

"Supporting Carers in Hillingdon"

Strategy 2015 - 2018



Contents

- 1. Foreword**
- 2. Executive summary**
- 3. Strategic aims**
- 4. Carers - definition and key facts**
- 5. National and legal context**
- 6. Services for carers in Hillingdon**
- 7. Consultation and engagement**

Appendix A Carers Strategy Delivery Plan 2015-16

Appendix B Consultation and engagement results as at 31 March 2015

Appendix C Membership of the Carers Strategy Group

1. Foreword

This Carers Strategy for 2015 to 2018 has been developed in partnership with local carers, the London Borough of Hillingdon, Hillingdon Clinical Commissioning Group, Hillingdon Carers, Central and North West London NHS Foundation Trust, Hillingdon Hospital NHS Trust and members of the Carers Strategy Group (membership to which is provided in Appendix C).

A number of significant changes have taken place recently as part of the Health and Social Care agenda. The Health and Social Care Act of 2012 is now business as usual with the Health and Wellbeing Board itself now firmly in place. The passage of the Care Act 2014 and Children and Families Act 2014 has set out to improve services and support, especially for carers.

In addition, closer integration of health and social care has moved further up the agenda with the development of joint work, for example under the Better Care Fund and in Mental Health and Children's services.

The strategy reflects the intentions of the Health and Wellbeing Strategy, which acknowledges the vital role of all carers and the support they provide.

Many carers don't see themselves as carers. It takes carers an average of two years to acknowledge their role as a carer¹. It can be difficult for carers to see their caring role as separate from the relationship they have with the person for whom they care, whether that relationship is as a parent, a son or daughter, or a friend.

It's likely that every one of us will have caring responsibilities at some time in our lives with the challenges faced by carers taking many forms. Many carers juggle their caring responsibilities with work, study and other family commitments. Some, in particular younger carers, are not known to be carers. They don't tell relatives, friends or health and care professionals about their responsibilities because of fear of separation, guilt, pride or other reasons.

This means that the sort of roles and responsibilities that carers have to provide varies hugely. They can range from help with everyday tasks such as getting out of bed and personal care such as bathing, to emotional support such as helping someone cope with the symptoms of a mental illness.

We want to enable our residents to recognise and identify their role as a carer so they know where to access the right support.

The vision we have for all carers of all ages in Hillingdon, is that we want our carers to be able to say:

- "I am physically and mentally well and treated with dignity"
- "I am not forced into financial hardship by my caring role"
- "I enjoy a life outside of caring"
- "I am recognised, supported and listened to as an experienced carer"

We extend our thanks and admiration to all our carers, those who are known to us and those that aren't. We are confident that through this Carers Strategy we will continue to bring improvements to the health and wellbeing of all carers living and caring in the London Borough of Hillingdon.

Cllr Philip Corthorne

Cabinet Member for Social
Services, Health and Housing

Dr Ian Goodman

Chairman, Hillingdon CCG

Cllr Judith Cooper

Carers Champion

Tony Zaman

Director of Adult Social Care
and Interim Director of
Children and Young
People's Services

2. Executive summary

According to Census 2011 there are over 25,000 carers in Hillingdon who provide unpaid support. Their contribution to the health and wellbeing of those they care for is significant. Carers say that supporting someone to live an independent life at home, in the community they know, can be very rewarding. However the cost to carers themselves can be considerable in terms of their own health, financial situation, employment position and independence.

This Carers Strategy sets out our vision and strategic aims for carers of people within the London Borough of Hillingdon.

The strategy provides a definition of a carer, local and national carer specific demography, an overview of the National Carers Strategy, the services that we provide and the feedback from our own local carers. It is deliberately high level, reflecting National priorities and legislation.

The Carers Strategy has four priority areas based on what we want carers to be able to say, as shown in the foreword. The priority areas are:

- Health and Wellbeing;
- Financial circumstances including advice and information;
- A life outside of caring; and
- Recognition of the caring role

The key messages from the consultation activity were that carers said they wanted a wider variety of respite opportunities, assistance and advice with finances and benefits, greater flexibility for GP and hospital appointments and one to one support.

To meet both national and local priorities identified in the development of this Strategy, the council will establish a programme of work in conjunction with voluntary sector partners to initially deliver the following:

- Increased assessment capacity across the borough to provide additional support to carers via the provision of on-line support through Connect to Support Hillingdon, in addition to telephone and face to face support.
- A review of the carers pathway and contract arrangements for carers services building on the feedback from carers through the consultation process and new Care Act responsibilities.

- Targeted communications campaign to increase awareness and take up of carers support/services - focusing on "hidden" and "young" carers.
- Increased capacity for carer support through ensuring mainstream and universal and existing health and social support services meet carers needs.

Finally, the strategy commits all the strategic partners to monitoring and delivering the actions identified through the Carers Strategy Delivery Plan. This plan will be reviewed and refreshed on an annual basis and we are committed to continue to consult on what carers identify as the main issues they face in their caring role.

3. Strategic aims

The Carers Strategy 2015-18 for Hillingdon builds on the Carers Commissioning Plan 2011-15, published in 2011 and shows how support will be delivered for those who help Hillingdon's residents to live independently in the community.

The strategy also covers the needs of young carers and replaces the Young Carers Strategy 2007-12. Their caring role must be acknowledged and appropriate action taken to ensure they are not providing significant and inappropriate levels of care. Young carers must be firstly treated as children and young people who are able to fulfil their own aspirations.

As important as supporting those residents who identify as carers, is assisting those who do **not** identify, to recognise their role and seek support if they need it.

The Care Act makes wellbeing a guiding principle for care and support. The principle applies equally to those in need of care and support and their carers. The Act is about meeting needs, rather than just about providing services.

The legislation recognises that ways of providing care and support and of promoting wellbeing, can be provided in many different ways, and that 'wellbeing' will mean different things for different people, depending on their circumstances, their needs, and what they want to achieve.

The principles behind the Care Act put the emphasis on the individual receiving or providing care, and on preventing or reducing the need for care and support:

- the individual is best-placed to judge their own wellbeing
- the individual's views, wishes, feelings and beliefs must be at the heart of any assessment
- preventing or delaying the development of needs for care and support and the importance of reducing needs that already exist
- decisions must have regard to all the individual's circumstances
- the individual should be allowed to participate as fully as possible in decisions about them
- the impact of an individual's needs on families and support networks should also be taken into account
- people should be protected from abuse or neglect, and any restriction on the individual's rights or freedom of action should be kept to the minimum necessary

The Care Act introduced a new set of rights and duties in relation to carers:

- For the first time carers will have the same legal rights as service users
- Local authorities will have a duty to assess carers who may have eligible needs
- Carers who meet eligibility criteria will have a right to a support plan and a personal budget
- Carers may be charged for services they receive in their own right
- Carers should be supported to retain and gain employment
- Carers will have new rights to be consulted on the cared for person
- Local authorities will have a duty to provide information and advice

The Children and Families Act 2014 requires local authorities to take steps to identify the extent to which there are young carers with unmet needs.

The Carers Strategy recognises that we need to find a different way to provide the greatest level of support i.e. through community based services rather than relying solely on social care resources. Identifying more people who are carers is expected to lead to a rise in demand for assessment, advice and support. As resources are increasingly under pressure, it is vital that we design the support we offer in line with the Care Act's principles.

We will work in partnership with carers and providers to achieve this while maintaining our commitment to the vision of high quality consistent care and support. We will promote equality and diversity to strive towards equity of access to services for all carers.

The strategy includes a detailed delivery plan to meet the priorities identified. This plan will be monitored quarterly by the Carers Strategy Group with updates to the Health and Wellbeing Board via the Joint Health and Wellbeing Strategy performance report and will be reviewed on an annual basis.

4. Carers - definitions and key facts

A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health issue or an addiction cannot cope without their support.

Young carers are children and young people between the ages of 5 and 18 who provide or intend to provide care, assistance or support to another family member who is disabled, physically or mentally ill, or has a substance misuse problem. They carry out, often on a regular basis, significant or substantial caring tasks, taking on a level of responsibility that is inappropriate to their age or development (Social Care Institute for Excellence (2005)).

Anyone can become a carer; carers come from all walks of life, all cultures and can be of any age. Many feel they are doing what anyone else would in the same situation; looking after their mother, son, or best friend and just getting on with it. Carers Trust

Hillingdon

- There are 25,905 unpaid carers in Hillingdon. Of these, 16,563 provide 1 to 19 hrs of care per week, 3,816 provide 20 to 49 hrs and 5,526 provide 50+ hrs.
Source: Census 2011
- The estimated value of carers' support is £442 million a year in Hillingdon alone. Source: "Valuing Carers 2011" Leeds University and Carers UK
- The Adult Social Care Outcomes Framework Carers Survey is completed biannually. From the 2012/13 survey, carers in Hillingdon gave the following feedback:
 - A score of 7.6 out of 12 for reported quality of life
 - 34% stated that they were extremely or very satisfied with social services compared to 35.2% for the rest of London
 - 66.3% stated that they were always or usually involved in the decision making process
 - 65.1% found it very easy or fairly easy to find information
- In 2013-14, the council and its partners carried out 515 carers assessments/ reviews. Of these, 15 carers were provided with services and 495 with advice.

The Hillingdon GP National Survey Data released in January 2015 identified the following:

- 7% of respondents had caring responsibilities of more than 10 hours per week,
- 3% stated they were providing more than 50 hours per week of support.
- A further 10% stated they were providing up to 10 hours support per week.

These responses are supported by the number of patients identifying themselves as requiring support to undertake a range of daily activities.

This data is refreshed every 6 months and a review of historical data supports the latest information.

The survey also notes a range of issues linked to Care Planning, access and information where improvements can be made.

In addition to this Hillingdon CCG has undertaken a range of engagement activities as part of its Integrated Care and Long term Conditions work, where carers have highlighted that improved and more responsive care for the person they look after will mean they have greater confidence in the NHS and thus feel more secure and have improved health and wellbeing as a result.

National

- There are around 5.4 million people in England who provide unpaid care for a friend or family memberⁱⁱ.
- Between 2001 and 2011, the number of unpaid carers has grown by 600,000 with the largest increase being in the unpaid care category, fifty or more hours per weekⁱⁱⁱ. This equates to 1.4 million people providing fifty or more hours of unpaid care per week^{iv}.
- Unpaid care has increased at a faster pace than population growth between 2001 and 2011^v and an ageing population and improved life expectancy for people with long term conditions or complex disabilities means more high level care provided for longer.
- Increasing hours of care results in the general health of carers deteriorating incrementally. Unpaid carers who provide high levels of care for sick, or disabled relatives and friends, are more than twice as likely to suffer from poor health compared to people without caring responsibilities, with nearly 21% of carers providing over 50 hours of care, in poor health compared to nearly 11% of the non-carer population^{vi}.
- Caring responsibilities can have an adverse impact on the physical and mental health, education and employment potential of those who care, which can result in significantly poorer health and quality of life outcomes. These in

turn can affect a carer's effectiveness and lead to the admission of the cared for person to hospital or residential care^{vii}.

- 84% of carers surveyed for the 2013 State of Caring Survey said that caring has had a negative impact on their health, up from 74% in 2011-12^{viii}.
- Carers attribute their health risk to a lack of support, with 64% citing a lack of practical support^{ix}.
- Carers make a major contribution to society. Estimates show that the care provided by friends and family members to ill, frail or disabled relatives is equivalent to £119 billion every year^x.
- 70% of carers come into contact with health professionals yet health professionals only identify one in ten carers with GPs, more specifically, only identifying 7%^{xi}.
- 66% of carers feel that healthcare staff don't help to signpost them to relevant information or support, and when information is given, it comes from charities and support groups^{xii}.

Young Carers

- The 2011 National Census indicated that there are 166,363 young carers, 20% up from 2001 (and widely believed to be an under-representation of the true figure; in 2010, a BBC and University of Nottingham survey suggested there could be around 700,000)
- One in 12 young carers is caring for more than 15 hours a week, and around one in 20 misses some school because of their caring responsibilities
- There is a fairly even split between the proportion of young carers aged 10–14 (41%) and 15–17 (46%); one in eight are under the age of ten
- Young carers are 1.5 times more likely than their peers to be from Black, Asian or minority ethnic communities, and twice as likely not to speak English as their first language
- The average income for families with a young carer is £5,000 less than for families who do not have a young carer
- There is no strong evidence that young carers are more likely than their peers to come into contact with support agencies

- Young carers have lower educational attainment at GCSE (equivalent to nine grades lower overall), and are more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19.

5. National and legal context

The national Carers Strategy

In November 2010 the government published Recognised, valued and supported: next steps for the Carers Strategy^{xiii}. This Carers Strategy endorses the vision and outcomes set out below.

Vision:

Carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen.

Outcomes:

- 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.
- Carers will be able to have a life of their own alongside their caring role.
- Carers will be supported so that they are not forced into financial hardship by their caring role.
- Carers will be supported to stay mentally and physically well and treated with dignity.
- Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhoods.

Over the summer of 2010, the Department of Health asked for carers' views on what the priorities for the next four-year period should be. The following priority areas were identified:

- Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and 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.
- Personalised support both for carers and those they support, enabling them to have a family and community life.

- Supporting carers to remain mentally and physically well.

Hillingdon Council, Hillingdon Clinical Commissioning Group and partners are committed to delivering against the above outcomes.

For more information on the National Carers Strategy, see the Carers UK website www.carersuk.org and the Department of Health website www.dh.gov.uk.

Legal

The Care Act and Children and Families Act both present major opportunities to improve local support for carers. The Care Act gives a duty to local authorities to identify carers' unmet needs as part of their preventative responsibilities, and a duty to NHS bodies to cooperate with local authorities on its functions. The Children and Families Act requires local authorities to take steps to identify the extent to which there are young carers with unmet needs. Both Acts strengthen the entitlement to carers' assessments – for adults this involves removing the requirement to provide 'substantial' and 'regular' care before an assessment is provided.

The Equality Act 2010 has also given carers new rights which mean that they cannot be directly discriminated against or harassed because they are caring for someone who is disabled. This would include being treated less favourably by employers, overlooked for promotion, or not allowed the flexibility they are legally entitled to request.

Local

This strategy has links to and supports the following local plans and strategies in Hillingdon:

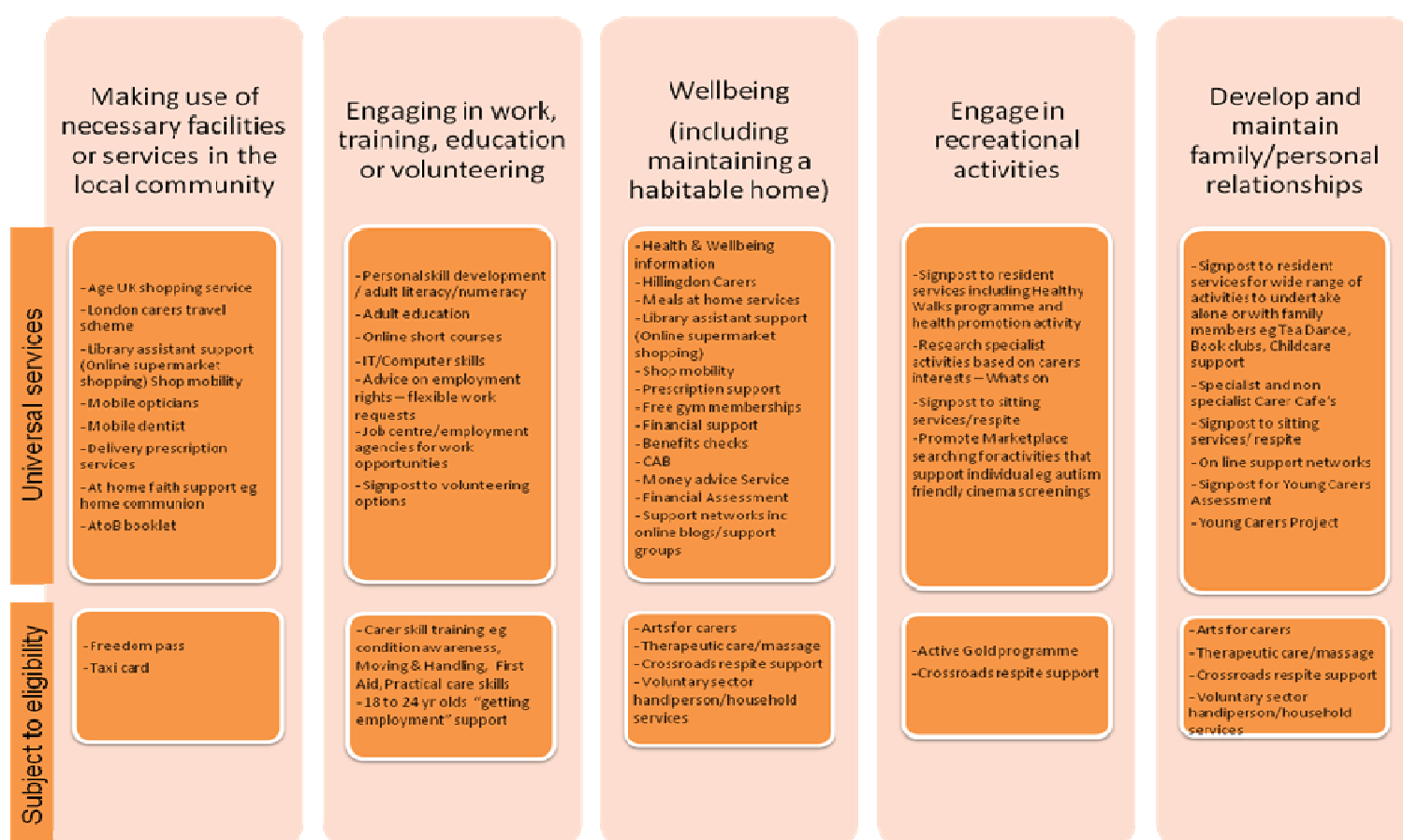
- Joint Strategic Needs Assessment [Joint Strategic Needs Assessment](#)
- Joint Health and Wellbeing Strategy 2014-16
- Better Care Fund Plan
- SEND reforms plan
- Hillingdon Clinical Commissioning Group Long Term Conditions Strategy
- Hillingdon Clinical Commissioning Group and NHS Partners Integrated Care Programme
- Hillingdon Clinical Commissioning Group Primary Care Transformation Plan

6. Services for carers in Hillingdon

The London Borough of Hillingdon provides support for carers both directly and indirectly. During the financial year 2013-14, approx £4.5m was spent by the Local Authority on services including in-house respite, private and voluntary respite for children and adults, commissioned services and corporate grants.

In addition the Local Authority also funded day care and transport for social contact and respite for people living in their own/family home.

The range of services provided for carers in the borough is represented in the diagram below:



7. Consultation and Engagement

The Delivery Plan, as shown in Appendix A, has been informed by the results of a consultation programme to establish what unpaid carers in Hillingdon want and need to be healthy, happy and supported in their caring role. The activities have been identified and agreed by the Carers Strategy Working Group and reflect what the council, CCG and partners will do to support carers in Hillingdon over the next three years.

Phase One of the Carers Strategy Consultation was completed from January to March 2015 with Phase Two continuing from April to October 2015, when a report of the full consultation results will be produced. The ongoing consultation will inform future refreshes of the Delivery Plan to ensure it is accurately reflecting what carers need.

Phase One of the consultation comprised of the following participation opportunities:

- An online survey.
- A postal survey.
- Face to face surveys completed by Hillingdon CCG Customer Engagement Officers.
- Drop in consultation sessions at Botwell and Uxbridge Libraries, Hillingdon Hospital and Hillingdon Carers Advice Centre.
- A stall at the February 2015 Disability Assembly.
- Uxbridge Dining Club and the Hillingdon Carers Cafe at Christchurch in Uxbridge

The consultation was promoted in the following ways:

- Posters were displayed in Hillingdon's 22 libraries.
- Publicity letters and posters were shared with specialist Council run resource centres including Queens Walk and the Rural Activities Garden Centre.
- Publicity letters and posters were sent to over 30 partner organisations and community groups to share with those they work with and/or represent. Organisations included the Hillingdon CCG, CNWL, Healthwatch Hillingdon, Hillingdon Hospital, Hillingdon Carers, DASH and Age UK and community groups including residents associations and parent carers groups.

As at 31 March 2015, 123 responses were received from adult carers and 9 responses from young carers.

The initial results of the survey are presented in Appendix B.

-
- ⁱ NHS Choices. (2014) *Understanding Carers* (online)
- ⁱⁱ Carers UK Policy Briefing. (2012) *Facts About Carers 2012* (online)
- ⁱⁱⁱ Office for National Statistics. (2013) *2011 Census Analysis: Unpaid Care in England and Wales, 2011 and comparison with 2001* (online)
- ^{iv} Carers UK Policy Briefing. (2012) *Facts About Carers 2012* (online)
- ^v Office for National Statistics. (2013) *2011 Census Analysis: Unpaid Care in England and Wales, 2011 and comparison with 2001* (online)
- ^{vi} Carers UK. (2004) *In Poor Health: the impact of caring on health* (online)
- ^{vii} Department of Health. (2012) *Assessment, eligibility and portability for care users and carers* (online)
- ^{viii} Carers UK. (2013) *The State of Caring 2013* (online)
- ^{ix} Carers Week. (2012) *In Sickness and In Health* (online)
- ^x University of Leeds and Circle. (2011) *New Approaches to Supporting Carers Health and Well-Being: evidence from the National Carers's Strategy Demonstrator Sites Programme* (online)
- ^{xi} Schonegevel, L. (2013) *Macmillan Briefing on Carers Issues* (online)
- ^{xii} NHS England & NHS Improving Quality. (2014) *Commitment for Carers: Report of the findings and outcomes.*
- ^{xiii} <https://www.gov.uk/government/publications/recognised-valued-and-supported-next-steps-for-the-carers-strategy>