# **Harrow Carers**

"Your local independent charity supporting unpaid family carers & creating a carer's 'hub' in Harrow"





A carer is someone of any age who provides unpaid support for family or friends who could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems. Carers come from all walks of life, all cultures and can be of any age.

### **Our STORY – Carers' Supporters**

" All councillors appreciate the hard work of carers who care for the most vulnerable people in our communities, in an unpaid capacity.

We want to raise the profile of carers in our wards and ensure that they receive the services and support that are there for them.

I have registered my support for the **Harrow Carers Pledge** as I too want to make people aware that they don't have to do this alone and that there is support and advice available to carers in our borough."



Councillor **Margaret Davine**, Harrow's cabinet member responsible for adults and older people with Harrow Carers Chief Executive, **Mike Coker** 



"Carers do amazing work in the community; the support and care they give loved ones, friends and families is truly humbling. There are nearly 25,000 carers in Harrow and it's a priority for the Labour Administration to give them the support they need."



Council leader, Councillor David Perry

Harrow Carers

376-378 Pinner Road Harrow HA2 6DZ T: 020 8868 5224 E: admin@harrowcarers.org W: www.harrowcarers.org

Twitter: @harrowcarers

Board of Trustees: Harshad Mehta, Peter Beynon, Chandrey Saha, Jayne Quigley, Peter Keeble

Patrons: Gareth Thomas MP

### **Our STORY – Supporting Carers**

We know from the most recent Census that there are almost **25,000** family or unpaid carers in Harrow – equivalent to **one in 10 people** living in the borough. The number of local carers has increased by a fifth in the last 10 years alone, which is more than any other Outer London borough.

**4,784** local carers now provide more than 50 hours unpaid care per week – a massive 37% increase from 3,496 carers a decade ago.

Harrow Carers is the local independent charity dedicated to supporting all carers when they need help.

Now two decades old Harrow Carers is currently supporting 2,750 unpaid family carers at any one time. It operates from a centrally located Carers Centre; and is the lead and only dedicated voluntary sector carers support organisation in the borough.

It is ambitious for the future, aiming to create a truly exemplar carers 'hub' in Harrow.

Funded by LB Harrow, the Big Lottery Fund, Harrow CCG and a host of private grant funders the charity aims to improve the lives of carers of all ages and the people they care for. The charity provides a wide range of support services (these are outlined on pages 10 & 11).

Caring for someone is likely to impact on many areas of their lives, such as their health, relationships, work and leisure activities. In this booklet we have spoken with local carers asking them to tell us about their personal stories of providing care.

We know from talking with them, and in recent consultation with carers, that more needs to be done by us and many other organisations to support them in their caring roles.

Many people who have a caring role do not think of themselves as carers either. They may, therefore, be unaware of the services and support which are available to them in their local community, such as financial assistance. This booklet is designed to highlight the support that is available from the charity and the difference we make to their lives as carers.







#### Over the coming years Harrow Carers has set itself ambitious goals

- Increase the number of carers supported by 30% from the current 2,750 to 3,500 by the end of 2017
- Position and strengthen Harrow Carers as the main dedicated voluntary sector carers support organisation and first point of contact for carers of all ages and their families; acting as a carers 'hub' and offering support services at the crucial times required by carers needing support in their caring roles.

Traditionally Harrow Carers has served around 10% of the local carer population. One of the key future objectives is to increase the number of carers supported by 10% a year for three years e.g. 30% overall. Hence, the charity will at any time be supporting about one in 10 family carers at a crucial time and point in the carer's life - when they especially need help, service support and interventions.

### Their STORY - Shivakuru & Meenadchyammah

Shivakuru and Meenadchyammah are Tamil refugees who in 2001 fled from the vicious and violent civil war that was then raging in Sri Lanka with their daughter. Having been first relocated to Liverpool by the National Asylum Service they then moved to south Harrow six years ago.

Their daughter, Anutha aged 37, has profound learning disabilities and life-threatening illnesses requiring around the clock care.



We went to talk to them about their caring experiences here in Harrow and learn about their story. They were clearly dedicated to sharing the care for their daughter. When asked what they did when they weren't caring – well, the list was truly inspiring.

Both are some of the most active volunteers you'd ever have the pleasure to meet. Although Meenadchyammah is keen to point out that she likes to care for Anutha whilst her husband gets out to do the bulk of the volunteering. Their spirited voluntary activity started as soon they arrived in Liverpool, and has grown exponentially since coming to live in Harrow.

The family had a magnificent array of awards – vying with framed posters and newspaper cuttings - displayed on the walls of their small ground floor flat. Photographs of award ceremonies with Royalty, MPs and other local VIPs are given pride of place.

Shivakuru, aged 70, has twice stood as a local councillor candidate and championed his housing estate as a resident leader, and in recent years he has consistently won the Harrow Heroes Volunteer Award. He is active in all sorts of local community activities, especially with the NHS, Age UK and also the British Legion and the Army Benevolent Fund.

#### What has Harrow Carers done to help you as a carer? And, for how long?

"For well over five years now they have helped us. And in so many ways. God bless them. They come to visit us and are always ready to talk with us on the phone.

"Harrow Carers have been providing us with all kinds of help and support, for example, with our housing problems, language difficulties with authorities, getting the right support from health service providers and money advice for our daughter who has some intensive and pressing needs. We needed their guidance to help us secure British citizenship as well, which we are delighted to say we now have."

#### Which living person do you most admire, and why?

Shivakuru and his family are very grateful to the UK Government and British people generally for the sanctuary, safety and care they have been offered. Tearfully Shivakuru reflects on the unimaginable horrors, violence and human rights atrocities in Sri Lanka; and adds:

"The British PM David Cameron is someone I truly admire. He is the first PM to ever go to Sri Lanka and speak of the rights of the Tamil people. We miss our home so much everyday."

- Carers come from diverse ethnic and social backgrounds. Some are working whilst they care, others not. Two thirds of carers are women.
- Recent census results clearly show that women are more likely to be unpaid carers than men. Women have a 50:50 chance of providing care by the time they are aged 59; compared with men who have the same chance by the time they are 75 years old. Women are more likely to give up work in order to care.
- Most carers nationally (5.7 million) are adult carers (aged over 18) and the peak age for caring is between the ages of 50 to 59 years. More than one in five people aged 50-59 (1.5 million across the UK) are providing some unpaid care. One in four women in this age group is providing some care compared with less than one in five men.





### **Her STORY** – Hannah

Hannah just loves sport. She is now off at university in Brighton training to become a special needs PE teacher. Cricket and swimming are her favourite sporting activities, including finding time in the holidays to be a part-time swimming instructor for young children. As Hannah admits: "Sport has always been a bit of an escape from everything else in my life."

When at home back with her family she voraciously watches 'Friends' episodes on TV, and even now still cares for her dad who has suffered from leukemia and an irregular heart condition.

Hannah has lived in north Harrow all her life, and attended Park High School. She struggled at school as they failed to detect her hearing difficulties and dyslexia, and when her dad fell very ill she was just 14 years old and doing her mock GCSE exams. Because of all of the worry about her dad Hannah didn't do well in her exams and her home life had become a real struggle, especially as her was mum highly anxious and unwell. The family had been hit hard. Hannah was very keen to do her bit, especially as her older sister was off at university, and always felt appreciated by her parents for the caring she did. "It was 24/7 with just me her to help - I helped out in the house, looking after dad, tidying and washing up, cooking meals, walking the dog and of course supporting mum who on some days was very poorly herself."

Hannah was very grateful for the support she got from the charity's Young Carers project, especially as this coincided with the bad news of a close friend dying unexpectedly of a brain tumour and Hannah's increased feelings of not being understood by her school friends as a young carer. She reports of then being 'grumpy', a little 'lonely', struggling with life and her schoolwork. The intervention of her Head of Year at school made all the difference, inspiring her to reach her potential and join in with Young Carers activities.

"Harrow Carers was my salvation, it relieved the pressures for me and gave me the relief of my own peer group."

The understanding and support she felt she got from the Young Carers project was instrumental in then helping her to continue in her caring role. As she explains: "Whilst all the activities, socializing and trips were really great, and just what I needed, often it was more about just the talking and sharing experiences with other young carers in the group that made the real difference to me."

Hannah has coped exceedingly well with her caring role and this now forms – with her general sense of selflessness - a core thread to her identity and her burning passion to help others. Hannah's determination – despite her hearing impairment and caring responsibilities - at school led to her getting excellent grades at A level.

Going away to university still means that Hannah worries about her dad and that the cancer will come back at any minute. But they have become a very close family and focused on enjoying their times together. Holidays to sunny climes – Portugal, Turkey and Spain – have become regular family treats.





### Which living person do you most admire, and why?

"My most inspirational person would, apart from my family, be Martine Wright who was involved in the 7/7 bombings and had both of her legs blown off. Despite the odds she survived but not only that she has learnt how to walk again and within seven years captained the Paralympic volleyball team in the London 2012 Paralympic Games. She didn't just spent all the time feeling sorry for herself, she got on with life as hard as it is and is now a motivational speaker and a real inspiration!"

What is your favourite word or phrase?

"Live your dream"

## LASH! NEWSFLASH! NEWSFLASH! NEWSFLASH! NEWSFLASH! NEWSI

### HARROW CARERS SCOOPS A MAJOR GRANT FOR YOUNG CARERS

Harrow Carers has just heard that it has been awarded a grant of almost £106,000 spread over three years from BBC Children in Need to develop its work more than 300 Young Carers, particularly those struggling to make a transition to early adulthood because of the strain and challenges of their caring responsibilities.

Caring for someone – usually a parent but also a sibling - is likely to impact on many areas of their young lives, such as their wellbeing, friendships and relationships, education and leisure activities. The new project aims to respond to these many challenges.

### LASH! NEWSFLASH! NEWSFLASH! NEWSFLASH! NEWSFLASH! NEWSFLASH! NEWSI



#### Impact of caring on Carer's health & wellbeing

The impact of caring is often harmful to the physical and emotional health of carers.

Carers UK's analysis of census findings found that those caring for 50 hours a week or more are twice as likely to be in poor health as those not caring. This difference is especially marked amongst younger people. In the 18-25 age group those providing 50 hours care or more per week are three times as likely to be in 'not good' health as people of that age group not providing care.

Carers providing high levels of care are twice as likely to be 'permanently sick or disabled' as those not caring. Other factors affecting carers are low incomes and lack of respite from their caring responsibilities.

### His STORY - Mukesh

Although not 100% well himself for Mukesh caring for his 72 year widowed mother is something he is very proud to be doing. Mukesh has suffered from his own ailments necessitating major knee surgery.





Family is one of the most important things in life for Mukesh, and helping his mother to overcome her debilitating illnesses and diabetes and combat the loneliness she often faces, is something that he clearly relishes. She has been staying with him and his own family for several years in Stanmore, but is now looking to go and live with his nearby sister.

Back in the early 1970s as a young boy aged 10 years old Mukesh migrated to Harrow with his family from East Africa. His father ran a local business for 25 years but his health deteriorated and he sadly passed away. His mother had always struggled with the loss of family and community back in Kenya so her ill-health was worsened by social isolation and a longing for 'home'.

Mukesh, aged 49, very much sees himself as 'global citizen' and wants the world to be a better, kinder and more humane place. As he explains: "I worry about the loss of community spirit and human connection at local and global levels. Too many people are almost 'cocooned' from each other – what we all need to again do is switch on our ability to care by lessening our suspicions of each other."

#### What has Harrow Carers done to help you as a carer?

"They really have been a lifeline – lifesavers! We badly needed their help to get the services and support. But most importantly they have been talking to my mother and helping her cope, and me cope as a carer."

#### If Harrow Carers had not been there to help you, what would you have done?

"The services from the council were so disappointing, not supportive at all. It was like they were just reading from a 'matrix'! They seemed only interested in the situation becoming dire rather than acting in a preventative way. It feels that support from councils and government is evaporating everywhere. We have to stand up on our own two feet, act together as a local community."

#### If you had a chance to tell the Leader of the Council something what would it be?

"This is one of the greatest countries – it's like a nirvana...food, jobs, money, shelter, healthcare...you name it. But something is broken at the local level, between communities and human connections. The Council leader should go undercover and see for himself what is really happening and how services could be more human, more carer and people-focused."

### Her STORY - Gill

George is 86 years old and has lived in Harrow most of his life. He has been suffering from Alzheimer's disease and vascular dementia for the past two years. Gill, his daughter, now cares for him on an almost full-time basis as there is no-one else to look after him. They love days out. George especially enjoys a Sunday meal out with a pint. Going out for breakfast is also a much looked forward to treat.

Gill is a busy person working most days. She is a Harrow Carers Champion. Although she lives nearby in Hertfordshire it has recently proved impossible for her to keep travelling back and forth all the time, so she has moved in to her father's house to care for him. When she is out she falls back on informal arrangements with neighbours who are willing to help out.



Gill talks of the challenges she recently experienced trying to get the help she needed for her dad from Harrow Council - calling it a 'scary path to be trod by carers especially at a time of budget cuts.' Gill is a determined campaigner and wants to see support services for carers improved, as she explains:

"I didn't find the people answering the phones at Harrow Council very helpful or even sympathetic to, or understanding of, carer's needs. Often carers are not treated as they have human needs. Getting a carer's assessment was a real fight, as was simply getting hold of the right information. The more a carer knows the better, you have to teach yourself how to be a carer and the right information is vital."

"Harrow Carers provides a fantastic service, really helped me when I needed it – picked me up from the floor."

Gill has now accessed support from the Millmans Day Centre in Pinner, Alzheimer's Society and of course Harrow Carers. She is really impressed with all of them. At Harrow Carers she attended a course: Positive Psychology, which was very helpful indeed, plus she received dementia awareness training.

#### What do you like to do when you aren't caring?

"Meeting up and socialising with other carers! I love yoga too. Ultimately raises a good question though: what happens to carers at the end of their journey, with the skills they've developed?"

#### Which living person do you most admire, and why?

"Janet Street-Porter – she calls a 'spade a spade'....its important to speak your mind as long as you aren't hurtful or rude!"

#### What is your favourite word or phrase?

"Walk in my shoes, and then judge me."

#### If you had a chance to tell the Leader of the Council something what would it be?

"Getting support is often frustrating and overly bureaucratic. With everything seeming like a battle and being pushed from pillar to post. The Council needs to review the way carer's support is offered, and have staff giving carers informed help, and stop them sounding like they are reading from a script or treating carers like they are just a 'budget' cost.



#### Impact of caring on Carer's finances

The financial costs of caring are significant. Research by Carers UK found that 72% of carers were worse off financially as a result of becoming carers. The reasons cited for this include the associated costs of disability and inadequacy of disability benefits, giving up work to care and the charges for services.

Carers face higher bills than the rest of the population (including extra heating, laundry and transport costs) and many fail to qualify for support from social services (which have diminishing budgets), meaning that they have to pay for care themselves. Nearly two thirds are spending their own income or savings to pay for care for the person they look after.

The same research also found carers reporting financial hardship in a number of areas. More than half were in debt as a result of caring. Three-quarters struggled to pay essential bills and could not afford repairs to their house. One in every two carers is cutting back on food just to make ends meet.

### **Your Support Services**

Chief Executive, Mike Coker has been leading Harrow Carers for almost a decade. Growing the organisation from small beginnings to the significant carer's support organisation it is today, and he is now focused on creating a truly inspirational carer's 'hub' in the borough.

Mike explains charity's core service offer under the following broad headings:

#### Self-Help

Harrow Carers supports carers to set up their own groups for social activities, training and learning, peer support, self-advocacy and peer advocacy, to volunteer in a wide range of roles and having a voice in service design. This includes Carers Action Groups, drop-ins and many other kinds of carer-led activities.

We are working with 'Harrow In Business' to develop support for carers who are interested in starting their own businesses and micro-enterprises. This is a particularly exciting area for carers who have told us that it is hard for them to hold down regular employment but could work from home to combine their caring roles with self-employment.

#### **Adult Support**

Whilst we provide several specialist services for carers such as Mental Health support, Young Carers activities and specific support for older carers and carers from Black Asian Minority Ethnic backgrounds, there are also a range of services which are generic and non-specialist. These include housing support, money and welfare benefits advice specifically tailored for carers, health and wellbeing services such as counselling and complementary therapies, emotional support with a consistent and holistic approach - which carers tell us is so important for them - and many other social, educational and therapeutic services.

Having a holistic support service which is free to access is critical for many carers who could not otherwise manage the experiences of repetitive assessments and navigation between different services. This model is being recognised in the development of 'whole systems integrated care' which is expected to help services work better with carers as real partners in care.

#### Impact of caring on Carer's social lives

Carers can often face social exclusion with profound feelings of loneliness and isolation. Carers also have problems accessing entertainment and leisure services (and a host of other social activities) due to the cost, lack of time because of their heavy caring responsibilities and poor accessibility. Many also lack access to digital and social media equipment and facilities including computers and the know how to use such technology. They are more likely to rely on traditional media sources including newspapers, radio and TV.









#### **Support For Young Carers**

A young carer can be defined as anyone under age 18 who is assuming a level of caring responsibility for another person which would usually be taken on by an adult. Young Carers generally care for members of their immediate family who may have a physical illness, disability, mental health problem or dependency on alcohol or drugs.

Harrow Carers recognises that being a young carer is something important. Our Young Carers take part in exciting outings, social and recreational activities. In this way they get the chance to have a break from their caring roles, have fun, meet new people, including other Young Carers. This makes them feel more confident, helps them develop friendships with other young people facing similar situations, and supports them in dealing with the significant level of responsibility for another person.

The Young Carers Project also targets schools and youth groups, raising awareness of Young Carers and their needs, and encouraging young Carers to come forward and receive the support that they and their family are entitled.

We have about 30 young Carers attending outings on a monthly basis. The feedback is always positive and parents feel extremely confident and very grateful when their kids are on the outings as part of the Young Carers Project. Apart from being very exciting activities, these events are important for them to develop self-confidence, independence, make new friends and try something new! If they feel a little insecure or shy they get support from each other as well as the staff. They provide an incentive for each other with optimism and friendship.

#### **Mental Health Support**

Harrow Carers provides advice, information, support and training for carers of people with mental illness. The current mental health service demand is one in 6 adults having some form of diagnosis, meaning that some 40,000 residents in Harrow are living with some kind of mental health problem, raising the question about how many mental health carers we have in Harrow. Cuts in the NHS will of course have an impact on all areas of mental health services offered in Harrow and also from Harrow Carers.

Harrow Carers' Mental Health project provides education and skills development for carers of people with mental health issues to enable them to cope better with their caring role and gain a better understanding of the condition of the person they care for.

To make sure carers are looked after, we are expanding our provision of specialist support for them. We are expanding psychological education, health education, offering speaking up and assertiveness training, positive psychology services, coping techniques, and medication classes. We train carers to help raise awareness about mental health in the work place.

#### Impact of caring on Carer's working lives

The majority of carers are compelled to combine their work with caring responsibilities. Eight out of 10 carers are of working age. An astonishing 400,000 people in the UK combine full-time work with their caring - for 20 hours a week or more (of these 200,000 are caring for 50 hours per week or more). Male carers are more likely to be in work than female carers, six out of 10 male carers work, and 90% of these work full-time.









### The Harrow Carers PLEDGE

Many people who have a caring role often do not necessarily think of themselves as carers. Therefore they may be unaware of the services and support that exists for them. Harrow Carers is now engaged in a major campaign: the Harrow Carers Pledge.

Many reports\* highlight in stark terms the difficulties faced by carer in relation to their own wellbeing, and therefore the wellbeing of the people they care for. Especially striking figures include:

- 96% of carers report a negative impact of caring on their health and wellbeing
- 86% of carers report suffering with stress, anxiety and depression
- 45% of carers experienced difficulties due to low income

The Pledge aims to increase carers' access to services as well as promote the view that the health and wellbeing of carers is as important as the person they are caring for. Support for the Pledge can be shown by emailing admin@harrowcarers.org or on Twitter using:

### **#SupportThePledgeHarrow**



<sup>\* &#</sup>x27;Sick, tired and caring' (2011)



" HARROW CARERS **PROVIDES A FANTASTIC SERVICE, REALLY HELPED** ME WHEN I NEEDED IT — PICKED ME UP FROM THE FLOOR."



" FOR ME, TO BE A CARER IS A BLESSING."



" HARROW CARERS WAS MY SALVATION, IT RELIEVED THE PRESSURES FOR ME AND GAVE ME THE RELIEF OF MY OWN PEER GROUP."

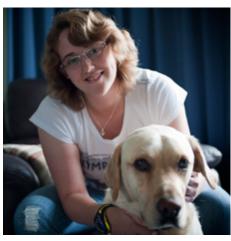
**COMMENTS MADE BY CARERS INTERVIEWED IN HARROW**, 2014







Harrow Carers is an independent voluntary organisation and the lead carers support agency in Harrow since 1996



Harrow Carers is supported by:







We are a network partner of Carers Trust



