



Recognised, supported and empowered

Hillingdon Carers Strategy 2015 - 2020



“I appreciated the time out
for myself. The course has
done more for me than
even a holiday.
It makes me happy and
even gives my life a sparkle
that I had lost.”



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Our vision:

“We will be recognised as the gateway to a better life for all unpaid carers in Hillingdon”

Part one: Introduction



Foreword

Carers make an enormous contribution to the health and social care economy both nationally and locally through the provision of essential care and support for relatives, friends and neighbours. Their efforts in providing this care improves the quality of life of the people they care for and often goes unrecognised, even by carers themselves who may not see themselves as ‘a carer’.

Hillingdon Carers’ vision is to be recognised as the gateway to a better life for all unpaid carers; we will strive to ensure that carers understand the critical role they play and can access the information, advice, training and support they need. Our services will support them to: make informed choices about their caring roles; remain healthy and socially-connected; access emotional support when caring gets tough, and; mitigate against some of the negative impacts that caring can have on lives.

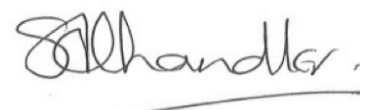
For young carers our support will help them to have as normal a childhood and adolescence as possible. We will give these young people the skills and strategies to better manage their home lives and allow them to be young and have fun in a supportive and social environment. Our N-Hance Transition project will also work to raise aspirations and help young adult carers to make smoother transitions into adulthood and to access training, further education, work or apprenticeships.

Our progress so far is significant. Feedback from carers of all ages shows that our services are valued and of a high quality. The year-on-year growth in our range of services - and the investment made by external funders - is indicative of their regard for the standard of support that we provide. However there is more to do.

This strategy sets out how we will build on that reputation over the next five years. It has been developed within the context of the Care Act 2014, the Children and Families Act 2014 and the current drive for integration of health and social care services in Hillingdon. It presents our vision of a society where carers are better-recognised, healthier and happier. We are aiming for excellence and we’re determined to achieve it.



Doreen West
Chair of Trustees




Sally Chandler
Chief Executive

On behalf of the Trustees, staff and the volunteers of Hillingdon Carers



“A carer is somebody who provides unpaid support to a relative, friend or neighbour who is ill, frail, disabled or has mental health, drug or alcohol problems.

This includes parent-carers of disabled children and young carers under the age of eighteen whose caring role may involve them taking on a level of responsibility that is inappropriate to their age or development.”



Mission Statements

1

We will work to ensure that carers are recognised and valued for the care and support that they provide and are acknowledged as expert care partners who are critical to the health and social care economy in Hillingdon.

2

Our support will be tailored to meet individual needs, enabling carers of whatever age to maintain a balance between their caring responsibilities and a life outside caring. We will create partnerships that ensure they can do that safe in the knowledge that the person they care for is well-supported and cared for.

3

We will grow our range of services and extend their 'reach', both geographically and in terms of seven-day access. In addition we will improve and strengthen our partnership-working and increase our range of collaborative projects.

Introducing Hillingdon Carers

Introducing Hillingdon Carers

1 Who we are

Our experienced staff team has over 100 years of experience working with carers in the diverse neighbourhoods of the London Borough of Hillingdon. We have an excellent reputation for quality support and advice and all our services have been developed in direct response to carers' 'lived experiences'.

Hillingdon Carers was established in 1988 by local people and was managed by Carers National Association (now Carers UK). In 1993, the Kings Fund commissioned research in four London boroughs, including Hillingdon, and it showed that Asian carers in the borough were marginalised and disadvantaged. Funding was secured from the City Parochial Foundation to provide culturally appropriate one-to-one support and advocacy and to enable Asian carers to participate in the planning and development of services to meet their needs. The Asian Carers Project was born and quickly became an integral part of the organisation.

In 1995, Carers National Association took a decision to establish its London projects as independent charities and Hillingdon Carers was launched as an unincorporated charity with a carer-led management committee. The organisation has now become a charitable company limited by guarantee, but retains the emphasis on 'by carers for carers'; a large proportion of the organisation's trustees and staff are either current or former carers.

2 What we do

Our current range of services is extensive and has been developed according to what carers have told us. These services are of great value to carers and many also provide valuable respite as an additional benefit.

Introducing Hillingdon Carers



Our services include:

Information and advice:

- A drop-in Advice Centre on Uxbridge High Street plus a borough-wide outreach programme
- Support from Carer Advisers for:
 - Expert Welfare Benefit advice
 - Help with form-filling
 - Assistance in accessing Social Services support
 - Advocacy
 - Signposting and referral to other services
 - Representation at tribunals
- A range of quality information through leaflets, website, Facebook, Twitter and LinkedIn

Health and wellbeing:

- A GP outreach and health liaison service
- Health MOT and Pamper days
- A series of drop-in Carer Cafés across the borough
- Relaxation sessions, weekly exercise, yoga and dance tuition
- Counselling and emotional support
- Training in back care, first aid and wheelchair handling
- Arts for carers and a Learn to be Well programme
- A therapeutic care service in partnership with the British Red Cross

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Young carers services (5 - 17 years):

- School/college liaison programme
- Specialist project supporting young carers looking after an adult with mental health or substance misuse problems
- 1:1 emotional support and support planning
- Young Carer Clubs across the borough
- School holiday events programme, every holiday including half-terms
- Residential breaks
- Arts projects, fun activities and family days

Young adult carers (17-24 years):

- Support and advocacy for young adult carers through the transition from school to work, apprenticeships or further education
- Bespoke, 1:1 support and help to develop a personal development plan
- A comprehensive programme of training to provide a range of life skills from money management to CV writing
- A social programme with trips, activities and residential trips
- Liaison and links to further education, apprenticeship schemes, local employers, training and volunteering opportunities
- Personal mentors and support with job applications

Introducing Hillingdon Carers



“A smile and a welcome lift the spirits. [Hillingdon Carers] is a place where I feel I won’t be judged and I am with people who understand what problems I am facing; most people don’t understand this.”

Introducing Hillingdon Carers

3 What we've achieved

In the past two years we have:

- Successfully applied for close to £2 million in entitlements for carers, improving their household incomes and contributing to the local economy
- Successfully bid for in excess of £250,000 in additional funding for new projects, clubs and services, in direct response to carer-identified gaps in services
- Supported around 6,000 adults and young carers and provided over 8,000 breaks from caring
- Provided over 4,000 health and wellbeing sessions, including physical activities, therapeutic care, yoga, dance tuition and arts and creative activities
- Worked with 46 GP practices across the borough and have identified Carer Champions in 17 practices to date
- Invested significantly in our organisation to ensure we are able to continue to secure resources, grow our services, uphold our excellent reputation and maintain and grow staff members' knowledge and skills
- Been a founding member of the Third Sector collaborative Hillingdon 4 All, which is leading the way in finding new ways to cut costs, coordinate activity, prevent duplication, share learning and skills and engage in mutually-productive activity

4 How we consulted

Following extensive consultation with the borough's carers, coupled with our learning from our work with carers, we have developed five strategic priorities (described in Part Two as Programmes of Work). The consultation process included:

- A 'Help us to plan the future' questionnaire completed by 95 carers
- Use of our existing services to talk informally to carers of all ages about what is important to them
- Meetings with councillors and public sector officers
- A retrospective analysis of our 6-monthly Carers Surveys and of the data we collect for funding bodies to identify trends and new needs
- An away day event with our Board of Trustees, staff team and volunteers
- A series of carer focus groups to test out and discuss our draft priorities

“You are a wonderful organisation for support, we are lucky to have you in Hillingdon.”

Introducing Hillingdon Carers

5 Our objectives

Our extensive consultation has led us to focus our activities on five key objectives. These are described in Part Two as our Programmes of Work.

5 key objectives

By 2020 we will:

- 1** Have found more 'hidden' carers
- 2** Have projects in place that help to tackle carer loneliness and social isolation
- 3** Have an extended range of services that reaches more carers and can meet the ever-increasing need for support
- 4** Be able to demonstrate improved physical and mental health in carers after contact with our services and provide more help for self-management of long-term conditions
- 5** Be supporting more carers to manage all elements of their caring situations

3 cross-cutting themes

Although our objectives cover five very different elements of caring, some issues are common to them all. These issues came up again and again in our consultation:

- Young carers: we will extend our support services for young carers and young adult carers
- The carer's voice: we will develop structures that improve carer engagement and that give them a voice in the services that support them. We will promote parity of esteem to ensure carers are being actively involved in the care-planning process for the people they care for
- Promoting equality: all our activity will be sensitive to the differing needs of communities and will ensure equity of access to support, irrespective of age, race, ethnicity, sexuality or gender

Introducing Hillingdon Carers

6 Overcoming challenges and our commitment to excellence

We have ambitious plans for Hillingdon Carers but will be delivering this strategy against a difficult backdrop of funding cuts, changing patterns of commissioning and more intense competition from large national organisations for contracts and tenders.

The growing profile of carers and caring in the UK is to be welcomed; however it creates an exponential growth in demand for our services, which we have to deliver on tighter budgets and in a challenging funding environment.

High quality services are our trademark and we need to ensure that this remains the case and that we can sustain our reputation for excellence, despite the challenges we face. We also want to protect our capacity to respond directly to carers and their 'lived experience'; an approach which has been critical to the development of appropriate services and to the effective targeting of resources.

Some of the new approaches we have identified to help us to make every carer contact count and to deliver our vision of becoming the gateway to a better life for carers include:

- The development of new partnerships and collaborations that will strengthen our market position, in particular:
 - The formation of a Community Interest Company, Hillingdon 4 All, in partnership with Age UK, Harlington Hospice, Disablement Association of Hillingdon (DASH) and MIND
 - Leading on the development of a Carers' Collaborative for Hillingdon, which will promote closer working across all organisations that have carers within their remit. We will start to work more closely with these organisations to coordinate the carer 'offer' in the borough
 - Creating a new strategic alliance with Carers Trust Thames to protect the Carers Trust network partner 'brand' and promote our specialist skills and knowledge in working with carers

Introducing Hillingdon Carers



- The continued commitment to bid for and draw down external resources in to the borough to extend carer support and add value to the statutory funding that currently sustains our activities
- In addition to bidding for traditional sources of funding, we will be more creative in our approach, for example we will explore opportunities presented by the private sector. We will:
 - Pursue private sector sponsorship to sustain and extend carer cafes, exercise programmes and other health and wellbeing services
 - Identify and utilise private sector community programmes: for example, our local Lloyds Bank mentor young adult carers and we have free monthly legal clinics for carers from Turbervilles Solicitors. We will grow these relationships over the next five years
 - Continue to raise our use of voluntary donations to develop complementary social opportunities for carers of all ages, in particular to tackle carer loneliness and isolation
 - Enhance traditional services by developing community assets and create a mixed economy of support for carers
- Developing capacity and flexibility to respond to the ever-changing demands for carer support and improving our ability to respond rapidly to new opportunities by:
 - Increasing our use of well-trained volunteers, particularly in the delivery of social and activity groups. We will actively seek the resource to have dedicated staff time to write and implement a Volunteering Strategy
 - Forming a pool of sessional staff to work alongside the staff team at times of high demand and to help deliver a growing range of Young Carer Clubs and Carer Cafés across the borough
 - Introduce overtime payments for those staff that are happy to do extra hours, particularly as one of our objectives is to introduce 7-day access over the coming five years

Introducing Hillingdon Carers

- Respond rapidly to new opportunities: for example in direct response to the new requirements of the Care Act, we put staff through an Advocacy qualification and key staff members have accessed training on Carer Assessments
- Finally, we will continue to invest in creating an organisation that is fit for the future through:
 - Restructuring the staff team to ensure we have the right skills in the right places to deliver our five-year vision
 - Investment in staff training and personal development – inspiring new thinking and finding new ways of doing things
 - The introduction of Charitylog to improve internal communications and better manage our database, including the production of more accurate statistics and monitoring information
 - Reviewing and improving our marketing and communications to ensure more effective stakeholder management and to continue to raise the profile of our organisation

Part two: Programmes of work



Finding 'hidden' carers

Much has been published in the last few years about demographic change: people are living longer both with lifelong disabilities and long-term health conditions. The continuing shift away from institutional care to care provided at home and in the community means that there are more carers than ever – an estimated 7 million in the UK. It can take years before someone self-identifies as a carer and this can mean essential advice and support doesn't reach them or reaches them too late.

In England and Wales, 1,277,693 people over 65 are carers and 65% of older carers (aged 60–94) have long-term health problems or a disability themselves.¹

It is estimated that, each year around 2 million carers cease caring and another 2 million begin² so there is by no means a 'static' population of carers. Efforts to engage with those new to caring roles therefore need to be constantly renewed and sustained.

Information and advice is needed to address different aspects of caring at different times and should be tailored to individual needs. It is important that carers have time to think through their options and make informed decisions about their own lives alongside their caring roles. To provide this we need to know who the carers are.

Everyone has a role to play in bringing about a cultural shift towards a society that recognises and understands caring, ageing and disability better. It is really important that those who come across people with caring responsibilities as part of their work should proactively signpost them to sources of information, advice and support.

Health professionals also need to engage better with carers in the care planning process and recognise the specific knowledge and expertise that carers bring about the person they care for.

“In the NHS there is little acknowledgement of how well we know the person and how long we have looked after them, all the things we have tried, researched, bought...”

Where we are now

We have an excellent carer identification rate with 20.2% of the borough's 26,000 carers known to the organisation and receiving regular information; this is compared to an average rate of between 10-13% across other London boroughs. However, this still leaves around 80% of the borough's carers not accessing support, so we know there is plenty still to do.

We know carers experience a lack of recognition by health professionals so we have developed outreach and education mechanisms to provide regular awareness-raising sessions to practice staff at GP surgeries and to advocate for carers struggling to access appointments.

We also deliver training to a range of other services from Library staff to GP receptionists to student nurses. Our Young Carers team runs a rolling programme of presentations in school assemblies and personal health and social education (PHSE) lessons.

Programmes of work

Our focus to date has been on health, social care and education providers; we need to extend this programme and think out of the box; we want to make caring and carers everybody's business.

Where we want to be

By 2020, we will have developed mechanisms that enable us to reach, identify and support at least 40% of the borough's carers and will have the resources to provide them with the support, training and practical skills they need to fulfil their caring roles.

In addition to the traditional awareness-raising with health and social care professionals, schools, colleges and other third sector organisations, we will target other services to enlist their help in the early identification and referral of carers. In essence we want to grow a 'carer movement' where all services are 'on message' and help to spread the word to carers that support is out there.

Through the development of a stronger, better co-ordinated outreach and education programme we will energetically engage with colleagues in health and social care to raise the profile of caring. We want to promote parity of esteem and ensure that carers are recognised for their expert knowledge and experience.

How we're going to get there

In the next two years we will:

- Identify a lead member of staff for outreach and education to better coordinate our activities
- Review and strengthen our outreach and education programme and explore new routes to identification of carers and young carers
- Establish Carer Information points in all 17 of Hillingdon's Libraries
- Engage a wide range of partners to develop a borough-wide collective 'Think Carer' campaign

- Set ourselves an annual target for numbers of new carers and young carers identified
- Develop GP and School Information packs that make the case for identifying carers
- Ask all new carers what prompted them to seek support so that we can collect better data about what is working. This will help to target our efforts where they are most effective
- Develop a stronger education programme for health staff that delivers a comprehensive introduction to effective working with carers and makes an irrefutable case for them to be recognised in the care planning process
- Review examples of good practice from other areas that are successfully identifying carers and adapt it for local implementation
- Ensure we are up to date with current research through national bodies and academia and apply learning locally

“Hillingdon Carers were the first people to recognise me as a carer after 20 years; my GP didn’t even do that.”

Tackling carer loneliness and social isolation

Each day in the UK, 6,000 people become carers and the transition to caring, and particularly to full-time caring, can plunge people into isolation. The loneliness carers experience is caused by a range of circumstances, many of which they have no control over. Indeed many carers describe feeling 'invisible' as the needs of the person they care for take precedence and their own needs fade into the background. These feelings are compounded when many carers find themselves having to give up work and manage on a significantly-reduced household budget, at the same time that their relationships are becoming increasingly transactional rather than affirming or sustaining.

Isolation is an objective state measured by the number of contacts and interactions that someone has with others. People who are isolated don't necessarily feel lonely. Loneliness refers to the negative feelings people have about the extent and quality of their social relationships; even people who have many social contacts may feel lonely. According to a study by Carers UK 8 in 10 carers have felt lonely or socially isolated as a result of their caring responsibilities.³

Research conducted by the National Campaign to End Loneliness⁴ in 2013 demonstrated that significant numbers of older people - many of whom are carers - attend GP appointments as a means of social contact. Following a poll of 1,000 GPs, the Campaign concluded that:

- Over three quarters of GPs were seeing between one and five lonely people a day
- One in ten doctors reported seeing between six and ten lonely patients a day
- A small minority (4%) said they saw more than ten lonely people a day

Social isolation can have a big impact on carers' health and wellbeing and academic research has demonstrated that the effects of isolation can mean an increased risk of high blood pressure, higher use of medication, higher incidence of falls, earlier entry into long-term care and an increased use of accident and emergency services.

As a society we need to reach out to carers so they know they are not alone.

Where we are now

Our current range of services, whilst not specifically designed to tackle loneliness, do give carers social contact with others who understand what they are going through. We have excellent anecdotal evidence from Carer Cafes that being amongst other carers is useful social contact for many and provides the opportunity to learn from each other.

We also know that new friendships form and new social networks start to develop over time. This is particularly helpful in tackling loneliness in carers as it is well-documented that established social networks often disintegrate with the advent of caring.

Young Carer Clubs and school holiday social programmes provide the same function; a recent questionnaire saw 86% of our young carers citing 'making new friends' as their main reason for attending Clubs. Again, we know that young carers often struggle to maintain 'normal' relationships with their peers and are frequently bullied and ostracized in school.

We are however acutely aware that making the case for investment in some of our most valuable low level services is becoming increasingly difficult against a backdrop of unprecedented cuts. We need to become better at evidencing the benefit to carers of these social opportunities and more creative in the ways we design and deliver support services.

“I didn’t feel isolated while I was able to work and care. Once I tried to be a carer full-time, I felt totally isolated because your whole network’s gone.”

Where we want to be

We want all carers to have a social life outside caring and be able to access activities and relevant, bespoke and age-appropriate breaks from caring within their local community. Crucially we need to do this in a way that doesn’t always rely on people identifying themselves as carers.

To enable carers to stay socially-connected we recognise that there needs to be a range of support available that reflect the fact that all carers have differing needs. By 2020, we will have increased access to drop-in sessions, social groups, learning, cultural and healthy ageing activities, faith and cultural support and complementary therapies.

In addition, we will continue to develop new self-help groups and counsellor-facilitated groups, such as cognitive therapy groups and bereavement courses.

We want to increase our use of volunteers to escalate our capacity to support more carers. By 2020, we will have doubled the number of volunteer hours supporting carers to 10,000 per year to enable us to increase our capacity for support.

“[It’s] always interesting to hear of [different carers] experiences and an insight/opportunity to learn of new ideas/services which might be useful.”

How we’re going to get there

In the next two years we will:

- Build a stronger body of evidence about the impact of our services using the Carers STAR outcomes tool and combine this with carers’ stories to secure investment for new social groups, trips and support services
- Use the new statutory requirement in the Care Act to focus on prevention and promoting wellbeing to make the case for continued investment in our range of low-level support services
- Develop new partnerships and new approaches to delivering social programmes and be able to evidence and articulate cost savings as well as improved outcomes
- Recruit, train and support three new volunteers to strengthen our outreach function and three new volunteers to run cafes
- Extend and formalise access to emotional support beyond our current offer and develop a menu of opportunities for carers that includes one-to-one and group sessions

Programmes of work

“It gave my wife a real opportunity to relax, enjoy herself and completely forget about the responsibilities of helping me. Too often there is all the focus on the patient and not on the carer; this was very helpful and rewarding. Thank you.”

3

Extending our range of services

Most care happens within families and often families do everything possible to minimise the need for formal care and support by finding what works for them – effectively personalised support in action.

We know that families have changed considerably in the past fifty years, with many families dispersing to follow work and relationships. Caring at a distance can be considerably challenging and many carers do not live with the person they care for. These are often adult children caring for older parents, whom are often juggling work and other family responsibilities and travelling to visit the person they care for. This can have a significant impact on them financially, at work and in their other relationships.

We are seeing a significant increase in ‘mutual’ caring situations. These are often older people, both with their own health needs; they manage by supporting each other but are extremely vulnerable and the situation is often sensitive to slight changes and subject to breakdown very quickly. There is a high incidence of dementia in these situations.

We have also witnessed a growth in the number of extended families with increasingly complex inter-dependencies. There are frequently young carers involved and often two or three caring situations under one roof. It is of real importance to understand the picture to ensure that each person that is caring can be acknowledged and supported in a way that is meaningful to them.

When you couple these changes in the profile of caring situations with ‘traditional’ caring relationships, it is instantly clear that there is no ‘one-size-fits-all’ approach and that carer support needs to be as diverse as the situations it is trying to help with. We are increasingly aware of gaps in our provision and the need to plug these gaps to ensure equity of access to support, hence our commitment to developing support systems, not just services.

Programmes of work

Where we are now

We want to ensure that we support the notion of 'real lives' and not just 'eligibility for services' in these, and indeed, all caring situations. In response we have developed a strong range of services that have reasonable geographical spread across the borough. We know that we have gone some way to addressing the multiplicity of caring situations but recognise that there is more to do.

We often have carers bringing the people they care for to cafés, clubs and trips in order for them to be able to access time with others.

We have well-developed assessment processes that ensure that the support we offer is tailored to individual caring situations. But we also need to consider our assessment processes against the changing backdrop of statutory carer assessments, the demand for better evidence of the outcomes for carers of our interventions and the possible future of outcome-based commissioning. We need to be better at measuring our impact.

We have strong support programmes for carers of whatever age, but, in situations where whole families are co-caring, we need to review and strengthen our assessment process, internal communications and our responses to the need for 'whole family' support.

“I feel much more relaxed and happy that all of us were together making family memories... it gave us a happy family.”

Where we want to be

We know that, by looking beyond the immediate relationship between a carer and the person with care needs we can maximise a wider network of support. We want to make sure that our approach is successful in enabling complex families to stay as independent as possible. We have started along this path and 2015 was the first time we were able to offer whole family activities; we know we need to develop this further.

We are also particularly keen to improve support to carers of people with dementia. Whilst carers are able to bring the people they care for to groups, they are still effectively 'on duty'. We will look at a partnership approach and new ways to offer dementia-specific collective respite so carers can have a couple of hours to themselves.

We want to ensure that a newly-identified carer in one part of the borough has access to the same range of support services as a carer from another part of the borough. We will extend our use of volunteers to make sure we can respond to the geographical demand for services and we want to establish a Carer Hub for the south of the borough.

We want to ensure that all resources are put to the absolute best use and that we don't do things just because we always have. Carer feedback is critical to ensure efficient and effective targeting of limited resources.

Programmes of work

How we're going to get there

In the next two years we will:

- Develop our approach to working with complex families and offer whole-family packages of support, particularly in those families where there are young carers
- Grow a pool of sessional workers across the adult and young carer teams to enable expansion and contraction in services according to demand
- Work with Carers Trust Thames to develop a collective respite offer for carers of people with dementia so that they can access cafes, classes and respite activities safe in the knowledge that their loved ones are professionally looked after
- Identify the necessary resources to introduce flexible 7-day working and explore mutually-advantageous cover options with other Third Sector partners
- Lead the development of a Hillingdon Carers Collective so that all organisations with a remit to support carers are working better together and coordinating opportunities
- Continue to improve the geographic reach of our services and use carer feedback to ensure these are needed and plug identified gaps
- Extend our use of volunteers to make sure we can respond to the geographical demand for services
- Work through the Carers Collective to develop a Carers Hub in the south of the borough

4

Supporting carers to look after their own physical and mental health

Providing care for a loved one should not cost carers their mental and physical health. Sadly however we know that, for some, caring can be emotionally and physically draining and that many carers experience significant stress caused by the nature and extent of their caring responsibilities.

2011 Census data shows that full-time carers are over twice as likely to be in poor health as non-carers and research carried out nationally by Carers UK consistently reflects the strain that caring can have on the physical and mental health of carers. Their 2014 State of Caring Report shows that 69% of carers find it difficult to get a good night's sleep as a result of caring and 58% have considerably reduced the amount of exercise they do since they started caring.⁵

Carers report that it is very difficult to look after their own health and the day-to-day physical demands of caring can have a significantly negative impact. Many are already living with long-term conditions of their own.

The impact of caring is not just physical, carers report increased levels of anxiety, depression, stress and poor sleep patterns; these are often exacerbated by social isolation and loneliness. Half of the carers responding to the 2014 State of Caring Survey reported being affected by depression.

Programmes of work

Where we are now

We have a strong exercise programme for adults (Active Gold) and for young carers (Activ8). We offer group exercise sessions for all ages and abilities, from chair-based exercise and yoga to more dynamic cardio and dance sessions. Our young carers have access to a good range of sports facilities from five-a-side football to professionally-facilitated gym training.

Our therapeutic care service (in partnership with the British Red Cross) and Pamper Days (in partnership with Uxbridge College) provide some light relief from the stresses of caring. For those carers needing more intensive support, we offer emotional support at every contact and a free counselling service.

In addition we have an Art for Carers programme, delivered in partnership with the London Borough of Hillingdon, that helps carers to rediscover old hobbies, or adopt new ones. The 6-week courses are hugely popular and provide much-needed personal time.

Young carers have access to creative activities at clubs and our school holiday programmes offer a whole range of new experiences and opportunities for the young people we work with; things they might never have had the opportunity to experience otherwise.

We also have a Learn to be Well programme, delivered in partnership with Hillingdon Adult Learning Service, which aims to tackle stress, anxiety and depression.

“The [exercise] programme has helped my mobility and reduced my back pain and [my use of] pain killers.”

Where we want to be

By 2020, we want a strong, well-resourced Carers' Health programme that gives carers access to a more comprehensive range of self-management and health-improvement activities. These will include:

- A more extensive physical activity programme
- An extended training offer, which covers topics such as healthy eating, depression management and better sleep
- Advocacy with health services where carer ability or motivation to access screening and preventative opportunities is poor
- An improved range of screening, health checks and MOT days

If carers themselves are living with a long-term condition we want to ensure they have access to good information and a range of opportunities to learn about - and better manage - their condition. This might include a menu of opportunities such as peer-to-peer and group support and, in those cases where there is an identified need, active case management.

We want to provide more opportunities for carers to have time away from caring and receive timely emotional support. In addition to our free appointment-based counselling service, we want to have trained volunteers at all our carer cafés.

We will develop clear channels of communication to ensure that carers are aware of the support that is available to them, including the introduction of Carer Information Points in libraries.

“This [Arts for Carers] course was a wonderful escape from the stress and pressures of caring. It took me to another place and it was wonderful!”

Programmes of work

How we're going to get there

In the next two years we will:

- Promote and widen opportunities for carer health checks, such as Health MOT days and opportunities for carers to meet health professionals face-to-face
- Develop a series of volunteer-led 'Healthy Carer' groups, such as walking groups, swimming clubs and dance collectives
- Work with our current volunteer counsellors to design a volunteer-led emotional support programme at carer cafes
- Continue to provide good training and support to all our volunteers and recruit a further 10 volunteers by summer 2017
- Work more closely with the emerging GP Networks to secure their commitment to promoting health and wellbeing amongst carers and to promote the early identification of carers
- Extend our range of quality information to include how to obtain equipment or arrange adaptations and also to encompass new developments such as assistive technologies
- Promote access to health information for carers and develop Carer Information Points in all 17 Hillingdon libraries
- Work with other Third Sector organisations to develop peer-to-peer support and group support to help carers manage their own longer-term health needs
- Develop a borough-wide Carer Training programme delivered in partnership with a range of other organisations

5

Helping carers to manage their caring situations

We know that the potential negative impacts of caring are numerous and well-evidenced. Carers are more likely to:

- Have poor physical health
- Suffer from low-level mental health problems such as sleeplessness, anxiety and depression
- Be financially disadvantaged with the advent of caring
- Lose contact with family and friends
- Experience loneliness and social isolation
- Lose confidence and self-esteem

We welcome the new statutory requirement of all carers having access to an assessment of their needs in their own right in the form of a Carer Assessment. However we are keen to ensure that this doesn't become an end in itself and therefore raises expectations of support services that might not be available to them.

For working carers, more understanding of caring is needed within the workplace as new research shows that 7 in 10 working carers have felt lonely or isolated at work as a result of their caring responsibilities.⁶

We know we need to continue to respond to carers lives by developing the range of help and support that they tell us makes a difference to how they manage their caring situations. We will find new ways of complementing statutory services and strengthening our contribution to a mixed economy of support.

Programmes of work

“You have no social life whatsoever as a carer. I don’t feel part of society at all, I feel a complete outsider.”

Where we are now

We currently offer carer training to help carers to better manage their caring roles. Young carers also have a range of life skills workshops and team-building exercises, all designed to help them to manage better at home.

We have an extensive range of support services that help carers to manage their caring situations, whether that is talking to other carers at our range of carer cafes or improving their own health through our yoga and exercise programme, we are supporting thousands of carers.

Our Information and Advice Service is highly-valued by carers and we have an excellent track record in successful claims for Carers Allowance and other care-related benefits.

We have ensured that all our services are carer-led and therefore meet their needs and guarantee the best use of our resources. We will continue to listen to carers in order to extend our support in the most meaningful ways.

In 2015 we launched a new monthly Legal Advice Clinic for carers through Turberville’s Solicitors and will promote this opportunity widely.

“It’s wonderful to have a chat with a variety of different carers.... It’s always interesting to hear of their experiences and gives an opportunity to learn of new ideas or services which might be useful.”

Where we want to be

We want all carers to receive a timely Carer’s Assessment and be able to access help in the day-to-day tasks that they carry out if a need is identified through assessment.

We want to ensure that everyone recognises that a carer’s assessment is the beginning, not an end in itself. Assessments should be dealing with carers’ rights to a future and we will work closely with the Local Authority to ensure that carers have access to the correct support to achieve this.

Carers will not be forced into financial hardship by their caring role. They will be offered benefits advice and support to claim entitlements; be able to access debt advice; and, be given help to manage money.

We want carers to have access to continued free legal advice about the multiple and complex legal situations that caring can create, such as powers of attorney, wills and trusts.

Working carers will be supported to continue working if they wish or helped to access the right benefits and support if they wish to give up work.

We want carers to feel supported and able to deal with the anxiety and stress created by caring and to manage any difficulties they experience in key relationships created by their caring role.

Programmes of work

“I feel relaxed and my body feels better and stronger.”

How we're going to get there

Over the next two years we will:

- Extend our training offer, in partnership with others, to ensure that carers have opportunities to learn about all aspects of caring
- Grow our Advice Service and provide more outreach and drop-in sessions across the borough to ensure that as many carers as possible can access the information they need to help them in their caring roles
- Further develop our range of Fact Sheets for carers to ensure that we have a rich and diverse range of quality information, about our own services and other sources of support
- Provide carers with the extensive range of Work and Career advice available through Carers UK and trial the new working carers' app 'Jointly' with those carers wishing to continue working
- Continue to develop access to free legal advice through existing and new partnerships and develop our range of legal Fact Sheets

Cross-cutting themes

These three priorities cut across all our areas for development and will be applied throughout our two year delivery plan. These are:

1 Young carers

We believe all young people have a right to a future; young carers can be disadvantaged in life as a direct result of their caring situations. We want to ensure that they do not have to carry out unsuitable levels of care or tasks that are inappropriate for their age. We will ensure that they are supported so that their life opportunities are not restricted by their caring roles.

Young carers often experience: restrictions on their social lives; a negative impact on their education; lower aspirations than their peers; restriction on life choices; financial hardship; lack of recognition, praise or respect; and, problems with peers such as bullying.

Many young carers have problems moving into adulthood - finding work, their own home and establishing adult relationships - and research conducted by Carers Trust shows that young adult carers are twice as likely to be 'not in employment, education or training' (NEET) than their peers.⁷

“Caring matters but it is not a career choice.”

Programmes of work

Where we are now

We have a good range of support for young carers with after-school and Saturday clubs across the borough, in addition to a strong school holiday activity programme. We also offer trips out and residential weekends away and provide information and advice, emotional support and advocacy for the young people we work with.

We run a specialist project for young carers supporting a parent or family member with a mental illness or drug or alcohol problem and funding for this project has been secured to 2018.

We are working closely with families as part of this project and have started to develop our whole-family offer.

Because of the easier access to funding for children and young people, over the last 12 months we have been able to identify gaps in our services and have successfully secured funding to develop new provision. Most notably we have:

- Developed a new Young Carers' Club in the north of the borough as we knew there were young carers there who couldn't travel to our other clubs
- Secured three-years funding for a new supported transition project for young adult carers – N-HANCE. This project is funded to 2018 in the first instance and will provide support, training and a social programme for young adult carers from 17-24 years to help them into training, further education, volunteering, apprenticeships or work

We have developed a strong range of partnerships and work closely with many other organisations to provide the range of support we do. We have also developed good relationships with schools, in order to help them better support young carers at school. Our outreach programme involves regular presentations in schools.

Finally we have aspiration-raising opportunities for young carers with Brunel and Bucks New Universities and a burgeoning relationship with Uxbridge College.

“It (caring) feels easier to talk about now because I know it’s nothing to be ashamed of and other people have the same situations.”

Where we want to be

We believe our range of support to young carers and the skills of our young carers team should be celebrated. We want to promote Hillingdon Young Carers as an example of good practice and we want to secure more expert leadership for the development of our young carers’ services into the future.

Support services for young carers are different to those for adult carers but the same principles of support apply. We will continue to develop a comprehensive range of support that meet the needs of young carers, teenagers and young adults and ensure that their needs and desires are fully reflected in the services that support them.

We want to improve geographical access for young carers by increasing the range of clubs and activities available to them.

We want to be instrumental in mitigating against the negative impacts of caring on young peoples’ lives and to equip them with the skills to better manage their caring roles.

We will advocate for young carers with all services to ensure that they receive the right levels of support and that their families receive all the services to which they are entitled and we want to develop our whole family support services.

“He now talks more openly about his feelings at school and his attendance is now the highest it has been since starting secondary school.”

How we’re going to get there

Over the next two years we will:

- Write a separate two-year delivery plan for young carers structured around our organisational objectives but with tailored responses to the unique needs of the young people we work with
- Recruit and launch a steering group specifically to develop our support to young carers. We will agree mechanisms with trustees to ensure that this group communicates effectively with the Board of Trustees
- Develop our supported transition project N-HANCE for young adult carers to help them to make a smoother transition into adulthood. We have clear targets for helping young adult carers to achieve accredited qualifications and access training, volunteering and employment
- Continue to grow the range of opportunities for young carers and increase their geographical spread to improve their accessibility

- Continue to raise awareness of young carers as part of the extension of our outreach and education programme and measure efficacy through referral recording
- Work with young carers to identify gaps in services and bid for resources accordingly
- Develop our whole family offer

**When asked to write a poem
I knew what I wanted to say
How much I appreciate Young Carers
They help me get through the day**

**I have a disabled brother
But I think he copes really well
If you look at him from a distance
You wouldn't be able to tell**

**But now I have my own club
And he's not allowed to attend
I get to have my fun
All me and sometimes a friend**

**And there's always someone to talk to
To scream out when life feels unfair
And they don't tell me to grow up
They take time and pull up a chair.**

Sarah, aged 12

2 The carer's voice

Consultation and co-design have long been recognised as critical to the development of effective support services and to improved targeting of resources. Indeed, a guiding principle of Hillingdon Carers is that carers play a major role in shaping and directing our work.

We have made some progress in going beyond a 'tick box' approach to engagement by enabling carers to participate in collective decision-making, service design and project delivery. By involving and empowering carers we will ensure that our priorities reflect those of the carers we support and that we develop in tune with their needs and desires.

We also recognise that carers want to influence the statutory services that support them and the people they care for. Therefore we will continue to work with health and social care professionals to promote parity of esteem and establish structures that ensure that carers are being actively involved in service design and the care and support planning process.

Where we are now

Our services have been developed according to the needs of carers and we use carers' stories and experiences to ensure that our efforts are focused appropriately.

In addition we:

- Organise an annual Carers' Fair in partnership with the London Borough of Hillingdon where carers have face-to-face contact with services
- Organise an Annual Carers' Conference in partnership with London Borough of Hillingdon and other third sector partners
- Collect information from carers through our 6-monthly Carers' Survey with around 80 responses for each
- Run a Carers' Forum after our AGM where carers raise issues with senior managers from health and social care

- Support a wide range of carer consultations for an extensive range of local and national organisations, including local statutory services, other third sector partners and national organisations such as Carers UK and Carers Trust
- Carers and former carers volunteer throughout the organisation providing around 5,000 hours per year and around 25% of members of our Board of Trustees and staff team are carers or former carers
- Collate qualitative data such as case studies and personal experiences of our services and use this evidence to support our case for investment in new and existing services
- Young carers co-design their summer and school holiday activity programmes with members of the young carers' team and in 2014/2015 contributed to a review of young people's mental health services across the borough, which was conducted by Healthwatch

However, we know that this can be improved. Now, possibly more than ever before, the carer's voice in the development of policy, plans and services is critical to ensure the best use of resources and we aim to strengthen the carer voice and support others to adopt good practice in consultation, engagement and co-design.

“The Conference gave us access to senior council people and lots of information.”

Programmes of work

Where we want to be

We want to put an end to the frequent demands for ‘carers to consult with’. Effective co-design should engage willing participants from the start of a process and all services should have effective, built-in systems to engage with, and work alongside, carers.

We will support carers to work closely with providers of services, be involved in service design and have a voice in the things that affect their lives, their health and their wellbeing. Through the strategic application of co-design principles, resources will be targeted appropriately and services will be developed according to ‘lived experience’ and be responsive to need.

We would like to establish structures that reach more isolated, less engaged carers to ensure that their voice is heard and want to work more closely with a broader range of partners to ensure that everyone is encouraged to ‘Think Carer’.

We want to develop a borough-wide body of carers who come together in a way that is meaningful to them and that provides opportunities to influence policy and practice more effectively.

We also want to ensure that all carers are treated as expert partners in care and be involved in the care-planning process by all professionals, whatever their discipline.

How we're going to get there

Over the next two years we will:

- Establish a Carers Collective for the borough
- Research and scope a carer engagement protocol to encourage best practice in carer consultation and engagement
- Work closely with Carers Trust Thames and other partners to develop mechanisms that better reach isolated and house-bound carers
- Redesign our website to make it clearer and more user-friendly for carers. We will improve navigation and ensure that information is easier to access
- Increase our use of information technology and social media to advertise consultation activities for those carers that would like to get involved

3 Promoting equality

Like many other groups carers can experience discrimination relating to poverty, gender, sexuality, health, disability, ethnic origin, age and, indeed, their caring responsibilities. We've made equality a cross-cutting theme because we want to reduce the impact of discrimination on carers of all ages, particularly those who are experiencing disadvantage and marginalisation.

In addition we want to ensure fair access to our services for all carers: support appropriate for some may not be relevant to others, so an inclusive, flexible and responsive approach is needed. Promoting an awareness of specific groups of carers and their sometimes unique caring issues is another key aim of this theme.

Where we are now

We already have an excellent track record in terms of the profile of our client group and we maintain statistical data records to give us a profile of the carers we work with. We collect data on age, sex, ethnic origin and disability and our records show that currently:

- 57% of our clients are non-white British
- 70% of our clients are women, but we still support and engage with nearly 2,000 male carers
- We support people of all ages from 5-105 years

In addition, we provide bespoke advocacy for lesbian, gay and transgender carers and we support carers across the whole range of caring situations from parent-carers of children with disabilities to older people caring for someone with dementia.

Our Carer Advice team offers support for non-English speakers and the team speaks Punjabi, Urdu, Hindi, Gujarati and some Swahili.

All our services welcome any carer, irrespective of their background.

Where we want to be

By 2020, we will have ensured that all our services remain sensitive to the differing needs of the diverse communities in the borough and beyond. Our aim is that all our services are fully-accessible and we will strive to provide equity of access irrespective of postcode, age, gender, nationality, religion or sexuality.

We want to sustain the current profile of our registered clients and ensure that it reflects the borough-wide demographic profile. We will therefore keep abreast of the changing nature of immigration and are aware that there is a growing population of middle-European residents in the borough. We will consider this when we are developing our outreach and education programme to make certain that we engage with carers from these newly-forming parts of our communities and think creatively about where we might meet 'newly-arrived' carers.

We would like to grow the number of male carers we support and have gender-appropriate provision wherever possible.

Programmes of work

How we're going to get there

Over the next two years we will:

- Cross-reference the profile of our clients against national and locally-available statistics to ensure that our support reflects the hugely-diverse range of needs
- Develop our advocacy function and invest in bespoke training for the staff team to ensure we have expert advocacy skills and can represent those carers who might be struggling to access mainstream support and advice for whatever reason
- Explore opportunities to engage with more male carers and develop groups and services that offer activities that are more appealing to men
- Include places of worship for different religions and belief systems in our outreach programme
- Develop our services in the heart of the communities that they serve

“The first thing I enjoyed was the place was near my house...”

Part three: Making it happen



Making it happen

The current state of caring

Nationally:

There are 4.5 million carers in England and 7 million in the UK. They are saving the economy around £119 billion per year.

The 2014 “State of Caring Survey” (Carers UK) showed that:

- 84% of carers said that caring had had a negative impact on their health
- 52% said that they expected their quality of life to get worse over 2015
- 40% say that they have been in debt as a result of caring and 36% say they struggle to afford utility bills such as gas, water or telephone
- There are approximately 700,000 young carers across the UK and 37,000 of these provide more than 50 hours care per week

New research carried out by Carers Trust reveals that:

- Around 48% of young carers said that caring made them feel stressed
- 44% said it made them feel tired
- Young carers are twice as likely to become NEET (not in education, employment or training) than their peers

Locally:

Data from the 2011 Census for England and Wales shows that there are 25,906 carers in the London Borough of Hillingdon, which is around 10% of the borough’s population.

Of these 5,526 carers provide over 50 hours of care per week, with a further 3,816 carers providing between 20 - 40 hours.

Making it happen



It is estimated that the value of carers' support is £442.6million per year in the London Borough of Hillingdon based on replacement care costs of £17 per hour.

It is difficult to estimate the number of young carers in the borough but we are currently working with close to 400 young people and we know there are many more out there.

We work with children as young as five years old and, in the past 12 months, have seen a sharp increase in the number of new referrals between 5-10 years old.

We have 112 young carers registered to the Young Carers Plus project which provides support to children caring for parents with mental health or substance misuse problems. Of these 22% are classified as Children in Need or are on the Child Protection register.

Policy context

At Hillingdon Carers we are fully conscious of the need to remain flexible and agile in terms of our ability to respond to changes in the political, economic, health and social care environments that form the backdrop to our work. Our forward strategy is, of necessity, broad, but more explicit activity will be detailed and regularly reviewed and refreshed through our two year Delivery Plan.

Nationally:

This strategy has been developed at a time of unprecedented change, most notably the significant changes taking place across the statutory sector and the recent introduction of a range of new legislation.

Following on the heels of the Health and Social Care Act of 2012⁹ two new significant pieces of legislation became mandatory on 1 April 2015 – the Care Act 2014¹⁰ and the Children and Families Act 2014¹¹. These are both positive steps for carers and they lay out new requirements for improved services and support. In addition to making wellbeing a guiding principle for care and support for both those in need of care and those carers that provide it, the Care Act introduces a new set of rights and duties in relation to carers.

Making it happen

At the same time the government published the Carers Strategy: Second National Action Plan 2014 – 2016¹² which refreshed the vision laid out in the 2010 document Recognised, valued and supported: Next steps for the Carers Strategy.¹³

In addition to the statutory requirements of social care services, NHS England published their Commitments to Carers¹⁴ in 2014, which is structured around eight key priorities. They also published a sister document, 'Commissioning for Carers'¹⁵, to help Clinical Commissioning Groups better identify and help carers to stay well. These documents form the basis for the National Health Service's commitment to give carers greater support and improve their quality of life.

Locally:

Locally, there is a positive drive towards closer integration of health and social care services and there is a range of local policy and strategies that have all been considered in the development of our strategic aims, most notably the new Hillingdon Carers' Strategy 2015-2018. We have also considered the aims of the Hillingdon Health and Wellbeing Strategy and are involved in the planning and delivery of work under the Better Care Fund and the Whole-Systems Integrated Care programme.

In response to the Children and Families Act, reform of 'Statement of Educational Needs and Disability' (SEND) arrangements¹⁶ and the Team around the Family (TAF) initiative have also formed a backdrop to our work with young carers.

We are confident that our specialist skills and experience will further ensure that we are working in close partnership with the statutory sector to deliver against all the new legislative requirements. However, let us not forget that these initiatives do not come with new money and there is the pressure to deliver against a backdrop of further public sector cuts.

Delivering the strategy

Delivery plans:

As previously articulated, we have, of necessity, kept our strategy relatively broad. It will be under-pinned by a two-year Delivery Plan for adults and a separate two-year Delivery Plan for young carers, based on the two year actions detailed in Section 2, Programmes of Work.

The staff team has an annual planning day with Trustees to review progress, and delivery plans will be available from Hillingdon Carers in June 2015, June 2017 and June 2019.

Each Delivery Plan will detail a series of indicators and SMART targets that will enable us to measure our progress against our two-year actions and our vision for each programme of work.

Staff supervisions and annual appraisals will be informed by their commitments in the organisational Delivery Plan and we have reviewed our processes and documentation accordingly.

Governance:

Regular progress reports will be presented at Trustee Board meetings and staff members will be asked to present on their own specific areas of work to Trustees.

Progress will also be detailed in the regular monitoring reports that we produce for funders.

Making it happen

Measuring and recording progress

Current arrangements:

We have a well-established range of mechanisms to monitor and evaluate our services; indeed we have to produce detailed and comprehensive monitoring information for a range of funding bodies. We generate this information through the consistent application of:

- Twice-yearly Carers Surveys – securing feedback from around 80 carers per survey
- The maintenance of statistical data which gives us a profile of our service users and quantifies the volume of support we provide
- Use of anecdotal qualitative evidence and case studies to bring carer experience to life
- Short evaluation questionnaires after every trip, arts course or other activity to evaluate the impact of each service and carer responses to the interventions
- Young carer questionnaires and parental questionnaires help us to monitor the responses to, and value of, our young carer support programme
- Feedback and testimonials from partners, funders, health and social care professionals

However, we are conscious that the current shift to outcomes-based funding and, in some cases, payment by results, presents us with a significant challenge over the next five years. We have invested our energy over the past 12 months to improving how we assess our impact and maintain outcome-based monitoring information.

Improving outcome and impact assessment:

Over the next two years we will:

- Introduce the Carers STAR assessment tool to assess the impact of our services on carers' lives. Developed by Carers' Trust, the Carers Star provides a framework and resources for a consistent approach to working with carers and measures outcomes in all the key areas of a carer's life
- Our work through Hillingdon4All and our developing relationship with Hillingdon Clinical Commissioning Group has necessitated the five third sector partners that constitute Hillingdon4All to look at tools to measure residents' engagement with their own health needs. We will therefore be using the Patient Activation Measure (PAM) tool in our Carer Health programme. The Patient Activation Model or PAM has been identified as a tool to help both measure the impact of interventions and also to identify what interventions will have the best impact in improving a patient or carers self-management of their health needs
- Finally we are improving internal communication, record-keeping, data production and overall coordination of our activities through the introduction of a new Charitylog system from April 2015

The new tools detailed here represent a significant investment in time, staff training and licenses, which indicates our commitment to improving outcomes for carers.

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We would like to thank all the carers that completed our questionnaire, helping us to set the priorities detailed here.

In addition, thank you to all of you who have passed on comments, suggestions and personal stories at cafés, clubs and classes – your experiences are critical to ensuring we are focusing our efforts where they are most needed.

Our further thanks go to the carers that gave up their valuable time to attend one of our focus groups. You are too numerous to mention by name but we really appreciate all of your feedback – please keep it coming!

We would also like to take this opportunity to thank the London Borough of Hillingdon for their significant financial support which makes the majority of our services possible. In addition many thanks to other funding bodies who have helped us to extend opportunities for valuable support for the borough's carers. We look forward to a continuing relationship with you.

Finally our thanks to our many colleagues across both the voluntary and statutory sectors who have commented, read, supported and generally helped to shape our thinking. We appreciate your input and look forward to our continued partnerships as we deliver on our plans.

The Staff, Trustees and Volunteers of Hillingdon Carers



“The young carers’ project helped me because I can get a break when times are difficult at home, you can forget what’s worrying you.”



Hillingdon Carers

Luther Bouch House

126 High Street

Uxbridge

Middlesex UB8 1JT

t: 01895 811206

e: office@hillingdoncarers.org.uk

w: www.hillingdoncarers.org.uk

