minded – Working together for mental health and Wellbeing across North West London: A programme of work to improve mental health services. An early phase of this work is the Like Minded 'Case for Change' paper.

Primary Care Transformation Programme: To address the significant challenges, the implementation of Shaping a Healthier Future (SaHF). The transformation programme allows more local patient and public involvement in developing services, with a greater focus on prevention, staying healthy and patient empowerment. This will then enable accessible provision, coordinated and proactive care.

Self-Care Strategy: To support patient empowerment and self-management, there are a number of new and existing initiatives that support the movement towards offering people more choice and control. This includes providing motivational training for patients and carers and in other languages for hard to reach communities and supporting the voluntary sector.

Mental Health Transformation: Carers of people with mental health problems, and of people with dementia, have been involved in a programme of work to improve mental health services in the borough, and are represented on the Ealing Mental Health Partnership Board.

Transforming Care for People with Learning Disabilities and/or Autism with Challenging Behaviour: Carers of people with learning disabilities and autism have been involved in developing the Transforming Care Plan and are also represented on the Ealing Learning Disabilities Partnership Board.

Carers are also part of the Older People Consultative Forum, the Older People and Long Term Conditions Partnership Board, Dementia Partnership Board, Carer's Partnership Board, the Carers' Forum and the Ealing Parent Carers' Forum.

4. Level of Need in Ealing

The following section summarises data related to carers from a number of different sources.

4.1. Provision of unpaid care by Ealing residents according to Census data

The most comprehensive data source about provision of unpaid care in Ealing was gathered at the last Census in 2011.According to the census,

"a person is a provider of unpaid care if they look after or give help or support to family members, friends, neighbours or others because of long-term physical or mental ill health or disability, or problems related to old age. This does not include any activities as part of paid employment. No distinction is made about whether any care that a person provides is within their own household or outside of the household, so no explicit link can be made about whether the care provided is for a person within the household who has poor general health or a long term health problem or disability."

Please note that column percentages are used in all tables of Census 2011 data. Hence, percentages represent the proportion of individuals within each group who provide some level of unpaid care. For example, looking at the proportion of the population providing unpaid care by age of the care giver (in Table 2), 16.5% of all 50-64 year olds provide unpaid care (rather than 16.5% of all unpaid carers being 50-64 years old).

The number of unpaid carers in Ealing increased between 2001 and 2011 from 25,736 to 28,773 (Table 1). In 2011, the proportion of unpaid carers among the total population was lower in Ealing (8.5%) than in England (10.2%). This may reflect the lower average age in Ealing compared to England.

Table 1: Number of individuals and proportion of total population providing unpaid care in Ealing and England, 2001 and 2011

	2001			**2011**		
	Number unpaid carers	**%**	**Total population**	**Number unpaid carers**	**%**	**Total population**
Ealing	25,736	8.6	300,948	28,773	8.5	338,449
England	4,877,060	9.9	49,138,831	5,430,016	10.2	53,012,456

Source: Census 2011 (ONS)
Note: percentages represent the proportion of individuals within each group who provide some level of unpaid care.

The proportion of individuals who provide unpaid care increases with rising age, until decreasing slightly in the 65 and over age group (Table 2). In Ealing, the age group with the largest proportion of unpaid carers is 50-64 year olds (16.5%). Across England one in five (20.2%) individuals in the 50-64 age group provide unpaid care.

Table 2: Number of individuals and proportion of population providing unpaid care by age of care giver in Ealing and England, 2011

	Age of unpaid care giver												**Total population**
	Under 16		**16-24**		**25-34**		**35-49**		**50-64**		**65 and over**		
	Number	%	Number	%	Number	%	Number	%	Number	%	Number	%	
Ealing	703	1.0	2,508	6.4	4,265	6.3	8,664	11.3	8,239	16.5	4,394	12.1	338,449
England	111,423	1.1	302,356	4.8	473,891	6.6	1,420,318	12.6	1,929,420	20.2	1,192,608	13.8	53,012,456

Source: Census 2011 (ONS)
Note: percentages represent the proportion of individuals within each group who provide some level of unpaid care.

A higher proportion of females provide unpaid care compared with males (Table 3). This is seen in both Ealing (9.5% females v 7.6% males) and England as a whole (11.8% females v 8.9% males).

Table 3: Number of individuals and proportion of total population providing unpaid care by gender of care giver in Ealing and England, 2011

	Gender of unpaid care giver				Total population
	Male		Female		
	Number	%	Number	%	
Ealing	12,638	7.6	15,995	9.5	334,725
England	2,285,192	8.9	3,124,241	11.8	52,059,931

Source: Census 2011 (ONS)

Note: percentages represent the proportion of individuals within each group who provide some level of unpaid care.

Of all resident of Ealing recording in the 2011 Census, around one in twenty people provide 1-19 hours of care, one in sixty seven people provide 20-49 hours of care and one in fifty people provide 50+ hours of care (Table 4).

Table 4: Number of hours of unpaid care provided by all individuals in Ealing and England, 2011

	Provision of unpaid care (hours per week)								Total population
	0		1-19		20-49		50+		
	Number	%	Number	%	Number	%	Number	%	
Ealing	309,676	91.5	17,668	5.2	5,033	1.5	6,072	1.8	338,449
England	47,582,440	89.8	3,452,636	6.5	721,143	1.4	1,256,237	2.4	53,012,456

Source: Census 2011 (ONS)

Note: percentages represent the proportion of individuals within each group who provide some level of unpaid care.

In Ealing, one in ten (10%) Asian/Asian British people provide unpaid care (Table 5). This rate is higher than in any other ethnic group. Nearly one third of all Ealing residents are from this ethnic group. In contrast, across England the highest rate of unpaid care provision is seen among the White ethnic group (10.7%).

Table 5: Number of individuals and proportion of population providing unpaid care by ethnicity of care giver in Ealing and England, 2011

	Ethnicity of unpaid care giver										Total population
	White		Mixed		Asian/Asian British		Black/Black British		Other ethnic group		
	Number	%	Number	%	Number	%	Number	%	Number	%	Number
Ealing	13,255	8.0	908	6.0	10,003	10.0	2,856	7.7	1,751	8.6	338,449
England	4,839,604	10.7	67,192	5.6	353,301	8.5	131,356	7.1	38,563	7.0	53,012,456

Source: Census 2011 (ONS)

Note: percentages represent the proportion of individuals within each group who provide some level of unpaid care.

Among individuals aged 16 and over, the highest rate of unpaid care provision is seen among those looking after their home/family (18.2%), those who are retired (13.2%) and those who are unemployed (10.6%). These rates are comparable to the England average (Table 6).

Table 6: Number of individuals and proportion of population providing unpaid care by economic activity in Ealing and England, 2011 (16+ years only)

				Ealing	**England**
Economic Activity	**Economically active**	**In employment**	Number	16,109	2,880,279
			%	9.7	11.4
		Unemployed	Number	1,674	198,682
			%	10.6	9.8
	Economically inactive	**Retired**	Number	4,677	1,412,271
			%	13.2	15.5
		Student	Number	1,066	104,805
			%	5.7	4.6
		Looking after home or family	Number	2,671	420,057
			%	18.2	24.6
		Long-term sick/disabled	Number	953	196,461
			%	9.8	12.0
		Other	Number	920	106,038
			%	9.8	11.3
Total population aged 16+			Number	269,572	42,989,620
			%	10.4	12.4

Source: Census 2011 (ONS)

Note: percentages represent the proportion of individuals within each group who provide some level of unpaid care.

It is worth noting that the Census tells us the number of individuals who provide unpaid care but not the number of families who provide care. It is likely that Ealing has a higher proportion of large extended families compared to the England average. If one person per family is a carer this would give a low rate of carers in Ealing, which is what we see in the data. Despite this, we may still find a higher rate of families providing care.

4.2. Individuals Receiving Carer's Allowance According to the Office for National Statistics

Eligibility for carer's allowance is complex, with a large proportion of unpaid carers not meeting the criteria. The person being cared for must be in receipt of a benefit related to their need, such as Attendance Allowance. This means that most carers' allowances are claimed by people caring for those with more severe needs rather than older people whose needs do not qualify them for the relevant benefits. Among other criteria related to the unpaid carer, they must spend at least 35 hours a week caring and earn a maximum of £110 per week (excluding pension payments). Hence, those in receipt of carer's allowance represent a relatively small subset of all unpaid carers in Ealing.

Carer's allowance is administered by the Department of Work and Pensions and is different from payments that carers' may receive directly from their local authority (see section 4.6).

In 2015 there were 3,570 individuals in receipt of carer's allowance in Ealing (Table 7). This represents a small subset (around 10%) of the unpaid carers identified in the 2011 census. Possible reasons for the small number of individuals receiving carer's allowance include the stringent eligibility criteria for both the carer and the cared for person.

Table 7: Number of individuals in receipt of carer's allowance in Ealing and England, 2013-2015

	2013	2014	2015
Ealing	3,260	3,320	3,570
England	553,730	588,250	643,870

Source: NOMIS (ONS)

Three quarters (76%) of individuals in receipt of carer's allowance are female (Table 8). In contrast, of all unpaid carers identified in the 2011 census, 56% were female.

Table 8: Individuals in receipt of carer's allowance by gender in Ealing and England, 2015

	Gender of individuals in receipt of carer's allowance			
	Male		Female	
	Number	%	Number	%
Ealing	870	24	2,700	76
England	175,840	27	468,030	73

Source: NOMIS (ONS)

The highest proportion of individuals in receipt of carers allowance were aged 35-49 years (41%) and 50-64 years (32%) (Table 9).

Table 9: Individuals in receipt of carer's allowance by age group in Ealing and England, 2015

	Age of individuals in receipt of carer's allowance													
	Under 18		18-24		25-34		35-49		50-64		65+		Unknown	
	Number	%	Number	%	Number	%	Number	%	Number	%	Number	%	Number	%
Ealing	<5	-	140	4	600	17	1470	41	1150	32	200	6	<5	-
England	1,710	<1	32,090	5	113,890	17	253,680	39	228,750	36	13,740	2	10	<1

Source: NOMIS (ONS)

The majority of individuals in receipt of carer's allowance had been receiving the benefit for more than 2 years, with 40% having claimed for more than 5 years (Table 10).

Table 10: Duration of claim by individuals in receipt of carer's allowance in Ealing and England, 2015

	Duration of claim by individuals in receipt of carer's allowance									
	<1 year		1 - <2 years		2 - <5 years		5+ years		Unknown	
	Number	%	Number	%	Number	%	Number	%	Number	%
Ealing	630	18	450	13	1,070	30	1,430	40	<5	<1
England	127,160	20	98,090	15	182,190	28	236,430	37	-	-

Source: NOMIS (ONS)

4.3. Projections of unpaid care provision

The Projecting Older People Population Information System (POPPI) is a database designed for analysing population data and projecting numbers into the future. With a focus on people aged 65 and over, figures from the Census 2011 are applied to Office for National Statistics (ONS) population projections to give estimated numbers.

Projections of the number of unpaid carers aged 65 and over in Ealing indicate a rise of 42% by 2030 (Table 11); this increase is consistent across all hours of unpaid care (1-19, 20-49 and 50+ hours per week). The projected increase in Ealing is larger than that predicted across England & Wales (32%).

Table 11: Number of people aged 65 and over providing unpaid care by hours of care provided in Ealing and England & Wales, projected to 2030

	Hours of unpaid care provided	Year				Change 2015 to 2030
		2015	2020	2025	2030	
Ealing	**1-19 hours**	2,538	2,833	3,156	3,593	42%
	20-49 hours	754	847	949	1,073	42%
	50+ hours	1,740	1,948	2,184	2,493	43%
	Total	**5,031**	**5,627**	**6,289**	**7,161**	**42%**
England & Wales	**1-19 hours**	678,891	721,989	784,462	874,213	29%
	20-49 hours	175,185	189,912	208,467	232,519	33%
	50+ hours	530,420	585,651	649,617	725,746	37%
	Total	**1,384,497**	**1,497,552**	**1,642,547**	**1,832,479**	**32%**

Source: POPPI

The number of people aged 65 and over who are unable to manage at least one self-care activity on their own is projected to increase by around 50% by 2030 (Table 12). The projected rise is slightly higher among males (55%) than females (45%). The projected increase in Ealing is higher than that projected for England & Wales.

Table 12: Number of people aged 65 and over unable to manage at least one self-care activity on their own in Ealing and England & Wales, by gender, projected to 2030

	Gender	Year				Change 2015 to 2030
		2015	2020	2025	2030	
Ealing	**Male**	4,683	5,402	6,316	7,271	55%
	Female	8,507	9,552	10,821	12,348	45%
England & Wales	**Male**	1,135,714	1,292,189	1,488,987	1,703,540	50%
	Female	2,099,492	2,322,219	2,602,684	2,951,416	41%

Source: POPPI

4.4. Health-related quality of life

The Clinical Commissioning Group Outcomes Indicator Set (CCG OIS) is produced by the Health and Social Care Information Centre (HSCIC). This indicator set aims to provide comparative information about the quality of health services commissioned by CCGs and, as far as possible, the associated health outcomes. Indicator 2.15 measures the health-related quality of life for people who identify themselves as helping or supporting family members, friends, neighbours or others with their long-term physical or mental ill health/disability or because of problems relating to old age.

Health-related quality of life is based on responses to a question from the GP Patient Survey and is measured by the extent to which people:

- Have problems walking about
- Have problems performing self-care activities (washing or dressing themselves)

- Have problems performing their usual activities (work, study etc.)
- Have pain or discomfort
- Feel anxious or depressed.

The indicator can be used to draw a comparison between the health-related quality of life for carers in Ealing CCG and neighbouring CCGs. Being ranked 1st indicates the highest level of health-related quality of life in relation to the problems listed above.

Ealing CCG is ranked 84th highest out of 207 CCGs in England for whom data is available, suggesting that health-related quality of life is slightly better than the national average (Table 13).

Table 13: Health-related quality of life for carers aged 18+ in Ealing and North West London CCGs, 2014-15

	2014-15	
	indicator value	**rank***
NHS Harrow CCG	0.835	10th
NHS Hammersmith and Fulham CCG	0.823	36th
NHS Hillingdon CCG	0.815	50th
All registered patients in England	0.804	-
NHS Ealing CCG	0.804	84th
NHS Hounslow CCG	0.800	96th
NHS Brent CCG	0.797	110th

* Out of 207 CCGs in England for whom data is available

Source: CCG OIS 2.15 (HSCIC)

4.5. Carers accessing services

London Borough of Ealing holds data about the number of carers who access services within the borough. Figures include all carers who received a carer assessment that lead to either information and advice being given or services being accessed (see the Service Mapping section for examples of services offered).

In the twelve month period from April 2015 to March 2016, a total of 1,851 carers accessed services in the London Borough of Ealing. The majority (60%) of carers accessed services through voluntary organisations (Table 14).

Table 14: Number of carers accessing services by type of service provider, 2015-16

Type of service provider	Number of carers
Voluntary Organisation	1119
Mental Health	245
Council	487
Total	**1851**

Source: Adults Performance & Management Team, London Borough of Ealing

Nearly all carers accessing services were aged 18 or over. The majority (61%) were aged 18-64 years and 38% were above 65 years old (Table 15).

Table 15: Number of carers accessing services by age of carer, 2015-16

Age band	Number of carers
Under 18	5
18-64	1123
65-74	294
75-84	224
85+	178
Not recorded	27
Total	**1851**

Source: Adults Performance & Management Team, London Borough of Ealing

The majority of carers accessing services were female (68%) (Table 16).

Table 16: Number of carers accessing services by gender of carer, 2015-16

Gender	Number of carers
Female	1256
Male	569
Unknown	26
Total	**1851**

Source: Adults Performance & Management Team, London Borough of Ealing

The rate of carers accessing services is higher in Southall (7.1 per 1,000 population) than any other area within the borough (Table 17).

Table 17: Number of carers accessing services and rate per 1,000 population by locality of caree, 2015-16

Locality	Number of carers	Rate per 1,000 population
Acton	272	4.1
Ealing	311	4.3
Greenford	230	4.8
Hanwell	218	4.7
Northolt	126	4.1
Southall	509	7.1
Perivale	62	4.0
Not Recorded	92	-
Out of Borough	31	-
Total	**1851**	5.3

Source: Adults Performance & Management Team, London Borough of Ealing; ONS ward level population estimates

Ethnic groups with a higher than average rate (per 1,000 population) of accessing services are: Indian (8.4); Black Caribbean (7.6); Other (7.3); and Pakistani (5.4) (Table 18).

Table 18: Number of carers accessing services and rate per 1,000 population by ethnicity of carer, 2015-16

Ethnic group	Number of carers	Rate per 1,000 population
White	721	4.3
Black Caribbean	98	7.6
Black African	48	2.7
Black Other	22	1.6
Indian	406	8.4
Pakistani	79	5.4
Bangladeshi	10	4.9
Chinese	8	1.7
Asian Other	4	0.1
Other	197	7.3
Unknown	258	-
Total	**1851**	**5.3**

Source: Adults Performance & Management Team, London Borough of Ealing; GLA Ethnic Group Population Projections

London Borough of Ealing also collects data on outcomes for adult users of local authority-funded social care and support. These data are published in full on the Adult Social Care Outcomes Framework website (http://ascof.hscic.gov.uk/). Outcomes which relate directly to carers look at payments, quality of life, social contact, inclusion in discussion about the cared for person and ease of finding information about support. In all but one of these indicators (ease of finding information about support), performance in Ealing is worse than the England average (Table 19).

Table 19 Adult Social Care Outcomes relating to carers, Ealing and England 2014-15

Code	Outcomes	Ealing	England
1C1b	Carers receiving self-directed support	30.6%	77.4%
1C2b	Carers receiving direct payments	20.7%	66.9%
1D	Carer-reported quality of life	7.4 out of 12	7.9 out of 12
1I2	The proportion of carers who reported that they had as much social contact as they would like.	29.4%	38.5%
3B	Overall satisfaction of carers with social services	32.0%	41.2%
3C	The proportion of carers who report that they have been included or consulted in discussion about the person they care for	60.3%	72.3%
3D2	The proportion of carers who find it easy to find information about support	62.3%	65.5%

Source: Adult Social Care Outcomes Framework (ASCOF):

5. Evidence of What Works/Good Practice

5.1. As our understanding of carers and their needs has increased there has been research nationally and internationally to evaluate what interventions are successful in improving carers' lives. If we understand better what the impact of caring has on those involved, we can try and reduce the negative impact and enhance their experience.

5.2. There is a good evidence base on the problems that may be associated with caring responsibilities including mental and physical health problems[14], social isolation and lowered social functioning, and increased mortality as a result of mental or emotional distress, especially in older carers. There is some evidence of financial savings in supporting carers[15] since enabling people to be cared for in the community can reduce the need for inpatient care in hospitals and residential or nursing home care.

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[14] Hirst, M. (2004) Health inequalities and informal care, Social Policy Research Unit, University of York, York

[15] Local Government. Economic case for local investment in carers support. http://www.local.gov.uk/documents/10180/5756320/The+Economic+Case+for+Investment+in+Carers/a39c3526-c8a4-4a18-9aa4-b5d8061df8a2 (accessed May 2016)

5.3. However, there are difficulties in focusing on evidence of improved outcomes for carers from single carer-specific 'interventions'. Rather the evidence from research shows that effective support to carers usually goes beyond a single intervention and encompasses good quality mainstream services, and sensitive and carer-aware professional practice (across health, social care, education and all local services). As importantly, evidence shows that a joint strategic approach by health, local government and voluntary organisations is needed for a local population to develop and commission a range of local services suited to the local needs of carers and people using services.

5.4. In terms of effective carer-specific services and interventions, quality standards were developed as part of the first national strategy for carers in 1999. These were based on research evidence of what works and what is important to carers.

5.5. The standards relate to five outcomes that carers identified as key to their well-being –

- Being informed
- Having a break
- Accessing emotional support
- Maintaining their own health
- Having a voice.

5.6. In the reformed adult social care system, the Government expects people receiving adult social care to be able to articulate clear outcomes from their experience through "I" statements[16]: The I statements are what older and disabled people, carers and citizens expect to feel and experience when it comes to personalised care and support.

- "I am supported to maintain my independence for as long as possible";
- "I understand how care and support works, and what my entitlements and responsibilities are";
- "I am happy with the quality of my care and support";
- "I know that the person giving me care and support will treat me with dignity and respect";
- "I am in control of my care and support and I have greater certainty and peace of mind knowing about how much I will have to pay for my care and support needs

5.7. The Triangle of Care: Carers included: A Guide to Best practice in acute mental health care. The 'Triangle of Care' is a therapeutic alliance between service user, staff member and carer that promotes safety, supports recovery and sustains well being. This document identifies the six key elements required to achieve better collaboration and partnership with carers in the

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[16] Care Act 2014 an overview. http://www.futureyears.org.uk/uploads/files/Care%20Act%20Overview%202014%20%20FINAL.pdf (accessed June 2016)

service user and carer’s journey through a typical acute episode and suggests good practice examples and resources that may be helpful.

5.8. The six key elements state that:

- Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
- Staff are ‘carer aware’ and trained in carer engagement strategies.
- Policy and practice protocols re confidentiality and sharing information are in place.
- Defined post(s) responsible for carers are in place.
- A carer introduction to the service and staff is available, with a relevant range of information across the acute care pathway.
- A range of carer support services is available.

6. Current Interventions & Assets

6.1. Carers have access to a range of services in Ealing, the majority commissioned by the Council or by the NHS, although some are independent or funded through national or local grants. The table below describes these according to the target group they serve. However, it is sometimes difficult to disentangle services which are provided for people with particular care needs, such as learning disabilities or dementia, from services directly provided for carers themselves. In reality, the provision of respite care or day opportunities for people with care needs can, at the same time, provide a break for their carers. The list below includes both types of services, i.e. those directly aimed at carers, and those aimed at people with care needs where the service provides respite to their carers.

Service Mapping

Target Group	Service Name	Provider	Commis-sioner	Description
Parent – Carers Children with Additional Needs	Family Links Sitting Service	LBE	LBE	Ealing Family Link Service provides short break support to disabled children and their families within the London Borough of Ealing. The children are aged between 0-18 and will have severe to profound learning, neurodevelopmental and/or physical disabilities, which delay their development. Some may have medical conditions. The support is provided in through: 1. Sitting service - the support takes place in the child's home and / or the community during the day and evening. 2. The Family Link Carer service - the support is provided in an approved carer's home and the community, during the day and evening and may include overnight stays. The Ealing Family Link services is committed to providing high quality practical support that enables parents to have a break from their caring responsibilities and for the child to have a safe and enjoyable short break experience.
Parent Carers	Family Information Service	LBE	LBE	Ealing Family Information Service (FIS) provides relevant information on childcare and early years education and other support services for children aged 0-19.
Parent Carers - Children with Additional needs	Ealing Local Offer	LBE	LBE	Online services directory and information resource for children, young people and families living with additional needs and disability in the London Borough of Ealing https://www.ealingfamiliesdirectory.org.uk/kb5/ealing/directory/localoffer.page?localofferchannel=0
Parent Carers –	Early Bird Parenting	LBE	LBE	The programme aims to support parents in the period between diagnosis and school placement, empowering and helping them facilitate their child's social communication and appropriate behaviour in their natural environment. It also helps parents to establish good practice in handling their child at an early age, so as to pre-empt the development of inappropriate behaviours.
Children with Additional Needs Short Breaks	After-school Club	Mencap	LBE	A weekly afterschool club for young people with additional needs supporting 10 to 15 young people. The club offers a variety of group activities focused on social skills development, healthy living, and developing independence for transition and beyond.
Children with Additional	Short Breaks	Log cabin Children with	LBE	Log cabin runs an afterschool and holiday club for children and young people aged 4-15 years with additional needs, with exciting and stimulating play

Target Group	Service Name	Provider	Commis -sioner	Description
Needs		additional Needs Short Breaks		activities in a safe, caring and fun environment.
Children with Additional Needs -	Information advice and support	MENCAP	LBE	Ealing HELP Website. www.ealinghelp.org provides impartial information and advice for parents and carers of children and young people with disabilities on national and local policies; and programmes and services across the London Borough of Ealing.
Children with Additional Needs -	Information advice and support	Contact a Family	LBE	Contact a Family runs an independent information and advice service to families of children with additional needs aged 0 to 18 years. The project helps families understand their child's condition and provides information and advice on the support networks and services available. It provides support with :- Enquiries and casework: by telephone, email and face-to-face, support with form filling, interpretation and translation, letter reading etc. Support groups and workshops: mutual/social support, exchange of information and enhancing parents' knowledge. The project runs a carers group and condition-specific group for Autism & ADHD.
Children with Additional Needs -	Information advice and support	P.E.S.T.S Parents of Ealing Self Help Training Group	LBE	P.E.S.T.S. provides free, impartial and confidential advice, support and guidance to parents and carers of children with disabilities, complex health and additional needs aged 0-5. Services include:- Play and Stay session, twice weekly offering an environment to allow parental friendships and support. 6 Parents Support Evenings per year where speakers (from statutory and voluntary organisations) give free, confidential, impartial advice and support on a range of topics including health, benefits, housing, education and counselling.
Children with additional needs	Ealing Parent Forum		LBE	Run by parents and works with the council to ensure that parents voice are heard in the delivery and development of services.
Children with additional needs	ISAID Parent Partnership	Family Action	LBE	Independent advice and support service for children and young people with additional needs and disabilities Covers Education, Health and Social Care
Young carers	Ealing Young Carers Project	Brentford FC	LBE	Runs the Ealing Young Carers Project. The project provides one to one support as well as a programme of fun activities offering young carers a break from their caring role and to meet other young carers who are in a similar situation. Activities include a weekly after school club, homework support, swimming clubs and holiday activities
Young Carers	SAFE – Service	LBE	LBE	SAFE lead and provide the young carers needs assessment. Children and Young People that are identified as young carer should be referred to SAFE

Target Group	Service Name	Provider	Commis -sioner	Description
				for a young carers assessment of need
Young Carers	Connexions	Mencap	LBE	Mencap Connexions PA's are funded by Ealing's Connexions service to provide specialist support to young people with additional needs who are NEET or at risk of becoming NEET. This support includes supporting those young people to understand, explore and apply for education, training or work opportunities that will move them on the way to achieving their goals as well as support regarding CV writing, interview skills and professionalism.
Young Carers	Transition Team	Mencap	LBE	Mencap's transition's team are funded by Ealing Council's Children's services to provide specialist support to young people in the transition period, from year nine until their eighteenth birthday. This support includes but is not limited to, direct work to support young people to think about and plan for their future, partnership work with colleagues in the ESCAN team and schools to improve outcomes for individual young people, work to improve the accessibility and relevance of information available to young people regarding preparing for adulthood, work to increase the young person's voice throughout services for young people in transition and work with partners and stakeholders to improve the outcomes for children and young people in transition at a strategic level.
Older People with Dementia	Call & Care Service Respite	Dementia Concern Ealing	LBE	Provides short breaks (dementia for carers, and support for people with dementia. Call & Care provides specially trained Care Attendants to give regular short breaks (normally 3 -4 hours) in the home for carers of people with dementia. The service is flexible and accommodates both regular and occasional users. Weekend Day Care is offered to carers for one day per weekend (occasionally two days), and transport is provided if required. Care Attendants carry out activities with people with dementia varying from conversation, reminiscence, maintaining skills, hobbies, and board games and going for walks. At the weekend day centres therapeutic activities are held in small groups to allow members to take part according to their ability. Activities include reminiscence therapy, quizzes, exercises, arts therapy and dancing as well as culturally specific activities.
Older People with Dementia	Michael Flanders Day Centre	LBE	LBE	Provides respite to carer who are assessed by social services as in need of respite by providing day care at MFC
Older People with Dementia	Dementia Cafe	LBE staff volunteers Dementia Concern	LBE	Provides social events for carer and the person with dementia. While at the same time making information available for carers on services and support available. One located at MFC.

Target Group	**Service Name**	**Provider**	**Commis -sioner**	**Description**
		Ealing		Second located at Ealing Town Hall (ETH)
All Carers	Carer Centre	Ealing Centre for Independent Living	LBE	Provision of Ealing Carer Centre services. Provides a range of events and activities for carer .information available for carers on services and support available. Service available at the carers centre and five other locations across the borough.
Adults 18 onwards with physical disabilities	Short Breaks / Respite	The Asian Health Agency consortium	LBE	Short breaks/respite care service for carers incorporating: 24 hour 7 day a week domiciliary care including personal care, emergency care and hospital discharge care packages, night sitting, cooking, cleaning, shopping etc; a home based befriending service, escorting service; day care and centre/ community based short breaks; holiday breaks for carers; and respite through enabling carers to participate in social, leisure, educational and cultural activity in community settings. There will also be a multi lingual advice, information, & signposting service and health and wellbeing awareness raising activities and workshops.
Older people	Being part of the community	Neighbourly care Southall consortium	LBE	Community Activities for Older People .I provide a wide range services for older people at mini health hubs situated throughout the borough. Social inclusion activities include outings, music, dance, discussions, access to computers and the internet, and friendship and relationship building. Preventative health activities include keep fit classes, chair exercise classes, yoga classes, healthy eating advice and counselling and talking therapy. There will also be services designed to reduce falls and accidents at home; support and activities for individuals experiencing depression; and a community based service for supporting patients post hospital discharge; as well as support for carers. Activities will be provided for people with dementia and there is a befriending scheme for older people experience abuse. There will be basic skills and English language classes, plus a training programme delivering key skills training aimed at employability and volunteering opportunities
Older people primarily but will also benefit carers of the elderly	The Restore Plus Project	Age UK Ealing	LBE	Isolated people -support people who have either had a long stay in hospital, a fall or bereavement. Home visits and provide support and activities such as falls prevention support, chair based exercises at home and support with new aids and adaptations; or accompany users to shops or social events until confidence is regained. Home visiting support will provide specific one-to-one support to respond to the issues identified by the older person. There will also be one-to-one support for people living with dementia, providing emotional and practical support. The aim is to reconnect users to the local community and the activities that they wish to participate in, and ensure

Target Group	Service Name	Provider	Commis-sioner	Description
				that they can continue to live in their own home, for as long as possible
Older people Primarily but will also benefit older carers and carers for people with mental health needs	Borough-wide Befriend-ing Scheme	Neighbourly Care Southall	LBE	Reaching socially isolated older people in their own homes via home visits and follows up phone contact. In addition the scheme will provide information and links about services, benefits, other support organisations, support with accessing health and social care services, escorted outings, and activities in the home including seated exercises, strength and balance exercises, craft and reminiscence. The main beneficiaries are frail older people who cannot or may not wish to leave their homes, and older people who may with support be able to access services and opportunities outside the home.
Learning Disabilities	Short-term respite breaks	Certitude	LBE	Short-term respite breaks to family carers of adults with learning disabilities in Ealing. This service offers the carer's relative different centre and community based activities and bespoke holiday packages.
Over 18 adults including carers	Talking Therapies	Ealing Abbey Counselling Consortium	LBE	The service provides psychological therapies and/or other BACP approved talking therapies for adults with mild to moderate mental health issues, depression or anxiety in Ealing, often working in partnership with statutory services and offering a choice of options for therapeutic support. The service aims to reach black, Asian and minority ethnic communities, refugees, unemployed people, lone parents, people living with chronic illness, people coming out of hospital, older people, people who have experienced a bereavement and carers One part of the consortium offers specific therapies for people living with Long Term Conditions, many of whom are also carers. A therapist is based at the Carers' Centre to offer this service.
Over 18 vulnerable adults and carers	Ealing Specialist Advice Service	Ealing Mencap consortium	LBE	ESAS provides 2 key support functions for borough residents. The service delivers outreach advice and information (including home visits for individuals who are unable to leave their home) to people with learning disabilities, physical disabilities, sensory impairments, autistic spectrum conditions, older people, people with substance misuse issues, people with mental health issues and their carers. ESAS also delivers free information and advice services through appointments based at a centrally located hub in West Ealing. Visitors can also drop in from 10am-4pm on Mondays, Tuesdays and Thursdays and 10-1pm on Fridays. Residents are able to access ESAS directly via face to face appointments, telephone, and internet and smartphone services. Out of hours appointments are available on request.
Learning Disability	19 Haymill Close	Certitude	LBE	Residential respite service for adults with LD and challenging needs. Service includes overnight, activity and community based respite.

Target Group	**Service Name**	**Provider**	**Commis-sioner**	**Description**
Learning Disability	Short Breaks Service, Green Lane	LBE	LBE	Residential respite service for adults with LD including people with profound and multiple learning disabilities.
Learning Disability	Cowgate Centre	LBE	LBE	Centre based day opportunities for people with LD and challenging needs living at home with their families.
Learning Disability	Northolt Centre	Seva Care	LBE	Resource centre providing day opportunities for adults with LD living at home with their families
Learning Disability	Dominion Centre and The ARC	Certitude	LBE	Resource centre providing day opportunities and activity based respite for adults with LD living at home with their families
Learning Disability	My Space	Yarrow	LBE	Resource centre providing day opportunities for adults with LD living at home with their families
Autism	The Acton Centre	National Autistic Society	LBE	Resource centre providing day opportunities and activity based respite for adults with autism and challenging needs living at home with their families
Learning Disability	Solutions	Solutions Social Care	LBE	Community and centre based day opportunities and activity based respite for people with LD
Learning Disability	Abilities Development, All Saints Hall	Abilities Development	LBE	Resource centre providing day opportunities and activity based respite for adults with autism and challenging needs living at home with their families
Learning Disability	Impact Theatre	Impact Theatre	LBE	Community arts theatre – creative and performance arts provides activity based respite
Learning Disability	Real Me	Ealing Mencap	LBE	Centre and community based day opportunities for people with LD living at home with their families
Learning Disability	Beadsew Crafty	Beadsew crafty	LBE	Social enterprise providing day opportunities for adults with LD living at home with their families
Learning Disability	Monthly Drop in	Ealing Council / London North West Healthcare NHS	LBE	Monthly surgery for families hosted by the Community Team for People with Learning Disabilities
Learning Disability	Peer support for Carers	Certitude and Ealing Council	LBE	Regular coffee mornings for carers using the Short Break Service and 19 Haymills Close
Learning Disability	Carers Support Group	London North West Healthcare Trust	LBE	Bi-monthly support groups for carers, facilitated by LD psychologist
All carers	CCG - Carer Friendly GP Project	Carers Centre	CCG	To provide training and support to all 78 GP practices to help them achieve “Carer Friendly” status by raising awareness and understanding of the needs of carers. The practices have dedicated notice boards that allow a focus in the waiting areas for raising awareness about unpaid carers and support available at the

Target Group	Service Name	Provider	Commis-sioner	Description
				Carers centre and in the borough in general. A Carers policy is being adopted by practices and over half of practices are using the single referral form for Carers. Practices refer to the Carers Centre to ensure that Carers get ongoing support and signposting services.
Mental Health Carers	Support workers	West London Mental Health Trust	LBE	Two Carers Support workers are employed in Ealing as part of the Recovery Teams (secondary mental health community teams). As well as supporting individual carers and promoting assessments, they help with facilitating carers support groups and a Carers Strategy Group for Ealing.
All adults, including carers	Ealing Improving Access to Psychological Therapies (IAPT)	West London Mental Health Trust	CCG	This service is available anyone in Ealing who has a mild to moderate common mental health difficulties such as depression and anxiety. Carers can be vulnerable to these issues and many do access the IAPT service.
Substance misuse	Support Group and individual counselling	Ealing Centre for Independent Living	LBE	Ealing Centre for Independent Living (ECIL) has offered individual counselling for group members and also agreed to facilitate a regular group. At ECIL, family and carers of drug and alcohol users are able to access a range of carer support initiatives including benefits and money advice, information about carers' assessments and wider carer activity groups and events. RISE attend the drug and alcohol group on a monthly basis to offer specialist advice and support either through Q & A sessions or presentations on topics identified by the group members. From April 2017, the needs of drug and alcohol family, friends and carers will be addressed by Ealing's Carer Support Service, a "One Stop Shop for Carers" offering direct information, support and referral on to other appropriate services, as well as a space for a range of carer support activities, and a safe and welcoming place for carers to meet one another.

7. Consultations/Feedback with Carers

7.1. The Council and the NHS try to involve carers in the development and ongoing monitoring of services as well as in individual care planning. From time to time during the year there are specific consultations with carers about certain topics or more generally about their experience. The table below sets out the key themes which we have heard about in our consultations with carers over the last few years.

Group of carers	Themes
All carers	A Carers Survey was undertaken in Ealing during 2014-15 (see foot note for details)[17]. The Survey found that: Overall satisfaction with support or services received is the area that needs most improvement across all the borough services Being involved or consulted as much as carer wanted to be, in discussions about the support or services provided to the person cared for is the top outcome that needs improving within social care. In response to questions on quality of life the more positive responses came from those carers receiving services from the voluntary sector **Having time to do the things they want, having control over their daily lives and social participation are the top three outcomes that need improving the most.** **Communication / Support** Carers want a named social worker Carers want one point of contact. They are frustrated at having to keep explaining their situation to different people (within social care and across different agencies) Continuity of social workers – too many changes, which relates to the point above. Carers want more support and regular contact with a social worker **Respite** Respite – confirmation of respite is very last minute, which makes it difficult to book holidays and check placement options There is not enough respite available Not enough information about care homes, to make an informed decision about respite placements Some carers don't have any confidence in the care workers, and are afraid to leave their cared for with them

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[17] A Carers Survey was undertaken during 2014-15. The survey sample consisted of 770 carers who had been assessed either directly by Ealing Social Care (SC), West London Mental Health Trust (MHT) or Voluntary Sector Organisations (VS) in receipt of a grant from the Council. 273 carers completed a survey. Social Care received roughly 50% of the total responses and the MHT & the VS received roughly a quarter of the total responses each.

Group of carers	Themes
	Homecare Issues with care workers turning up late Carer workers are not adequately trained Poor service from care workers **Information / Other** Social workers/agencies do not listen, are not flexible, and try to fit people into boxes Cuts to services are having a negative effect on them Information is difficult to find and not readily available It is difficult to get to meetings, as there is no one to look after their cared for Carers are unsure of services available to them General concerns about the future Some carers are ageing and have problems of their own More feedback from other carers consultation events More funding for social care to support the care Act No Charging for Carers More breaks for Carers/respite/sitting services Carers with Mental health issues, must be key partners Carers of people with Dementia must be supported properly Young carers must be identified and supported More support for Adult carers More events looking at raising awareness raising with carers
Young Carers	A young carers day round table event was held in Ealing in January 2016 One of the prevalent themes that came out was ‘being understood’; the young carers wanted to be understood by others and they wanted help understanding things The young carers also expressed the frustrations they face in their everyday lives that others do not even have to consider. Frustrations like going to pick their parents prescription but being told they cannot because they are not 18.
Young carers and Parent carers of children with additional needs	**Information at the time of diagnosis** The impact of the news of a child’s additional needs is critical to the lives of parents, children and their families. While there have been improvements over the past couple of years there is still scope for improvement around. The way by which the child's diagnosis was given Clarity of information provided to parents Ease of access to services Getting help at the right time **Satisfaction with services** Improvement in satisfaction with services over the years however there is room for improvement **Communication with services** This has shown some improvements but as the parental comments demonstrate it can still be patchy; parents felt some services were poor at responding to phone calls and emails. Parents also indicated that some

Group of carers	Themes
	services were poor at communicating the processes and criteria for accessing service **Coordination and key working** Past research on the experiences of families with disabled children found that one of the most common causes of problems for families was lack of coordination of services and lack of key workers. **Information Sharing** Parents indicated concerns within the professional network and during transition to schools within and outside the borough. **The voluntary sector and information to families** Talking and working with parents in Ealing gives clear evidence that services from the voluntary sector are highly valued by parents. Access to information is still a concern for families. As part of the Aiming High initiatives this was addressed and an information officer post is now provided as part of Ealing Council's Family Information Service. The Ealing Help website is very helpful in providing up to date information and the PESTS handbook has been updated and augmented as it provides a valued alternative to online information. **Care Packages and Short breaks** Not many respondents in this survey used existing short break and leisure opportunities. Families who receive direct payments generally felt that it enhanced the quality of life for their child in terms of accessing suitable provision, which allowed the parent's choice and respite. **Disability Network register** Increase in the number of names now on the register which is encouraging, but still not enough to make it effective as a planning tool.
Carers of people with learning disabilities and autism	There were two local engagement events with carers of people with learning disabilities and autism. They gave the following suggestions for improvements: . Pro-active planning and support would help manage some of the anxieties carers feel about their relative's future Emphasis on maintaining family values and identity, and family centred support Better support for families to stay healthy and well, including flexible respite and use of contingency support hours to allow the carer to attend medical appointments More access to local respite One main point of contact who co-ordinates the support provided. Creating family networks and more opportunities for families to meet which enable the sharing of information, support and experiences

Group of carers	**Themes**
	All health services should make reasonable adjustments to enable their relative to easily access them. This includes GPs making home visits if the person finds attending the clinic difficult.
Carers of people with mental health problems	Carers of people with mental health problems meet regularly and provide peer support to one another, as well as taking up generic issues with service providers and commissioners. They have identified a number of issues which they want addressed: a discrete service for mental health carers, with a team to address their needs family therapy services family help before, during and after sectioning/hospitalisation of a family member/friend training for carers with information, communication skills and coping strategies respite care peer support/befriending liaison with carers' groups and carer support workers 24/7 advice line working with care coordinators advocacy Carers have participated in the West London Mental Health Transformation Board and identified an action plan for including carers appropriately in strategic commissioning and development of services. The plan is attached at Annex A. Like Minded (North West London – wide programme working with transformation of mental health services) worked with the West London Collaborative (social enterprise made up of 'experts by experience') to host an event called 'Who Cares for Our Carers'. The event looked at real life situations and problem-solving with professionals, carers, and service users working together. Carers are involved in service development and redesign, for example in being part of the West London Mental Health Transformation Board and the Ealing Mental Health Partnership Board and Ealing Implementation Group for Planned and Primary Care. Coproduction with Carers is seen as a priority area for development, and has been addressed as part of the West London Transformation Board programme.
Carers of people with substance misuse problems	Carers of people with substance misuse problems have expressed concern at the changes to the support group formats that previously existed.
Carers of people with dementia	Carers have been involved in North West London in developing a specification for dementia care which includes a set of "I statements" identifying the needs of carers of people with dementia. These are attached in Annex B.

8. Identified Gaps

8.1. From the information above, we know that there are probably around 35,000 carers in Ealing. Of these, only a small proportion are known to the Council and/or their GP. We think that there are particular communities where carers do not self-identify or seek support. We know that our services are not spread across the whole geography of the borough.

8.2. Census 2011 data reveal that there were 3,200 young carers aged 0-24 years old living in Ealing; of these, 700 were aged under 15 years. This is thought to be a significant underrepresentation of the true number of young carers in the borough. Based on national research[18] it is estimated that there may be around 4,000 carers aged 17 and under in Ealing[19].

8.3. The issues that have been raised by carers over the last few years are not new, and in some cases the services are there but they may not have enough capacity (for example limited access to respite care) or be flexible enough to meet people's needs. NHS and Social Care Staff may still not always be aware of carer needs and may focus solely on the client, neglecting to work in partnership with the family or friends of the client. We need to explore and expand the use of personal budgets for carers and for clients to increase the flexibility and responsiveness of their care package and involve family and friends in the planning and implementation of care, with the consent of the client.

8.4. In particular, people may not realise the impact caring has on young carers in a family, whether they are caring for a parent or sibling. Information and communication is a repeated theme from all types of carers, and a request for respect and acknowledgement of their role in the "care plan" of their family member.

8.5. There are currently no services specifically targeted at carers who look after terminally ill people.

9. Recommendations

From the information gathered above, on needs, services, policies and practice, we have identified the following recommendations for commissioners.

9.1. The outcomes for carers identified in the current Ealing Carers' Strategy are as relevant today as in the past. Within these outcomes some progress has

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[18] BBC News press release http://www.bbc.co.uk/pressoffice/pressreleases/stories/2010/11_november/16/carers.shtml (accessed May 2016)

[19] The estimated number of carers aged 17 and under in Ealing has been by calculated by applying the estimated proportion of children who carry out personal care of someone in their home either "a lot of the time" or "some of the time" to the estimated population of people aged 17 and under in Ealing.

been made, but it is clear from the JSNA that there are still gaps to be addressed, both in relation to the number and type of carers being identified and provided with support, and in relation to the range and capacity of services being delivered.

9.2. The following recommendations are made to achieve the agreed outcomes.

Outcome 1 - Carers as Partners in Care - A Whole Family Approach

What? Ensure that health and care staff take a whole family approach and consider the needs of carers when developing a care plan to meet an individual's needs including, where possible, a clear and continuous point of contact.

How?

Develop and implement a cultural change programme with health and social care staff so that they understand and apply it in working with individuals and their families and friends. The Triangle of Care approach in Mental Health emphasises cares as partners in care and similar approaches should be applied for other care groups.

Carers' rights to an assessment and services should be made clear to them and made available as required under the Care Act, through Carer Support Workers or other mechanisms.

Statutory organisations should each identify a "Carers' Champion" to ensure that the approach is understood and applied throughout the system and that reasonable adjustments are made to accommodate the needs of carers.

Does it work? This could be measured through successful implementation of Carers' Champions across organisations; increased level of Carer Assessments offered and/or undertaken or contact with Carer Support Workers (where appropriate); evaluation of carer satisfaction with involvement in care planning.

Outcome 2 - Improving Carer Awareness and Access to Support

What? Increase carer awareness and identification, access to carer support, and involvement in service monitoring and development across the whole borough and all communities.

How? A continuing campaign on Carer Awareness with different parts of the community including schools, faith communities and local centres; and encouragement of carers to access carer support services and establish peer support networks.

Does it work? This could be measured by an increase in the total number of carers of all ages and backgrounds who self-identify and who access information and support; and a growth in carer support networks in different settings.

Outcome 3 - Balancing caring with a life apart from caring for all carers

What? Continue to encourage health and care professionals to identify carers and signpost them to a carer assessment or to carer support services to enable carers to balance their caring responsibilities with life away from caring. This should include effective use of direct payments, assistive technology and information/training tailored to the needs of the family.

How?

Implement a rolling programme of training and briefing staff on services available and monitoring referrals and care plans for outcomes to ensure they are making use of all available options. Options such as direct payments, assistive technology and appropriate information, training and counselling should be made available.

Continuing contact between Carer Support Services and health and care staff so that routes for referral are well used and new staff are aware of the need to identify carers and refer them for support.

Does it work? This could be measured by increased use of direct payments and assistive technology and higher satisfaction from carers in relation to care planning and contact points; an increase in referrals received by the Carer Support Services from different professionals and an overall increase in carers linked to the carer organisations.

Outcome 4: Development of Information, Training and Peer Support

What? Increase the amount of training, information and peer support available, tailored to the needs of different types of carers (eg young carers; carers of people with dementia; carers of people with substance misuse problems) and using different modes of communication.

How? Build information and training for carers into care pathways for people with particular conditions or needs; link carers with other carers in the same position so they can support one another.

Does it work? This could be measured by audit of appropriate reference to carers in care pathways and guidance on materials to inform the carer; an increase in peer support groups for particular carers; carer satisfaction within particular groups of carers (were you given information, training, support, a link to other carers?).

Objective 5: Development of Respite Care

What? Additional respite care – including a range of offers including sitting in services, short breaks and residential respite, flexibility to meet different needs (eg weekends, planned holidays or urgent circumstances) and greater confidence in quality of care provided.

How? The Council and providers should work together to develop a more flexible and responsive range of high quality respite care offers, including sitting in services, short breaks, residential respite and expanding the Shared Lives approach.

Carer views on the quality of care should be taken into account in monitoring services.

Does it work? This could be measured by carer satisfaction with time available to do what they want in their lives, and reduction in care package breakdown.

Objective 6: Supporting Young Carers

What? Protect children and young people from inappropriate caring, and ensure they have the support they need to learn, develop and thrive and enjoy positive childhoods.

How?
Raise the awareness of young carers across and will focus on developing promotional material, such as a DVD, leaflets and events involving young carers to ensure their voice is heard

Training courses for young carers - Consider holding training courses for young carers, so that they are educated on various conditions and illnesses that affect the people they care for and also useful courses such as health and safety, First aid / CPR.

Training for frontline staff - Develop a training plan for frontline staff so that they are educated and aware of what the needs of the young carer are.

Health of the young carer - Explore how CCG and LBE can ensure that the health of young carers is a priority after some of them shared that when they are unwell there is no one to care for them.

Does it work? Meet with and work with young carers to develop and evaluate on going.

Objective 7: Provision of Support to Parent Carers

What? Expand the provision of short breaks services and advice, information and counselling to parent and other carers of children with disabilities and complex health needs.

How? Consider how to make use of limited resources to continue to make this service available as far as possible, and to improve the quality and responsiveness of services.

Does it work? Evaluate the impact of the short breaks and counselling services with families.

Objective 8: Carers Involved in Service Monitoring, Design and Strategic Development

What? Ensure that carers are involved in service monitoring, design and strategic development.

How?

Service transformation or changes should include an assessment of the impact of the proposals on carers, as part of the Equalities Impact Assessment, with appropriate mitigating actions.

Ensure an effective carer recruitment and training programme for involvement in work to monitor, design or develop services and sustain the Carers Forums or mechanisms for bringing carers together.

Enable carers to participate in planning and monitoring of services through: recruitment of volunteers; training; peer support; reimbursement; reasonable adjustments to meeting times and locations and funding should be made available to facilitate this.

Statutory and voluntary organisations should work with Carers to identify ways in which social media can be used to communicate with and involve carers in care, and in service development.

Does it work? Include Carers in Equalities Impact Assessments; carer recruitment and training programmes in place and functioning; Carers' Forum in place and functioning; carer voices heard in all appropriate boards and committees; social media being used effectively to communicate with carers; carer satisfaction.

Annex A – Transforming Mental Health in West London through Co-Production with Carers: Recommendations

Transforming MH in West London through Co-Production with Carers - Recommendations				
	Recommendation	**Action By**	**Lead Person**	**Time**
1.	The Triangle of Care approach needs to be understood and adopted by mental health service commissioners and providers as part of a cultural change programme, including clarification of when and how information should be shared between staff and carers.	CCGs Trust GPs		By June 2016
2.	Commissioners and providers should each identify a “Carers’ Champion” to ensure that the Triangle of Care approach is understood and applied throughout the system.	CCGs Trust		By June 2016
3.	Carers’ rights to an assessment and services should be made clear to them and made available as required under the Care Act, through Carer Support Workers or other mechanisms.	Local Authorities		By June 2016
4	The Trust, CCGs and Local Authorities need to have an effective carer recruitment and training programme for involvement. Carers should be logged on IT systems with an indication as to whether they would wish to be involved more broadly, so that they can be invited to participate. Each borough/CCG/unit should have a Carer Forum or mechanism for bringing carers together.	CCGs Trust Local Authorities		By Sept 2016
5.	Carers’ representatives should be enabled to participate in planning and monitoring of services through: recruitment of volunteers; training; peer support; reimbursement; reasonable adjustments to meeting times and locations and funding should be made available to facilitate this.	CCGs Trust Local Authorities		By Sept 2016
6.	Service transformation or changes should include an assessment of the impact of the proposals on carers, as part of the Equalities Impact Assessment, with appropriate mitigating actions.	CCGs Trust Local Authorities		From April 2016
7.	Statutory organisations should work with Carers to identify ways in which social media can be used to communicate with and involve carers in care, and in service development.	Trust Local Authorities		From July 2016

Annex B - Locally defined outcomes for carers of people with dementia[20]

Vision Statement	Objective	Outcome	Measure
I was listened to by the GP when I said that my relative had some memory/ behavioural problems	Improve the local diagnosis rate and reduce stress on family carer who knows there is a problem but no one listens	Increased number of individuals will receive a timely diagnosis Increased number of people referred early to dementia support groups	Increase in referrals to memory assessment services. Increased number of people on dementia registers Increased number of patients and carers getting timely support at the early stages of dementia in order to put in place POA and address other legal and financial issues
I understand so I make good decisions and provide for future decision making in my caring role	Reducing stress and its consequences for family carers	Family carers receive high quality and meaningful information, advice and support. The patient and carer will be supported by a care navigator, dementia advisor or care coordinator from diagnosis and at all stages of the care pathway Information should be presented clearly and in different formats as required – carer training programmes	Individuals and carers report that they are appropriately supported
I get the support and ongoing guidance to help me care for my relative	Helping me to continue to care for my relative and allowing me to lead my own life to some extent	Clear support and guidance for individual carers for the entirely of the journey Guidance and advice on all the practical issues of caring for someone with dementia Referral to psychological therapies if required (IAPT services) Raised awareness and access to information	Reduction in carers no longer being able to care- Method and measures to be agreed with commissioner, carer rep and provider Robust information sharing systems in place Reduction in carer illness and psychological problems Patient and carer feedback

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[20] with acknowledgement and grateful thanks to Barbara Benedek

Vision Statement	Objective	Outcome	Measure
		and advice Support along the patient and carer journey from a named care navigator, dementia advisor or care coordinator	
I am treated with dignity and respect and my views are listened to by clinicians, social workers and other support workers	Reducing the stress of my caring role and providing me with support and help in making decisions	All staff have access to appropriate training in dementia. Range of opportunities to engage and listen to family carers. Issue raised are identified and acted upon.	Individuals are treated with dignity and respect (based on consistent method of gathering feedback)
I know what I can do to help myself and who else can help me	Reducing stress and helping me lead a fulfilling life	There is a clear person centred plan in place for every carer known to the service.	Number of people with named carer support worker
I can enjoy life and am helped to have the necessary respite from caring	Reducing stress and helping me lead a fulfilling life	Carers for people with dementia have access to a choice of appropriate activities and services which provide stimulation for the person with dementia and respite for carers	Choice of access is evidenced from consistent method if gathering feedback
I have enough support and respite in my caring role that I have time and energy to participate in engagement activities as well as life enhancing ones (theatre, friends etc)	Provide invaluable input from family carers who have knowledge from years of experience caring for people with dementia	Clinical and social service support becomes more person centered and is able to respond more appropriately to the needs of the person with dementia and their carers	Good practice evidenced from consistent method if gathering feedback
I don’t have sole responsibility for end of life conversations with the person I care for. Clinical services are able to engage the person with dementia in this conversation as it is very hard for close relative to do this	End of Life Care plans made with the person with dementia – reducing the stress and anxiety of the carer who may not know what the person they care for really wants	The dementia pathway from late stage dementia to EOL is clear and well communicated to family carer and clinicians	Number of people with dementia with advance directives in place