

Carers Strategy 2009 - 2012 Consultation Document

Introduction

Brighton & Hove City Council and NHS Brighton and Hove Primary Care Trust are developing a Carers Strategy for the city which will enable us to implement the key principles of the national strategy for carers as well as address local issues in the city. The document will inform decision making and expenditure on carers' services over the next few years. This consultation document outlines some of the key issues for carers in the city with suggested ways of addressing these needs. We welcome comments and contributions to the development of this strategy from carers, service users and professionals.

Definitions:

- A carer spends a significant proportion of their life providing unpaid support to family or friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems. Parent carers are people with parental responsibilities (parents, grandparents, foster parents, adoptee parents and others) who also provide additional care, assistance and support to children with learning or physical disabilities, complex health needs or illness, or emotional behavioural difficulties.
- Young carers are children and young people under 18 who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility, which would usually be associated with an adult.
- Sibling carers are children and young people who contribute to the care of their siblings who have additional needs.

Who are carers - nationally?

- 1 in 6 of the population
- 3 in 5 of us at some point in our lives
- 42% of carers are men and 58% women

Who are carers in Brighton and Hove?

- 21,800 in Brighton & Hove
- 24% of people aged 50 to 64 are carers
- Almost 500 aged 8-17 years
- Almost 4,000 caring for more than one person
- Over 10,000 caring for 5+ years
- Over 1,000 carers in Brighton and Hove may sustain a physical injury through their caring role and over 1000 may be treated for a stress related illness
- More than 4,500 carers have been caring for at least 10 years and almost 10,000 for five years or more
- Nearly 4,000 carers look after more than one person

Health Issues

- More than 50% have sustained physical injuries
- 52% treated for stress related illnesses
- 94% manage medication
- 23% manage dressings
- 12% give injections

Who are they caring for in Brighton and Hove?

- One in five people over 65 say they do not have good health, compared to one in ten of the total population
- 18% of population have limiting long-term illness
- 400 adults with a learning disability living in the community
- Over 3,000 people with dementia
- 190 people with young onset dementia
- 2,500 problematic drug users
- 14,500 harmful drinkers
- 2,300 mental health service users aged under 65
- 3,900-5,900 people aged 65+ with depression
- 2,000 disabled under 16 year olds in Brighton and Hove

Key Principles

Integrated & personalised services

Vision: Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role. **(Services that are joined up but also meet your needs and those of the person you care for on an individual basis)**

What have carers in Brighton and Hove already told us?
<ul style="list-style-type: none"> • Information and support provided within NHS settings including hospitals, mental health services and GP practices
<ul style="list-style-type: none"> • GPs are essential in encouraging their patients to recognise themselves as carers and signposting them to appropriate support
<ul style="list-style-type: none"> • Confidentiality is a barrier to communication between carers and professionals in mental health services. It needs to be flexible, discussed and negotiated.
<ul style="list-style-type: none"> • Poor communication between professionals can lead to a poor quality of service
<ul style="list-style-type: none"> • Dual diagnosis can lead to people falling between two services and not having their needs met
<ul style="list-style-type: none"> • Mental health service users would benefit from support in daily living skills but this is not always available
<ul style="list-style-type: none"> • Carers don't always want to manage services directly themselves and need choice and control over the delivery of services including the choice not to manage services themselves
<ul style="list-style-type: none"> • Carers need to be involved from the beginning of discussions

<p>about Individual</p> <ul style="list-style-type: none"> • Budgets and any impact on the carer as a result of changes to services needs to be taken into account
<ul style="list-style-type: none"> • Carers need information and advice about how to access services for the cared for person when that person is self-funding
<ul style="list-style-type: none"> • Better information about Carers Needs Assessments
<ul style="list-style-type: none"> • Training for NHS staff in hospitals, primary care and mental health services to increase their awareness of the issues facing carers
<ul style="list-style-type: none"> • Parent carers whose child has a severe learning disability feel that existing third sector providers are limited in what they can offer as this cohort is such a small minority of all parent carers
<ul style="list-style-type: none"> • There is no specific support for parent carers whose child has mental health needs
<ul style="list-style-type: none"> • Good communication between families and professionals is essential at point of diagnosis
<ul style="list-style-type: none"> • Professionals use too much jargon and language that can exclude users and carers
<ul style="list-style-type: none"> • Patients need to have all their needs met when in hospital, e.g. existing medication to be given at right time etc
<ul style="list-style-type: none"> • Services shouldn't be so dependent on one individual that they are unavailable when that individual is ill/leaves etc

<p>Proposed Priorities</p>
<p>1. Provide and further develop appropriate, good quality information</p>
<ul style="list-style-type: none"> • Information Prescriptions • Fund different media including websites, fact sheets, help lines • Map of Medicine is a web based reference guide for NHS staff to ensure best practice in delivering patient care – a local carers' pathway will be developed as part of this
<p>2. Information Sharing Policy Implementation</p>
<ul style="list-style-type: none"> ▪ Monitor implementation in Sussex Partnership Foundation Trust and develop practice in other areas including primary care and substance misuse services
<p>3. Develop equality of access to services for all carers through targeted information and outreach work across all communities underrepresented in statutory and provider services</p>
<ul style="list-style-type: none"> • Ensure needs of BME carers identified and addressed • Ensure needs of LGBT carers identified and addressed • Provider services to work towards promoting their services across all communities in the city and ensuring they are open and accessible to all carers • Ensure needs of carers of people with HIV/Aids identified and addressed • Ensure needs of parent carers identified and addressed • Take forward good practice from 50+ Project and ongoing work in East Brighton

<p>4. Offer good quality, timely and proportionate outcome focused carers' needs assessments and reviews</p>
<ul style="list-style-type: none"> • Increase in number of carers assessments • Increase access to carers' needs assessments/reviews through voluntary sector and NHS services and housing • Development of a self-assessment tool for carers will give carers more choice about how their needs are assessed and may offer facilitated assessments with third sector providers • Holistic joint assessments/reviews to complement development of personalised services e.g. Reablement and Individual Budgets • All services responsible for carers assessments/reviews to develop strategies to meet performance targets • Monitor outcomes of assessment/review through city-wide carers' survey and service specific surveys/evaluation tools
<p>5. Self Directed Support options available to carers</p>
<ul style="list-style-type: none"> • 30% of carers of adults access carers' services via Self Directed Support by March 2011 • Carers' needs taken account of in the development of self directed support with service users • Appropriate support to voluntary sector providers to ensure sustainability of universal services • Appropriate levels of funding available for direct payments to parent carers
<p>6. End of Life Care</p>
<ul style="list-style-type: none"> • Link with End of Life Care strategy for Brighton and Hove to ensure carers' needs are included • Provision of appropriate services to carers supporting cared for at end of life • Access to bereavement support services
<p>7. Carer involvement in the development and provision of services</p>
<ul style="list-style-type: none"> • City-wide carers' survey • Community Engagement Framework - ensure Gateway services are carer aware • Use of Amaze's Compass database • Inclusion of carers on key decision making boards
<p>8. Carers' needs and views taken into account on admission to, discharge from and during stays in hospital as well as in discussion and decisions about diagnosis, ongoing treatments, therapies and services</p>
<ul style="list-style-type: none"> ▪ Care Passports ▪ Support to carers at Millview Hospital ▪ Support to carers at the Nevill Hospital ▪ Support to carers at the Royal Sussex County Hospital ▪ Ongoing support to carers in the community following new diagnosis/hospital discharge
<p>9. Provision of key workers for children and young people with special needs and their carers to ensure services and care are well integrated</p>

A life of their own

Vision: Carers will be able to have a life of their own outside of their caring role.

What have carers in Brighton and Hove already told us?
<ul style="list-style-type: none"> • Parent carers would like funding for breaks for the whole family
<ul style="list-style-type: none"> • Carers benefit greatly from the opportunity to go on holiday, some with, others without, the cared for person
<ul style="list-style-type: none"> • Eligibility criteria for learning disability services means that some cared for people are receiving few or no services but carers are still undertaking regular and substantial caring roles
<ul style="list-style-type: none"> • Day services for people with dementia following diagnosis
<ul style="list-style-type: none"> • Assistance with transport to and from hospital
<ul style="list-style-type: none"> • Peer support
<ul style="list-style-type: none"> • Media representation of poor quality services can discourage users and put additional pressure on carers
<ul style="list-style-type: none"> • Some users and carers are reluctant to pay for services putting additional pressure on carers
<ul style="list-style-type: none"> • Care at home can be more appropriate for people with dementia but there is limited availability
<ul style="list-style-type: none"> • Support services available within local communities rather than everything being based in city centre
<ul style="list-style-type: none"> • Sustainability of support groups professional input withdrawn

Proposed Priorities
1. To extend the choice and accessibility of quality break opportunities for carers
<ul style="list-style-type: none"> • Support a range of voluntary and independent organisations to provide flexible breaks for carers • Use of self directed support to develop flexible breaks and services for carers • Explore need for home-based relief care for carers of people with functional mental health needs • Development of services to meet the needs of people under 65 with dementia including those whose condition has developed beyond early to moderate dementia and whose needs can not be met by the current day service provision. • Development of short breaks for children and young people with special needs to provide respite to parent carers • Accessible leisure opportunities for children and young people with special needs and their parent carers • Funding available for parent carers to increase choice and control through use of Direct Payments
2. Provision of carers' services that support carers in their caring role

<ul style="list-style-type: none"> • Through development of Self Directed Support • Explore use of Telecare in supporting carers
3. Support to carers wishing to access leisure activities
<ul style="list-style-type: none"> ▪ Extend benefits of Compass card for parent carers and their children
4. Support to carers to plan for the future
<ul style="list-style-type: none"> • Emergency Back Up Scheme

Income & employment

Vision: Carers will be financially supported so that they are not forced into financial hardship by their caring role.

What have carers in Brighton and Hove already told us?
<ul style="list-style-type: none"> • Concern about employer's perception if they request flexible working
<ul style="list-style-type: none"> • Caring responsibilities leading to poor health can be reflected in sickness records and impact on employment opportunities

Proposed Priorities
1. To work with partners and local employers to help carers take up and/or remain in employment.
<ul style="list-style-type: none"> ▪ Introduce target for local employers to have in place a carers policy ▪ Provide training (using the DVD) to local employers to increase understanding about the role of caring and their needs as employees. ▪ Working carers who have had an individual carer's assessment will be encouraged to share this assessment with their line manager as a first step in exploring how caring responsibilities impact on work patterns, and thereby providing an opportunity to begin a meaningful dialogue on what might be done to assist both the employee and the employer.
2. Partnership working with JobCentre Plus
<ul style="list-style-type: none"> • We will explore ways to engage and work with JobCentre Plus (exploring work opportunities with or without formal qualifications. Refresher course or preparation for work retaining programmes can often give confidence and help update and learn new skills for competing in the employment market)
3. Access to education and training.
<ul style="list-style-type: none"> ▪ Provision of alternate care to enable carers to take up education and training ▪ Develop links with the Learning and Skills Council to provide discounted/free access to courses for carers. ▪ Explore opportunities for working with Connexions (targeting young carers in supporting all 13 – 19 years old on learning,

training and work)

Health & well-being

Vision: Carers will be supported to stay mentally and physically well and treated with dignity.

What have carers in Brighton and Hove told us already?

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| <ul style="list-style-type: none"> • Carers worry about how they would manage in a crisis |
| <ul style="list-style-type: none"> • Carers, particularly those caring for an adult son/daughter, would like plans to be put in place for the future with input from key professionals to address both care and financial issues |

Proposed Priorities

1. Access to support in primary care

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| <ul style="list-style-type: none"> • Development of GP Link Worker scheme • Ensure PALS information service includes information relevant to carers • Develop a network of Carers' Advisers based across a range of NHS settings to include acute and community services and provide continuity of support to carers in their own homes following diagnosis/treatment/in-patient care. • Parent Carer Plus: a flexible specialist key worker approach built around informing, supporting and involving parent carers during and after the discharge process from RACH • GP Practices – Carers Advisers working within GP practices to offer a regular presence, advice to practice staff and direct support to carers |
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2. Access to advice and training

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| <ul style="list-style-type: none"> • Continue back care service for carers • "Looking After Me" courses • Pilot Mindfulness Based Cognitive Therapy course through Brighton Buddhist Centre • Dementia training for carers • Develop health care training, e.g. medications, wound management etc |
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3. Access to emotional support

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| <ul style="list-style-type: none"> • Provision of information, advice, support and advocacy • Provision of Insider Guide and Triple P courses to parent carers and development of Resilience Therapy techniques • Increased access to psychological therapies – monitor uptake of new counselling services accessed via GPs by carers and the outcomes for them • Develop transition services to support carers following bereavement/end of caring role and for parent carers during child's transition to adulthood with a focus on |
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work/education/training and reduction in isolation
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Young carers

Vision: Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes.

What have young carers in Brighton & Hove said is important to them?

young carers top ten wishes...

The most helpful groups are ones where you can talk about difficult feelings with young people in a similar situation

Carers project worker to support us to engage in new activities and attend activities provided by the Young Carers Project would most help with the difficulties of getting out to do activities and meeting new friends

We don't want to have to do personal care

8-10 year olds

Someone to support us to go out as a family

Paid domestic help would most reduce the impact of our caring role in the home

16-25 year olds

1:1 confidential support so that we feel informed about our choices and options

People in authority should let us know they are working for us and speaking up for us

We enjoy cooking to help at home

In an emergency we would like to have a pre-prepared plan of action (made with young person and family) to follow; kept by the school, Young Carers Project etc containing names and phone numbers of people to contact

The best way to raise awareness in schools is in PSHE lessons and sessions for pupils and teachers to understand some of the difficulties faced by young carers

Proposed Priorities
1. Identification and recognition of young carers at point of assessment of cared for person
<ul style="list-style-type: none"> ▪ Appropriate services to cared for person to minimise impact on child(ren) ▪ Support for parents to be parents and family to be a family
2. Joint working between services for adults and services for children
<ul style="list-style-type: none"> • Joint protocol between adult services and CYPT • Jointly commission young carers assessment services • Family Pathfinder • Transitions Project

3. Ensure needs of young carers of substance misusing parents identified and addressed
<ul style="list-style-type: none"> ▪ Assessment services ▪ support services
4. Support for young carers in schools
<ul style="list-style-type: none"> • awareness raising in schools with teachers & other staff • awareness raising in schools with pupils • support in schools
5. NHS Services
<ul style="list-style-type: none"> • Ensure that the development of Carers' Advisers in NHS settings includes recognition of and support for young carers
6. Emergency Back-Up scheme
<ul style="list-style-type: none"> ▪ Expand existing scheme to meet needs of young carers

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