



Brent Carers Strategy 2012-2014

Supporting Carers



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Introduction

At some point in our lifetime, many of us will either be a carer or know someone who is. You may not necessarily choose to be a carer; it could be sudden due to a health incident, or gradually due to a deteriorating physical or mental health condition. We know it can be exhausting and lonely, it can also be rewarding and satisfying on many levels, however being a carer can affect your own health, education, finances, employment opportunities and can have impact on relationships with friends, family and also the person you are caring.

NHS Brent and Brent Borough Council recognise the contribution you as carers make. Without your input the care economy would face tremendous difficulties.

When the government published the National Carers Strategy in 2010 NHS Brent identified our local strategy for carers ensuring that it also incorporated Better Care Closer to Home to meet your local needs. This strategy for the period of 2010 – 2014 highlights our commitment to local community services to meet the needs of the carers and the cared for. Although there are many corporate structural changes going on within the NHS at the moment with changes in how we purchase our services, we still have the needs of the carer in a priority position. We will explain those changes in a moment; however here are a few local facts for you to think about:



- Brent has a population of 311,200 (Government Census July 2011)
- We know of 22,900 carers within Brent
- **Brent** is **ranked** 53rd out of 354 **boroughs** in the Index of Multiple Deprivation (2007)
- A third of residents are under 19 years of age
- Over 35,000 are over the age of 65
- 55% of residents are from black and minority ethnic (BME) communities

How your health services will be commissioned in the future.

NHS Brent Primary Care Trust will not exist by April 2013. Commissioning will be the responsibility of Brent GP's who have formed a Clinical Commissioning Group (CCG) and once they have gone through the formal authorisation process with the special health authority NHS Commissioning Board, they will be known as NHS Brent CCG. This is obviously subject to final authorisation. Both groups will run alongside each other until the formal handover in April 2013 to ensure a seamless transition of governance, commissioning and management processes. Your local GP's will have a keen interest and involvement on the provision of your local services to ensure that patient and carers have their clinical needs met.

So, what is a Carer?

Many people who are carers do not always recognise themselves as carers. They understandably see themselves firstly as a parent, spouse, son, daughter, partner, friend or neighbour. In many ethnic minority communities, the idea of being a carer is not isolated from their normal family role.

“I’m not recognised as a carer. In China you wouldn’t say I’m a carer, you automatically care ‘because you should’... It’s the Chinese family way, our culture” (Quote from a Carer) (HM Government “Recognised, valued and supported: Next steps for the Carers Strategy 2010)

However, whilst many of you do not consider yourselves to be a carer, in society, and for the Carer’s Strategy, we now have a formal definition on what a carer is.

*A carer is someone of **any** age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems*

We often assume that carers are usually adults. This is not always the case. There are a special group of young carers whom we recognise need special support.

“Young carers are children and young people who look after someone in their family who has an illness, a disability, or is affected by mental ill-health or substance misuse.

Young carers often take on practical and/or emotional caring responsibilities that would normally be expected of an adult. The tasks undertaken can vary according to the nature of the illness or disability, the level and frequency of need for care and the structure of the family as a whole.

A young carer may do some or all of the following:

- *Practical tasks, such as cooking, housework and shopping.*
- *Physical care, such as lifting, helping a parent on stairs or with physiotherapy.*
- *Personal care, such as dressing, washing, helping with toileting needs.*
- *Managing the family budget, collecting benefits and prescriptions.*
- *Administering medication.*
- *Looking after or “parenting” younger siblings.*
- *Emotional support.*
- *Interpreting, due to a hearing or speech impairment or because English is not the family’s first language.*

Some young carers may undertake high levels of care, whereas for others it may be frequent low levels of care. Either can impact heavily on a child or young person.”



Often the caring role develops slowly – for example with the onset of dementia. When a family member or friend is suddenly in need of your support such as after a stroke, it can be difficult to find the time and energy to think through what the future may hold in terms of a caring role.

Many families are reluctant to ask for help – especially for those who are ill with mental health problems because of the stigma; discrimination and bullying that are still too often

associated with these conditions. Many young carers remain 'hidden' from health, social care and education services – partly as a result of ours and other services needing to do more to identify them but also because of family fears that their young carer will be taken into care or because the young people themselves are concerned about the reaction of others and bullying by their peers. Parents of children with long-term conditions or a disability often feel 'invisible' and those they are just seen as parents.

The result of that is that many of you who are carers are not offered or you don't seek help to get information and advice on the specific illness or condition of the person you are caring to help you care better at home. You may also find it hard to know how to access information and advice on how to balance your caring role with other responsibilities and opportunities in your life. Decisions about education and employment support from the welfare and benefits system, and your own health and well-being may be ignored. Many of you older carers may feel socially isolated – especially if you are caring for someone with dementia, have health problems yourself, or find it difficult to access public transport.

Access to relevant and timely information and advice is also vital throughout your caring role – particularly at times of significant change, for example to help patient carers negotiate the transition from children's services to adult health and social care services and of course, the transition from illness to end of life.

Our vision for carers in Brent

Our vision is for you, as carers, is to be recognised as key and expert care partners. We are trying to create and sustain a positive environment that enables you to be supported in your caring role for as long as it is practically possible.

Our strategy has been developed jointly with Brent Council on behalf of the multi-agency Carer's Partnership Board. It reflects national guidance and developments, surveys and patient/carer consultations, local pan London policies and changes in national policy and guidance and best practice.

It incorporates the changes happening within the NHS with the emergence of the NHS Brent Clinical Commissioning Group (CCG) and the developing models of provision of services for information and advice for Carers in the borough.

NHS Clinical Commissioning Groups

From April 2013 NHS Brent CCG will be the new statutory body and will commission health services for the people of Brent.

The CCG is a clinically led membership organisation made up of 67 general practices across Brent. Its members (the Brent GP practices) are responsible for determining the governing arrangements of the CCG which must be able to effectively discharge its responsibilities.

NHS Brent CCG's mission is to commission services that improve the health and well being of all patients and carers within Brent. Their aim is to secure sustainable care so Brent patients receive modern, responsive, high quality yet cost effective care. They aspire to reduce health inequalities within Brent's diverse population and improve the health and wellbeing in partnership with patients, their carers and the wider community. The core mission for NHS Brent CCG is to ensure needs led care that is sustainable, fair and cost effective.

Brent GPs recognise the importance of Carers and the vital role they play within the NHS. They respect you as expert care partners and support you being treated with dignity and staying mentally and physically well.

This strategy demonstrates Brent’s commitment to carers and responds to the invaluable feedback we frequently receive from you as carers locally and nationally. We will use our resources to sustain and build on a range of existing initiatives and activities in partnership with our local care agencies including voluntary agencies and more importantly you who are carers. The strategy gives direction for developing local support and services for carers over the next few years. We are confident that Brent will continue to improve the quality of life, health and well being for you who are living and caring in Brent.

Strategy – National Thinking...



- NHS National Operating Framework 2012/13
- National Carer’s strategy
- Dementia Strategy
- National Service Framework for Long-term Conditions
- Valuing People Now
- End-of-Life Strategy
- National Service Framework for Older People,

Strategy – Local Thinking...

- NHS North West London Commissioning Strategy Plan 2012-15
- NHS Brent Better Care, Closer to Home
- NHS Brent Eden Strategy
- Brent Health and Wellbeing Strategy
- Joint strategic Needs Assessment
- Aiming High for Disabled Children

We recognise and value carers as equal partners who have a right to a life outside of their caring role. We want carers to have choice and control over the services you receive which will be equitable and accessible. We will promote a carer focussed approach between all professionals, volunteers and service providers and we will continue to promote and involve you as carers as equal partners in our service planning, delivery and monitoring of the services you need.

Actions Speak Louder than Words

We have set actions which we have been building on since 2009 and will continue to deliver over the coming years. We want to share our vision and commitment to you by outlining our plans and what we are going to do about them to ensure you have a service that meets your needs.

Action 1 – Integrated and personalised services for carers

<p>We will support carers to have integrated and personalised services by:</p>	<ul style="list-style-type: none"> • Ensuring that carers are identified, recognised and respected by all agencies and are involved in the design and delivery of services • Providing timely accessible and relevant information to all carers • Providing training for key professionals in health and
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	<p>social care to support carers</p> <ul style="list-style-type: none"> • Ensuring carers have access to training to support their caring role • Improving data collection about carers and their caring experiences across all agencies supporting carers • Ensuring that the Local Improvement Networks focus on carers issues and monitor the effectiveness of local services
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Action 2 – Carers will have a life of their own alongside their caring role

<p>We will help carers have a life by:</p>	<ul style="list-style-type: none"> • Increasing the number of carers who have received an assessment of their needs or subsequent review • Increase carers access to flexible breaks service • Increase the number of carers accessing Direct payments and personal budgets • Work together to jointly commission services for carers in a personalised way • Provide prompt, convenient high quality services to people who use services and carers • Ensure all carers have access to emergency replacement care through the Carers Emergency Support Service • Ensure carers assessments are linked to telecare or other assisted technology
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Action 3 – Carers are not forced into financial hardship by their caring role

<p>We will direct you to the best possible information by:</p>	<ul style="list-style-type: none"> • Ensure that all carers have access to financial and welfare benefit advice • Provide information and appropriate advice for carers in employment, training or education so that they can combine their caring roles with work or study
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Action 4 – Help carers manage their own physical and mental wellness

<p>We will help with wellness by:</p>	<ul style="list-style-type: none"> • Develop joint working with GP's and health professionals to recognise and support family carers in their practices and avoid hospital admissions for those they care for • Improve carers access to health services and other health promotion initiatives • We need to develop services that reduce the negative effect of caring
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	enables carer to cope and encourages them to stay independent and healthy
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Action 5 – Children and young people protected from inappropriate caring responsibilities learn, develop and thrive

We will give support by:	<ul style="list-style-type: none"> • Identify a senior officer with lead responsibility for young carers • Develop a joint protocol between Adults & Children services • Identify and support young carers • Ensure services are available to support young carers to they can be children first • Ensure young carers are supported to stay in education, training, employment and leisure activities
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Action 6 – Carers are recognised

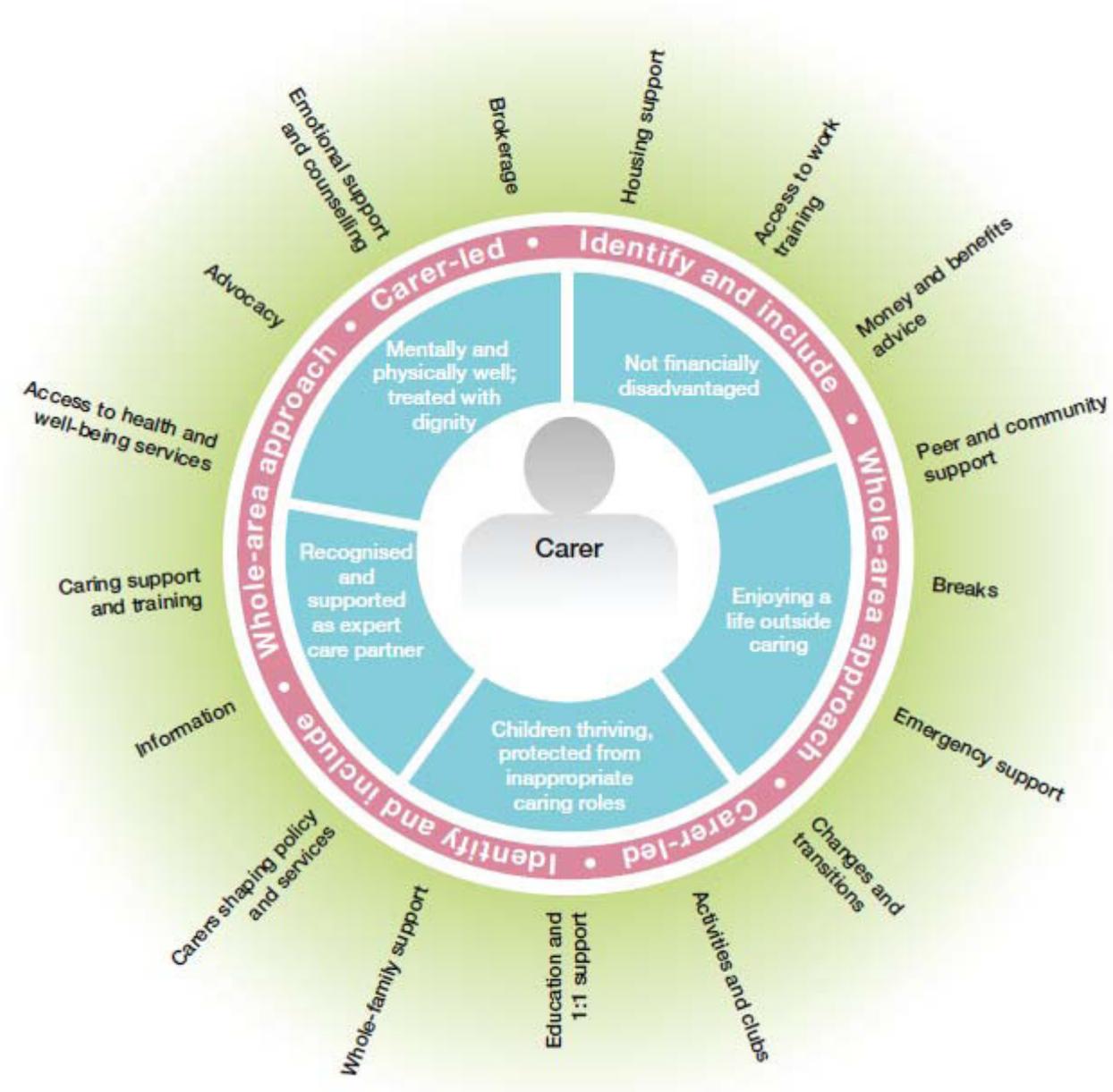
We will:	<ul style="list-style-type: none"> • Raise awareness of carer issues within the wider community
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How are we going to do this?

We are going to deliver carer support and information through a Carer Hub model as recommended through the Princess Royal Trust for Carers. This model, illustrated below, identifies that at the centre of the circle are Brent carers. The circle surrounding the carers show the outcomes we want to achieve to improve your quality of life. This model provides a useful tool to ensure all actions are achieved through working together. The actions in the outside circle are interlinked and achievements in one area may affect more than one outcome.

This model came from the Princess Royal Trust for Carers 2009 entitled *“Moving Towards Personalised Services for Carers”*

Comprehensive Carer Support Model



Local Needs of Local Carers

Brent is one of the most ethnically diverse boroughs in London. It also has some of the most deprived wards. Brent is going through major regeneration programmes to improve the built environment with many local initiatives to get long term unemployed and disabled residents back into jobs and or training. Developments will also bring renewed opportunities for affordable housing and work opportunities for the area. We need to ensure that carers are included and share in the benefits of this rejuvenation. Here are a few more facts on caring



- Many carers suffer social isolation, ill health, long term poverty and disadvantage. Paid work can offer carers financial independence, social contact, friendship and improved self esteem (Carers UK 2003)
- Research led by Carers UK found that the majority of working carers say they need at least one type of formal service which they are currently not receiving
- One third of carers in full or part-time work are struggling financially
- Very few working carers are getting breaks, and less than a quarter has access to respite care services.

Population projections suggest that the numbers of older people from black and minority ethnic communities and faith communities is set to rise significantly over the next 10 years. The largest increase is likely to be in the Asian population which is expected to increase to just under a third of the local population. Asian groups tend to have higher rates of diabetes and heart disease and develop these about ten years earlier than white groups. Whilst black groups have higher rates of diabetes, hypertension and stroke, and again tend to develop these earlier. This will not only impact on the demand for healthcare but will have an impact of people of working age – many of who will become carers (Source Joint Strategic Needs Assessment). Now for a few more facts on caring:



- Only a quarter of working carers feel they have adequate support from formal services to enable them to combine work and care.
- Carers lose an average of £11,050 annually by taking on significant caring responsibilities (Out of Pocket – The Financial Impact of Caring. Carers UK 2007)
- Over half of all carers have a caring related health condition (Carers UK 2003)

We have done the facts, now here are the statistics just for Brent:



- There are 22,900 known carers in Brent at this present time. This means that you as carers make up 12% of the overall population in Brent. Now you know you are not alone!
- 7,888 carers are providing between 20-50 plus hours of care each week
- 1,023 young carers (between the age of 10 and 17) providing between 1 and 50 hours of care a week to a parent, sibling or relative
- 14% of known carers are of working age (18-65) provide between 1 and 19 hours of care each week
- 3,333 (or 2% of you) carers of working age are providing more than 50 hours of care a week

- 10,499 carers of working age are female and 7,853 carers of working age are men
- 3,402 carers aged 65-90 plus years provide between 1-50 plus hours of care each week
- Women have a 50-50 chance of providing substantial care by the time they are 59. Men have the same chance by the time they are 74 (Census 2001 NSO 2003)

These figures compare nationally with the majority of carers who are of working age.

Nationally one in eight adults is currently a carer and 2.3 million adults become carers every year. There are over 6 million carers in the UK. 3 million carers juggle this care with paid work (Carers UK 2007)

Joint Partnership Working

We will not be making these changes or delivering these services alone. NHS Brent CCG and Brent Borough Council are involved with Brent Carers Partnership Board which is a multi-agency partnership to ensure that carers are supported effectively in Brent. Brent Carers have helped to identify some of the gaps in service provision, monitoring the effectiveness of services and influencing policy development and practice for health and social care. They have also played a significant role in raising the profile of carer's issues. These have included:

- Developing relationships within the voluntary sector
- Improving the level of support to carers through training of health and social care practitioners
- Promoting National Carers Week and Carers Rights Day in Brent
- Linking into the national and regional carer's networks

This involvement has ensured that good practice has been shared which is particularly important for those who support carers from black and minority ethnic communities.

Improved Funding and Resources

The Department of Health provides local authorities with an annual grant to support the development of services for carers. There is a recognised clear and transparent process in allocating the Carer's Grant. Information about how funding is allocated is shared with Brent Carers. Resources have been used to improve and build up the services we provide, including providing practical support as well as preventative services such as peer support and counselling. What NHS Brent CCG and Brent Council want is to commission carers services rather than pay for them through grant allocations, which is presently in place until 2013. There is over a million pounds being spent on Carers services at this time (2012/13).

At present NHS Brent and Brent Borough have a mixture of pooled and separate resources to pay for services for carers in Brent. The pooled budget between NHS Brent and Brent Borough is currently funded at £855,666 and this funding is commissioned for services that provide advice and information together with respite support. NHS Brent's contribution to this pooled budget is £200k which equates to approximately 25% of the overall budget. The pooled budget is allocated on the basis of 70% for respite and short breaks at home services and approximately 30% on information and advice services. Though there were plans for both Brent Council and NHS Brent to reduce their contributions to the pooled budget by 5% year on year as part of their individual organisational efficiency programmes, NHS Brent has not made this reduction for 2012/13 and does not intend to do so for 2013/14.

In addition to the contribution to the pooled budget NHS Brent also directly commissions additional services to support carers in the borough which in total amount to approximately £160k. This funding provides services for:

- Advocacy, signposting and training support for health professionals within acute settings such as the STARRS service.
- Healthcare competency training for parent carers of disabled children enabling children with complex health needs to be cared at home
- Early Support Service for newly diagnosed children with disabilities, enabling lead professional support for these families

In 2012 NHS Brent funded an additional £84k to Brent Carer Centre to enhance the information and advice service provision within primary care settings and provide support to young carers with specific focus on children and young people that are vulnerable as a result of parents with mental health or substance misuse issues.



This is to help professionals recognise young carers with specific focus on children and young people that are vulnerable as a result of parents with mental health or substance misuse issues. This isn't always that obvious and the young carers need to be identified quickly to ensure they have the right support to maintain their home lives as well as their education and social involvement.

Brent Borough Council's contribution to the pooled budget is approximately £600k of which £160k is for carer groups so jointly we have put substantial investment in the support of carers which will continue to grow.

Brent Borough manage some of the Mental Health budget of £132k – of which a substantial sum of £40k is for personal budgets which are developing as people want to manage how they get support and treatment. Brent Borough also provides some £51k for short breaks to those Carers of people with Mental Health needs.

NHS Brent contribute to the respite funds for “critical” and “substantial” risk at a sum of £131k although they are also investing in developing “Carer Breaks” at a moderate level within due course. Brent Borough Council's contribution to respite is approximately £364k – which again includes the DOH grant.

In all, both NHS Brent and Brent Council support carers by jointly funding 6919 breaks across eight carer groups which cover day breaks, leisure breaks and overnight breaks.

NHS Brent has also agreed additional investment of £500k for Carers from 2012 onwards in support of the following services:

- Primary Care Carer Liaison service who will be working directly with your GPs and their staff in order to inform each other about services for Carers. Providing advice, support, information and have a listening ear/emotional support to carer referrals made through GP surgeries.
- A Carers Register within primary care and GP practices. If you are a carer then you should identify yourselves to your GP or their receptionist so you can get on this register and get the support you are entitled to and need.

- Access to short breaks at home for those Carers who have moderate needs and are not currently receiving support through the council's respite services due not being high or substantial need and so not meeting the Fair Access to Carer Services criteria.

The Department of Health provides local authorities an annual grant to support the development of carers. In Brent, 55% of our total grant is used to provide breaks to carers from black and minority ethnic communities.

As part of reviewing the effectiveness of current arrangements, Brent CCG has been working collaboratively with the Brent Council, consulting with voluntary organisations as well as patients and carers about a proposed future development of carers' services.

We Can Hear You!



As already mentioned the Brent Carers Partnership has played a significant role in North West London in raising the profile of carer's issues. They have been involved in policy development. The consultation on the Green Paper "Independence & Choice" 2005 and more recently the Government Dementia Strategy in September 2008 are examples of where different groups of carers across the borough were involved in formulating Brent's response to government. Brent Carers review policy and practice through consideration of the Annual issues paper and highlights good and bad practice in relation to carers in Brent. The paper is also taken to the Community Care management Team and Health and Social Care Partnership Board.

In October 2011 a Standing Commission on Carers review was undertaken within Brent. Their recommendations back to NHS Brent and Brent Council identified the need for:

- Improved pathways into services so that carers understand where to go
- Carers to experience a similar journey through the system
- Improved communication of our vision with Carers
- More undertaken to reach hidden carers

In line with the report received from the Standing Commission on Carers we undertook consultation with key stakeholders about the proposals we want to develop to achieve:

- A single point of contact for carers
- Better co-ordination of services for carers
- Less duplication of services
- Better value for money
- Shared quality standards for Carers

It is our intention for the future to commission and provide Carers services following the Princess Royal Trust for Carers devised Carer's Hub model. The Carer Hub will put Brent carers at the centre of the circle and will offer a single point of access for unpaid carers, access to a comprehensive range of information and advice and will create greater links between Brent Council Adult Social Care and NHS Brent.

Meeting the Local Needs of Brent

At present we are working across the voluntary sector to ensure we can target help to the right areas. Carers from marginal and disadvantaged communities have benefited significantly – with the increased awareness especially with the Asian and African Caribbean communities. Together NHS Brent CCG and Brent Council have been active in promoting the Carers Week in the summer of 2012 and we have been involved in awareness days for some BME groups – these awareness days will continue and there will be ongoing publicity to encourage carers to participate in such events.

The Present at Brent

There is currently a range of health and social care services available to carers and the person they care for. Carers can contact the “One Stop Service” for information. This service is the gateway to council services and also signposts to other services not provided by the council. You can access the service direct via the internet or by telephone.



Adult social care provides practical help with every day living such as personal care, cleaning, shopping meals, aids and adaptations. Support for carers to take a break from caring, planned respite can be arranged at home or in a residential care setting. Emergency respite is also provided by the council.

To get the right help for you and those being cared for, your needs are assessed. The assessment is also for young carers over the **age of 16** providing support to an adult or older person (this is recognised under the ***Carers Disabled Children Act 2000***). This assessment is a great opportunity to discuss your specific needs. If you contact the One Stop Shop service they can refer you for a carer’s assessment.

The council has a duty to inform you of your rights to an assessment. Carers can request a separate assessment and receive services in your own right even if the person you care for refuses support.

Brent Council has the power to provide services to you. Carers eligible for services from adult social care must demonstrate that:

- You are providing “a substantial amount of care on a regular basis”
- There is a critical or substantial risk to the sustainability of the caring role.

The practice guidance of the Carers Act 2000 required Adult Social Care departments to grade the “extent of risk to the sustainability of the caring role” in 4 categories

- **Critical**
- **Substantial**
- **Moderate**
- **Low**

These 4 categories of carers need are aligned with those that apply when disabled people are being assessed under the community care legislation. The **critical** band covers risks that threaten life if action is not taken. The **substantial** band covers risks that will result in independence being severely compromised if action is not taken.

In Brent, carers can be eligible for services in their own right if there is a **Critical** or **Substantial** risk to their caring role breaking down now or in the future without support being provided. Carers with **Moderate** to **Low** needs will be provided with information and maybe signposted to other agencies. NHS Brent is doing more work on the **Moderate** to **Low** categories to see how we can help these groups more than at present.

Children and Families

Children and Families Services provide arrange of support to parent carers of children with disabilities. These include short breaks and respite care at home or in a residential setting and support in the school holidays.

For you to receive help Parent Carers of children with disabilities are also entitled to a carer's assessment and this will usually be completed whilst a child in need assessment is also being carried out on the disabled child.

Your local Voluntary Services who Support Carers

Organisation	Service
Asian People Disability Alliance Contact details 020 8902 2113	Befriending service for parent carers of children with disabilities and adult with range of disabilities
Crossroads West London (Formally Brent Crossroads)	Respite at home OP/PD & long term health conditions
Brent Carers Centre Contact details 020 8795 6240	Information and advice; Carers information Pack, Advocacy, support groups, consultation, training, welfare advice, young carers project and Flexible breaks fund provides carers with up to £300 to support them to sustain their caring role.
Elders Voice Contact details 020 8206 7511	Day Care respite for carers looking after an older person. Also provides information, welfare advice and support groups
Friends of African Caribbean Carers & Suffers of Dementia Contact details 020 8965 1112	Sitting Service in the home for carers caring for someone with dementia (Domiciliary Care Agency)
National Autistic Society Contact details 020 8962 3010	Brent Short Breaks Scheme for Carers looking after an adult or child with Autism
Harrow Helpline	Carers emergency support
St Lukes Hospice	Supporting Carers caring for someone at End of Life
Help Somalia Foundation	Identifying and supporting carers to access support

Services delivered by the voluntary sector include information, advice, advocacy and rehabilitative services which maintain carer's independence and improve their quality of life.

The Future is Brent

From what started out at Brent Carers Priority Action Group we have now created an active Carers Partnership Board. The Brent Carers Partnership Board has been successful so far in developing quality care service by listening to carers and engaging with the voluntary sector. NHS Brent CCG and Brent Council want to build on these foundations. This board has an increased number of carers as members with a greater say on how resources are used to support the carers in Brent and ensure that the statutory sector works in partnership to achieve our shared goals.

As part of reviewing the effectiveness of current arrangements, Brent CCG has been working with the Brent Council, consulting with voluntary organisations as well as patients and carers about a proposed development of a Carers Hub for Carer services. This hub model is based on evidence based research from the Princess Royal Trust for Carers which indicates that a Carers Hub model is more cost effective, results in equitable access to carer services, removes the need for you to navigate the multiple services, reduces duplication and improves the quality of services. It is anticipated that the consultation with you and patients as well as a decision by Brent Council on the proposed model of a Carers Hub will be complete by October 2012. NHS Brent CCG will continue contributing to the pooled funding arrangement which will support a reconfigured model of carers' services, in line with the Carer Hub model to enable:

- Single point of contact for Carers
- Better coordination of services for Carers
- Reduction in the duplication of service provision
- Better value for money
- Shared quality standards for Carers

The majority of our future resources are likely to be targeted primarily at those carers who most need support to carry on caring. However, in line with government policy, this strategy aims to deliver preventative services instead of reactive services.

What needs to Change

NHS Brent CCG and Brent Council have identified through consultation with carers and other organisations providing support to carers, that whilst the improvements highlighted above demonstrate significant improvements in support at a national and local level, a number of service gaps and problems remain in particular, inconsistency in assessing your needs and your health needs which are not consistently being identified. We have taken what you have said and we have identified areas for improvement which are set out below:

Speedy Assessment



We have found that we need to improve the level and consistency of assessment so that carers, wherever they enter the system, can be sure of effective and timely support in a personalised way. This is not to forget the wider context of identifying and responding to the needs of different groups of carers e.g. carers supporting people with drug and substance misuse issues.

Brokerage

We have found that brokerage for carers needs to be developed as part of NHS Brent's overall strategy for developing brokerage services and delivered in a personalised way.

Flexible Support

We have found that there is a need to develop innovative flexible support for carers particularly those caring for people with dementia; those with mental health issues; parent carers and carers trying to combine work with caring.

Linking together

We have found that there is a need to maintain links and agree protocols to ensure that disabled parents, parent carers and young carers are supported.

Supporting Carers

We have found that further work is needed to support carers' decisions on what they want for their own lives whether it be staying-in or resuming work, education, training and life long learning.

Early Intervention

We have found the need for early intervention and preventative services are a priority across government policy. In Brent, the Carers Grant (an annual allocation provided to all local authorities with social care responsibilities) is used to commission preventative services through the voluntary sector. This can be used for the many carers who may not meet the councils Fair Access to Care Services eligibility criteria. We need to build on and expand these services for you.

Emergency Support Services

In 2008 the Carers Emergency Support Services was set up. It provides replacement care in an emergency. We have found that this needs to be available to all carers and be better promoted.

Joining Up the Dots

We have found that we need to improve signposting by all partner agencies and improve the pathways between primary, mainstream and voluntary sector services to ensure a smoother and more flexible approach to supporting you and the people you care for.

Carer's Health

We have found that we need to improve support available to help carers maintain their health and well being. We need better identification and recording of carers at practice level; exploration of Health Checks; and better information on the condition of the person they cared for alongside more direct liaison between social care and primary care.in support you as a Carer.

Understanding the Carer's role

We have found that professionals need to recognise the importance of the carers' role supporting the cared for to maintain their independence particularly amongst health and mental health professionals where issues of consent create barriers and can impact negatively on the health and well-being of the carer.

Not a lot of people know this



- The number of older people with dementia and early onset dementia is under reported in Brent
- 25% of people with dementia are living alone. This would suggest that many families in Brent are caring for people with dementia and not accessing support
- In 2008/09 a total 1269 carers received an assessment of their needs by social service which is below the national average

What we are going to do next

Setting the wheels in motion



We firstly start to look at what is a priority. We aim to develop services that support carers in an integrated and personalised way so we need to ensure we link in with other services to find out what they are doing so we do not duplicate or miss anything out.

A Carers Partnership board was established in 2011 to build on the good work of the Carers Priority Action Group. This board will take forward the work that needs to be done

NHS Brent CCG and Brent Council are presently concentrating on developing services for carers in the following areas:

NHS Brent CCG will:

- Continue with our on-going commitment to existing funding for Carer Services which are pooled with Brent Council.
- Establish a standardised carer's register with GP's so we know who you are and we can identify your needs and potential needs from an early stage
- Provide Primary Care Carer Advice Liaison to support primary and community health professionals in early identification of Carers through training and advice service.
- Support short term breaks at home for Carers of patients in support of preventative and early intervention support.

Brent Council are in the process of:

- Commissioning a Carer Services Hub which will provide a one-stop-shop access to services for all carers in Brent. This will be a borough wide information and advice service to all carers covering both health and social care, including those who self-fund care services through the provision as a minimum you will get:-
 - Provision of a telephone support and advice service, including out of hours access and one dedicated number for enquiries.
 - The Hub should increase use of mainstream services that provide information, advice and advocacy and refer carers to these as appropriate in order to ensure you receive information and advice
 - A wide range of up-to-date, accessible and high quality information for carers of all client groups through channels such as the internet (including the Hubs own website as well as social media). Information should be made accessible to the diverse needs of the local community as and when requested.
 - The development, maintenance and distribution of a carer's information pack, informed by annual feedback from carers.
 - Signposting and support to access advocacy services to enable carers with be expert partners with health and social care Service providers

- Disseminate information through agencies such as health services, GP practices and community settings to make sure that carers' information is widely available
- Money and benefits advice so you can be supported to maximise your income
- Access to health and well-being services
- The Hub will provide you with whole family support advice and access to appropriate services
- Access to support and training for employment purposes
- Access to support and training to give you confidence in your role as a carer
- Emergency support for the whole family and access to services to meet that emergency need

This Hub was identified by carers and providers of carers' services as a priority during a comprehensive three month consultation in early 2012.

What Brent Carers Say

Appendix 1

Based on discussions around the strategy at the Carers Rights Day, Carer's support groups, the Mental Health Forum for Carers (December 2008).

Carers say that they want:

- A system that is on their side
- A system that responds in a timely and responsive way when it is most needed
- A system that treats them with respect and where professionals understand their specific needs, as well as value their knowledge and expertise about the person they care for
- "real help" in financing carers support needs

Carers specifically want:

- Access to breaks and respite in an emergency
- Better information and advice, not only from social services but from their GP surgeries
- Information about benefits and where to go to get help
- Training (i.e. First Aid courses) particularly for new carers
- Information about the person they care for both at primary and acute level
- Health checks for over 60s and prioritised appointments
- Information about health conditions, illness and treatment, so they can better understand the needs of the person they care for
- Access to bereavement services.

Carers value the benefits of support groups and they want them to be available at the weekend and in the evenings for working carers. Parent carers want holiday schemes for disabled children to be available during all school holidays.

The mental Health Carer Development Group highlighted that carers looking after people with mental health issues particularly valued support in an emergency, whether it was the first episode of someone's illness or a relapse.

Carers are particularly concerned about the lack of information and the exclusion they experience as a result of confidentiality and consent issues. This can also be affected by the lack of continuity in terms of staffing and a lack of co-ordinated working which place extra burdens on carers especially at times of crisis.

Many carers do not access services because of the stigma that they experience as carers of a person with mental health issues and there is an opportunity for work to be undertaken in the borough to address this at some level.

Carers value the emotional and practical support they receive from the Carers Assessors within the mental health service and Brent Carers Centre but would appreciate more ongoing support for the person they care for who they felt looked after their specific needs as carers.

Carers said they also want concessionary travel and a parking scheme available for carers in the borough.

Carers said they wanted more opportunities to meet with health and council officers to hear about and influence service redevelopments and improvements. Events such as

Carers' Rights Day and Parent Carers' Rights Day, were particularly valued by carers, it provided an opportunity to hear about a range of issues that affect their lives or the lives of the people they care for.

Carers said they also needed a website to provide a place where they can exchange information and newsletters to keep them up to date on new developments.

A Brent Carer's Bill of Rights

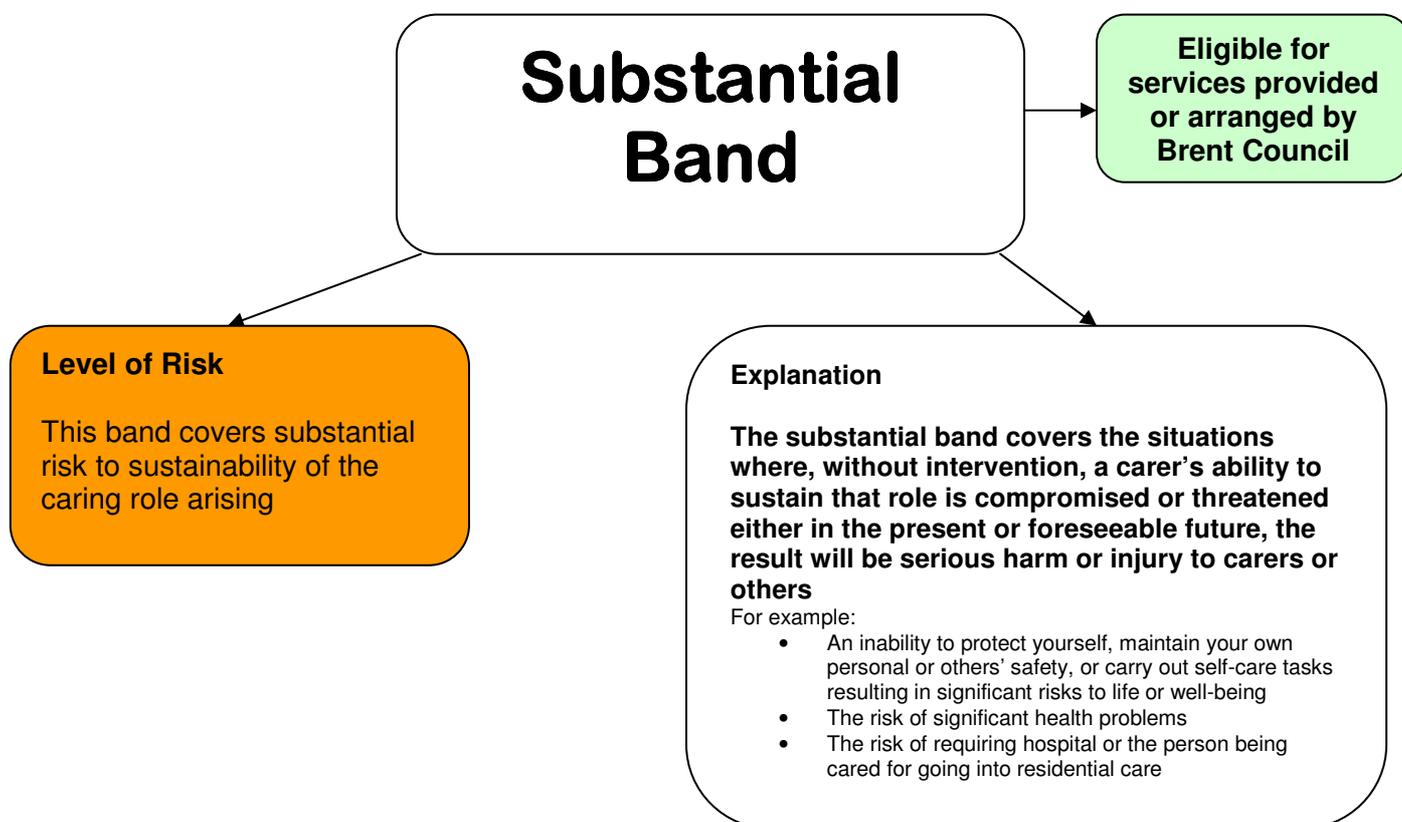
Written by the carers who attended the Managing Stress and Everyday Pressures training course, organised by Brent Carers Centre

- ❖ The right to a life of your own
- ❖ The right to be treated with respect
- ❖ The right to express your own feelings, opinions and ideas
- ❖ The right to be listened to and to be taken seriously
- ❖ The right not to be taken for granted by both the person being cared for and health and council services
- ❖ The right to recognition and value of carer's skills, time and experience that caring responsibilities require
- ❖ The right to be treated as equal partners in care by health and council services
- ❖ The right to have good understanding of the condition and treated of the cared for
- ❖ The right to have appropriate training and support to care safely
- ❖ The right to an emergency care plan in case something happens to the carer
- ❖ The right to ask for help with caring task
- ❖ The right to have regular breaks from caring
- ❖ The right to be involved in planning services for the cared for and for the carer's needs also to be taken into consideration
- ❖ The right to talk to someone that understands
- ❖ The right to financial support
- ❖ The right not to feel guilty

Carers Fair Access to Care Services (FACs) Criteria

Appendix 2

National Eligibility Framework – Carers



Description of Risk to Carer’s Ability to Sustain role – Substantial

Health & Safety

- Significant health problems for the carer have developed, or will develop
- A substantial risk of abuse has occurred or is likely to occur
- Carer has a serious illness or disability requiring intermittent hospital/medical care

Autonomy and Freedom to Make Choices

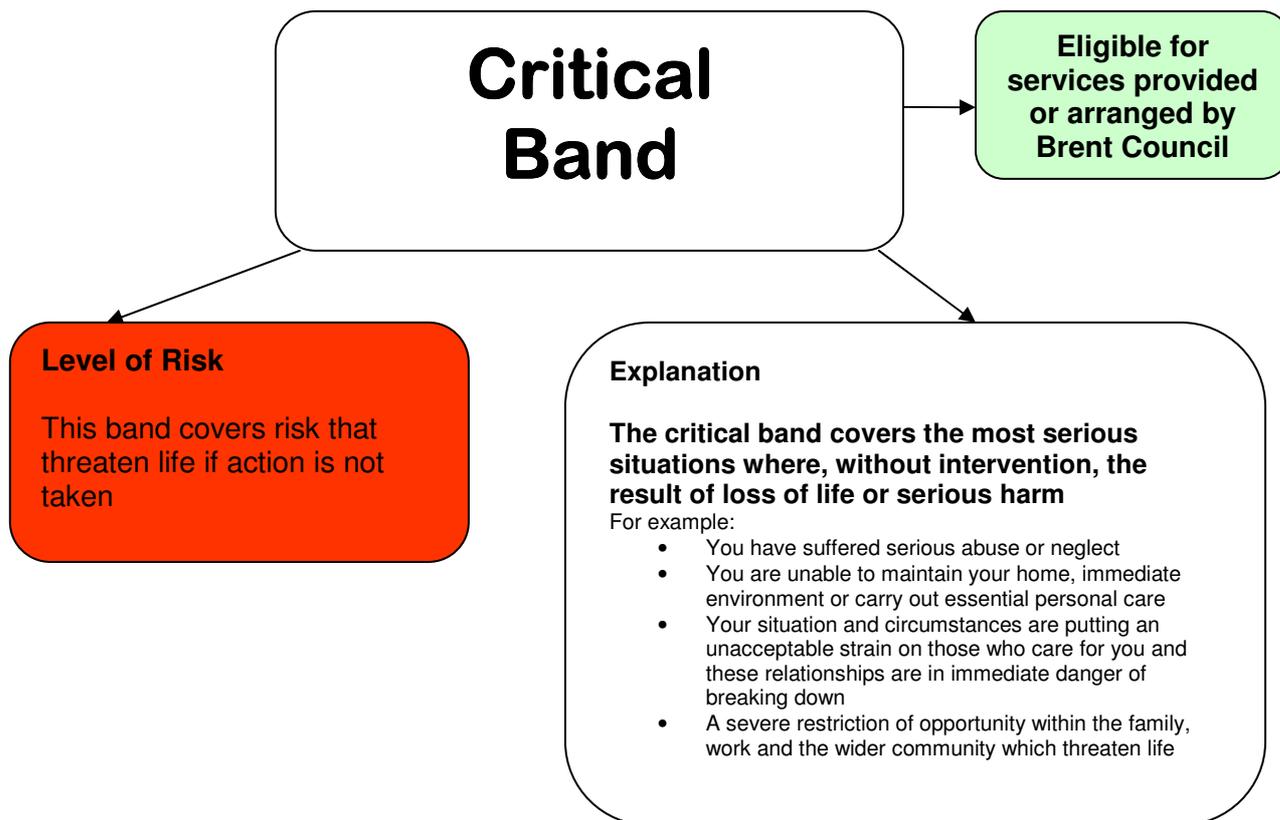
- Without support there is, or will be, some significant loss of autonomy for the carer in decisions about the nature of tasks they will perform and how much time they will give to their caring role

Involvement in Family, Work and Wider Community Life

- Without support, involvement in some significant aspects of work, learning or education cannot or will not be sustained resulting in significant risks to life or well-being
- Without support, some significant social support systems and key relationships are, or will be, at risk.

Personal and Domestic Routines

- There is or will be an inability to look after some of their personal care or domestic needs and other daily routines while sustaining their caring role



Description of Risk to Independence – Critical

Health & Safety

- Life is or will be threatened, significant health problems have or will develop resulting in threat to life
- Abuse or neglect has or will occur with the potential to threaten life or result in serious harm

Autonomy and Freedom to Make Choices

- Without support there is little or no choice and control over vital aspects of the immediate environment resulting in a threat to life

Involvement in Family, Work and Wider Community Life

- Without support, vital family and other social roles and responsibilities cannot or will not be sustained resulting in threat to life.
- Without support vital involvement in work, learning or education cannot or will not be sustained resulting in a threat to life.
- Without support, vital social support systems and key relationships cannot or will not be sustained resulting in a threat to life

Personal and Domestic Routines

- Without support, there is or will be an inability to carry out vital personal care or domestic routines resulting in a threat to life

Legislative and National Policy Context Appendix 3

A number of pieces of legislation introduced in recent years have impacted significantly on how carers are supported.

The Carers and Disabled Children Act 2000 made four principal changes to the law:

- Councils were given powers to provide services to carers directly
- Carers were given the right to an assessment independent of the cared for person
- Local authorities were given the power to make direct payments to carers
- Councils can provide flexible short breaks through voucher schemes.

The Carers (Equal Opportunities) Act 2004 made three main changes to the existing law around carers' services:

- Councils have a duty to inform carers of their right to an assessment of their needs
- During assessments councils must now take into account whether the carer works or wishes to work, undertakes or wishes to undertake education, training or leisure activities
- Local authorities must co-operate with other agencies locally in relation to the provision of services that are relevant to carers.

The Work and Families Act 2006 extended the right to request flexible working to employees who care for adults.

National Dementia Strategy

The National Dementia Strategy focuses on three themes; improved awareness, earlier diagnosis and intervention, and a higher quality of care. It identifies 17 key objectives which it proposes should result in significant improvements in the quality of services provided to people with dementia.

National Service Framework for Older People

The National Service Framework (NSF) for Older People was published in March 2001 and is a ten-year programme setting national standards and service models of care across health and social services for all older people, regardless of whether they live at home, in residential care or are being looked after in hospital.

The NSF emphasizes that carers' needs should be considered as an integral part of the way in which services are provided for older people

National Service Framework for long-term conditions

This National Service Framework builds on the government strategy first outlined in the NHS Improvement Plan; Putting People at the Heart of Public Service. It contains 11 "Quality Requirements" (QRs) which are expected to be fully implemented by 2014. All have relevance to carers but QR 10 focuses specifically on their needs:

QR10: Supporting family and carers – access to appropriate support and services that recognise carers' needs both in their role as carer in their own right.

Valuing People²

Valuing People is the government's plan for improving the lives of people with learning disabilities, their families and carers and focuses on their rights as citizens, inclusion in local communities, choice in daily life and independent living.

It identifies a number of issues that need to be addressed, including poorly co-ordinated services for families with disabled children, poor planning for young disabled people at the point of transition into adulthood, and insufficient support for carers, particularly for those caring for people with complex needs. It recognises that caring for a family member with a learning disability is a life-long commitment, which continues even after the person is living away from home.

National End-of-Life Care Strategy³

Most deaths follow a period of chronic illness such as heart disease, cancer, or stroke, and all have caring-related implications. The strategy argues that few people experience what can be regarded as a “good death” including being treated with dignity, in familiar surroundings and in the company of close family and friends. It calls for a whole systems and care pathway approach both for commissioning services and for delivery of integrated care.

Putting People First⁴

Putting People First is a concordat between the Local Government Association, the Association of Directors of Adult Social Services, the NHS and other key agencies, setting out a shared vision and commitment to the transformation of adult social care and describing a vision for development of a personalised approach to the delivery of adult social care.

Key elements are:

- Prevention
- Early intervention and re-ablement
- Personalisation
- Information, advice and advocacy

Councils will be required to introduce a system of personal budgets for everyone eligible for publicly-funded adult social care support, and to provide universal information, advice and advocacy services for all who need services and their carers, irrespective of eligibility for public funding.

Darzi Review of the NHS⁵

Lord Darzi's review of the NHS calls for a health service that empowers staff and gives patients choice, providing healthcare that is personalised and fair, with effective treatments within a safe system, and patients enabled to stay healthy.

Proposals include giving patients more say through initiatives such as care plans for those with long term conditions, a guarantee that the most effective drugs will be available to all, and the right to choose care providers including GPs. Personal health budgets are to be piloted for 5000 patients with complex conditions (2009)

World Class Commissioning⁶

The World Class Commissioning programme aims to transform the way health and care services are commissioned with a clear focus on delivering improved health outcomes. The vision of world class Commissioning includes the aim of giving people choice and control over the services that they use, so they become more personalised.

Brent Carers Strategy 2010-2014 – Local Action Plan Appendix 4

Strategy	Action	Lead	Resources
<p><i>National Strategy outcome 1: We will aim to develop services that support carers in an integrated and personalised way</i></p> <p>Having a Voice</p> <p>Carers are recognised and shape policy and service development</p>	<p>Establish a Carers Partnership Board to lead the planning and development of services for carers.</p> <p>Carers will be supported to participate in the board and play a leading role in monitoring the quality and delivery of provision</p> <p>Publish Brent Carers Strategy for the next 5 years</p> <p>NHS Brent and Brent Council to further develop joint commissioning arrangements to deliver carer services and support, managed by Carers Strategic Commissioning Manager</p> <p>Ensure carers issues are fully integrated within commissioning strategies of all client groups</p> <p>Develop a communication consultation strategy to ensure consultation and ongoing carer participation</p>	<p>Chair, Carers, PAG, Director Joint Commissioning</p>	<p>Within existing resources</p> <p>Additional resources required to create new Carers Lead Commissioning Officer Post</p>
<p>Information and Advice</p> <p>All carers have access to good quality information and advice to assist them with their caring responsibilities</p>	<p>Improve quality of information available to professionals, workers and general public about carer's rights and services</p> <p>Review information given to carers at initial contact and assessment and on receipt of support and after caring</p> <p>Improve and extend the distribution of information and ensure it can be accessed by the diverse</p>	<p>NHS/LA/voluntary sector</p>	<p>Additional resources may need to be identified</p>

Strategy	Action	Lead	Resources
	their caring role and have outside caring		
<p>Carers Assessments</p> <p>Carers asking for help get timely intervention and support</p> <p>Other agencies know how to identify and refer carers on for support</p>	<p>Develop clearly defined eligibility criteria to access services</p> <p>Improve the level and quality of carers assessment currently undertaken, that they identify carers wishes to undertake work/training/employment and record unmet needs</p> <p>Link Telecare to carers assessment and emergency planning for carers</p> <p>Increase the capacity within the access and assessment team and develop the role of the trusted assessor across a range of agencies to better support carers asking for help</p> <p>Provide information and training to health and other council front line services (e.g. Housing advice)</p> <p>Ensure all eligible carers offered access to the Carers Emergency Support Services</p> <p>Introduce carer assessments feedback monitoring forms to assess quality and outcomes of assessments</p>	LS	Within existing resources
<p><i>National Strategy outcome 3: Carers will be supported so that they are not forced into</i></p>	<p>All carers assessments will offer carers access to benefit checks or financial advice</p>	LA	

Strategy	Action	Lead	Resources
<p><i>financial hardship by their caring role by:-</i></p> <p>Supporting carers to maximise their incomes</p> <p>Carers will have access to welfare advice to enable them to manage their financial security</p>	<p>Ensure carers are identified as a priority group within the Local Area Agreement within the income maximisation target area</p>		
<p>Maximise the opportunities for carers to access work, training and/or life long learning</p> <p>Employers have caterer friendly policies</p> <p>Brent Councils and NHS Brent promote and share best practice on work life balance to support working carers</p>	<p>Work with Brent in 2 Work and Jobcentre Plus to develop specific support for carers wishing to get back to work.</p> <p>Provide open day for employment, learning and education providers</p> <p>Work with Job Centres to raise understanding of skills, constraints and opportunities for carers.</p> <p>Build relationships with business and employers in Brent through carers week for example</p> <p>To identify the number of working carers within Brent Council and NHS Brent and partner agencies through an annual staff survey</p>	<p>NHS/LA</p>	<p>Additional resources required to promote carers during Carers Weeks</p>
<p><i>National Strategy outcome 4: Carers will be supported to stay mentally and physically well</i></p> <p>Improving carers health and well-being</p> <p>GP's are able to build upon their</p>	<p>Provide additional support to work with primary care professionals and GP practices and hospital discharge to improve their support to carers.</p> <p>Promote good practice in the use of GP registers to identify and provide information to carers and or refer other health promotion initiatives such as flu jabs, smoking cessation or vascular screening</p>	<p>NHS</p>	<p>Additional resources needed to establish a Primary Care Development Worker Post</p>

Strategy	Action	Lead	Resources
<p>existing good practice in recognising and supporting unpaid family carers in their practices</p> <p>Carers are supported in dealing with emergencies as easily as possible</p> <p>Carers access health services and other health promotion services</p>	<p>Develop services that reduce the effects of caring on the carer support them in coping with the demands of their role encourage them to stay healthy and independent. This will support NHS Brent's overall aim to deliver more care closer to home. In particular support carers of people in particular care settings and with conditions that support NHS Brent priorities including:-</p> <ul style="list-style-type: none"> • People suffering from dementia • People in end of life care/palliative care settings • People within intermediate care settings • People within substance misuse services • People affected by stroke 		
<p><i>National Strategy outcome 5: Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive through:-</i></p> <p>Young Carers</p> <p>Young carers in Brent are identified and supported as a family</p> <p>Ensure services are available so they can be children first and support them to access education, training, employment or leisure</p>	<p>Identify a Senior Officer with lead responsibility for Young Carers</p> <p>Develop joint protocol between Adults & Children services</p> <p>Develop appropriate services to ensure disable parent receive services to support the family</p> <p>Train professionals to recognise and support young carers</p>	LA/Children & Families	Resources required for training

Strategy	Action	Lead	Resources
<p>Recognition of wider community</p> <p>Raise profile carers corporately</p> <p>Raise the profile carers within the community</p>	<p>Explore with Sports and Libraries services the possibilities of the Carer Emergency Cards entitling carers to:-</p> <ul style="list-style-type: none"> Discounted use of leisure facilities Twice as long to return library books <p>Promote access to carer friendly learning opportunities through adult and community services</p> <p>Ensure all partner agencies identify carers and promote career friendly policies within their organisations</p> <p>Promote Carers Weeks and other Carers days</p>	<p>All agencies</p>	<p>Resource implications</p>