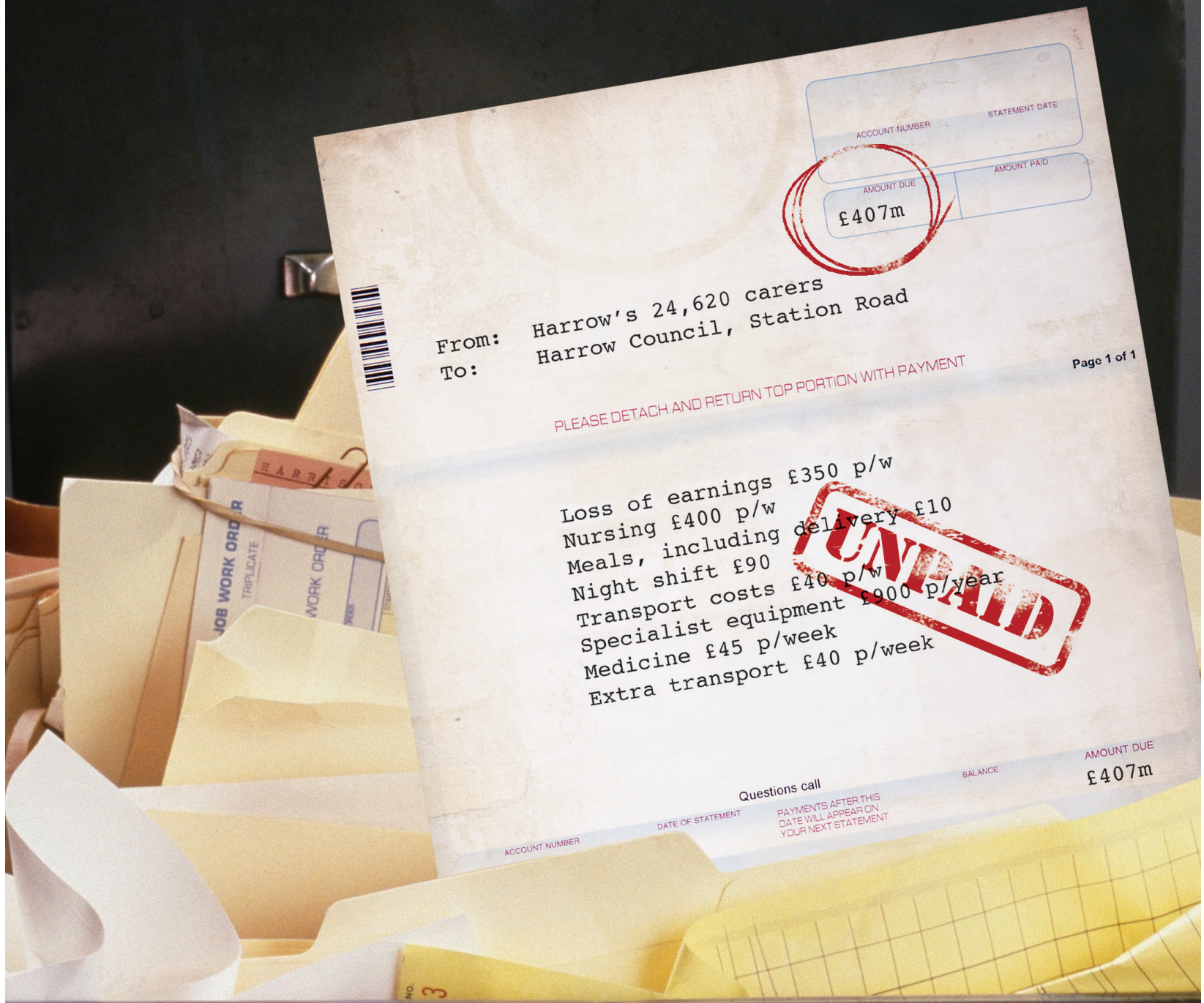


Harrow Carer Champion Project

Sharing stories to influence change

March 2014



Cost to council, per household, if carers could no longer care:

£31,096 per year care home fees | £750 per week nursing home fees

Having been forced to give up work, the Carers Allowance is less than £60 a week, way below the minimum wage amounting to £1.20 per hour for a 50-hour week

administering & managing medication

co-ordinating care

managing finances

making decisions about health care

practical support

toileting

emotional support

cooking

nursing

personal care

transport services

supporting mobility

cleaning

dealing with crisis

urgent care and medical arrangements

hospital treatment

emotional support

intimate care

On call 24/7 | 365 days a year

Foreword

Carers are one of the most valuable assets within our community. They make a vital contribution to the people they care for, to our local communities and to our economy. They do a difficult job in difficult circumstances, indeed our system would collapse without them. For this reason the carer contribution in Harrow needs to be better understood and recognised so our interventions deliver long term benefits for carers and their families.

If you are not valued or respected for what you bring to the community then you are unlikely to come forward for support.

In Harrow, over 24,000 people have caring responsibilities, including some 2,300 young people. Harrow has the second highest percentage of carers in London but their work is invisible to the public and decision makers.

Despite their prevalence, life as a carer is poorly understood – even by those working in public services, who struggle to comprehend the experience and its impacts. Carers often end up with health and physical problems because they can't get the support they need to look after themselves. Many are isolated, depressed, physically exhausted and facing hardship as they struggle to cope. Frustrated with the constant battles to get even the bare minimum of help, carers often shy away from asking for what is rightfully theirs.

Whether as a carer, service provider, supporter or public servant we can change this by developing new ideas to help lessen some of the problems carers encounter.

As even more people become carers our services need to be different. A new future for carers can only be designed by talking openly and stepping into the lives of carers to understand their experiences, fears and hopes.

Until now carers are barely acknowledged in public debate but their contribution in Harrow is estimated to be worth £407m – more than six times that of the council's total annual health and social care budget.

For too long, carers have been taken for granted and decisions about spending to support them have been hidden from view. For this reason investment in carer services has lagged behind.

Over the last 4 years council spending for carers has decreased from £1.25m per year to £900k representing a reduction in real terms of around 35%, whilst the number of carers and the cost of caring has increased.

The new Care Bill marks a moment full of opportunities to revitalise carer support. To face this challenge we need to reimagine support from first principles and step outside the usual way of doing things to expand our understanding of what life is like if you are a carer.

Listening to carer stories and entering into routine dialogue with carers to understand their lives is a powerful way to redesign services and connect with carers and their families. Stories and empathy are also important tools in closing the gaps in policy realms and building stronger bonds and relationships with carers. It is time we focused on carers as valuable community assets not just as a group of people with needs.

It is against this background that the, volunteer-led, Harrow Carer Champion project was keen to explore how the council and NHS might approach closing the gap in our understanding, and do more to help carers in a fresh way. So that listening and empathising with carer experience becomes an integral part of how we improve services for carers in future.

Councillor Victoria Silver | Harrow Council

Introduction

Carers are central to how adults and children



24,620

unpaid home carers in Harrow

1 in 10

lives constrained by caring

Only 15%

in receipt of support

7,700

more people over 65 years by 2024

There are 24,620 unpaid home carers in the borough. That's 1 in 10 people whose lives are constrained by caring. It is estimated that only around 15% of these (around 4,000) are in receipt of any kind of support. Over the next decade Harrow's elderly population is set to increase by 7,700. Getting the right help, in the right way, at the right time is triggering growing concern about how we plan carer support in the years ahead.

Traditional service-led approaches have meant carers have not always received the support they need. There are some specific local issues that we especially need to look at involving the commissioning of new research:

- Harrow is the most religiously diverse local authority in the UK and many carers are from Black, Asian and Minority Ethnic (BAME) backgrounds. These groups often experience greater levels of isolation because they take on multiple caring roles. Many have chronic health conditions but caring never ends.
- Many Harrow carers are of working age, but because of their caring responsibilities they have had to give up professional careers and are unable to work.
- Many carers need to work but require support in finding suitable, flexible, local employment and training opportunities.
- Harrow has a sharply rising incidence of autism. The Children and Families Bill brings new rights requiring different models of service delivery to support parents and families.
- There are 2,272 aged 10 to 24 year olds providing unpaid care in Harrow.
- There are 5,038 households in Harrow where one person has a long-term health problem or disability where one child under 16 lives – potentially increasing the numbers of young carers

The ability of traditional service-led approaches to keep pace with these changes needs to be examined. These are times of severe financial pressure and we need to make sure that money spent supporting carers is targeted in the

Children are supported in Harrow

right way to provide value for money and secure the best outcomes for carers. To achieve this change the council working with partners, and listening to carers, needs to identify areas for action based on new research and what carers say they need.

The Harrow Carer Champion Project spoke to 50 carers, using story telling methods, to inform this report. It does not claim to speak for all carers or to provide a comprehensive analysis. We know many carers are satisfied with the services they receive in Harrow. What we hope our report brings is to show the value of what volunteers can achieve when sharing insight, expertise and skills, and working together to put a spotlight on the hidden issues carers face.

With the introduction of the Care Bill it is time for a new prevention approach focusing on the value of the carer contribution and taking a more holistic view of care within families, and building better evidence about what works. The Harrow Carer Champion project believes we can better understand carer needs and design improved public services through genuine co-production and more story telling projects. We also believe that story and empathy projects can be used to cultivate local carer networks and help develop carer resilience. The point is not only to listen to carers, but to change the way we support carers through listening.

Carers are the last defense against the spiraling costs of social care. We need to act now.

Harrow Carer Champions

Mr Chandu Shah	Manish	Dawn	Mrs Varsha Dodhia	Gill West	Mrs Dianne Mathurin	Martin Biswell
Mrs Olivia King Boateng	Siouxsie Biswell	Mr Sudhir Shah	Mrs Moni Bhachu	Mr Derek Baker		
Councillor Sue Anderson	Councillor Margaret Davine	Councillor Victoria Silver				

What the council and voluntary sector currently do (2012/13):

- The council currently spends approx £900,000 a year on carers (2012/2013)
- The Council holds a monthly carers meeting 'Carers Revival'
- The Council has a dedicated officer 'Carers Lead Officer'
- The Council has introduced a monthly drop-in for carers at Milmans Day Centre 'Annie's Place'
- Between 2010 and Oct 2013 4,223 carers were assessed by the council for support
- 1,158 carers in Harrow are entitled to the Carers Allowance but are not claiming
- Carers registered with the council receive regular mailings about events and benefits
- Between March 2012 and 2013 the charity Harrow Carers supported 2,432 carers
- 338 carers asked for help with mental health problems
- 284 carers used advocacy and benefit advice services
- 227 received services specifically designed around the needs of BAME carers
- 147 carers attended the Positive Psychology Course
- 387 carers took part in outings, drop-in groups, meditation and relaxation sessions

This is an indicative list of services. It does not claim to identify every formal and informal carer service in Harrow.

Many carers are satisfied with the services and support they receive from the council and charity Harrow Carers, yet caring can be so tough that accessing drop-in sessions Monday-Friday, 9-5pm can be incredibly difficult.

Women tend to spend more time than men undertaking unpaid care work. Many are juggling employment and caring and need specific support about asserting their rights to flexible working and working unsociable hours, as well as access to support networks once traditional services have ended for the day.

63% of Harrow's population is from Black, Asian and Minority Ethnic (BAME) communities. Caring for relatives and partners will happen to all of us and understanding the barriers carers face from different communities in accessing services is really important.

We rely on carers for literally millions and millions of pounds of care that the NHS and council couldn't do without. It is vital carers understand their rights and that the public and others understand the experience and struggles behind the label carer.

Some groups of carers feel particularly discriminated against, especially those caring for relatives with mental health problems or facing challenges associated with drug and alcohol misuse.

Services for families and carers facing substance misuse problems are particularly hidden and more information is needed about the extent and nature of drug use among different groups in Harrow and how this impacts on carers, and carer services. Common factors, such as isolation, exclusion and 'social distance' may be important in understanding what the barriers are to carer services.

There is also a need for information on:

1. The effectiveness of different methods of providing carer information in meeting the widely divergent needs of people in different types of caring situations
2. The extent to which carer services are able to meet the needs of people in different types of caring situations, including for those:
 - juggling caring with work
 - from BAME communities
 - carers using residential care for their loved ones but still caring
 - parents and families caring for disabled adults with complex needs
 - carers needing to find flexible, local, work and training because of hardship
 - Grandparents, kinship carers and sandwich carers juggling caring for disabled children and care for elderly parents

What needs to be

- **Bring forward a clear 'local offer' of carer options set out in a 'charter' or handbook specifically focusing on rights, entitlement to support and opportunities for carer breaks**
- **Work towards a single point of access for carer information, including taking advantage of technology to enable carers to connect and feel connected to others**
- **Introduce sustainable carer to carer training and support available through a flexible 24/7 support network**
- **Provide more support and training in managing carer general health and wellbeing**
- **Deliver high quality training in lifting, handling medication, administering pain relief, safeguarding, managing aggressive behaviour, help with moving around and dressing**
- **Provide online advice resources and toolkits offering more support from other carers**
- **Introduce carer personal budgets to provide breaks from caring**

Why change is needed

Easily accessible carer support information and advice is not only better for individual carers, it could also lead to less duplication and pressure in the system. Embracing new technology and helping carers connect with each other through online networks for advice could also help link carers together for mutual support about accessing local resources. Often carers just want to connect and learn from others who've walked in their shoes, and know that someone understands how they are feeling.

different?

What carers say

“The hardest thing was asking for help. I’m trapped at home all day and services don’t come looking for you. I don’t have the internet and socialising is no longer possible. Caring doesn’t stop at 5pm on a Friday, in fact it never ends. I’ve sacrificed everything to look after my son. I cry myself to sleep knowing he’ll never get married, get a job or own a car. His only life is to be with me and it takes a long time to come to terms with that. But what happens when I’m no longer here? The council don’t ask me about that. The only support I get is being part of small group of parents who are in the same situation caring. I only found this group after my son tried to take his own life and someone gave me a leaflet. This group is a lifeline but it’s not funded by the council and we constantly worry we might have to close.”

“My son suddenly started hearing voices and getting up at night. He was made redundant and had to sell his car and soon after split with his girlfriend. He stopped making eye contact and eating and sleeping properly. Later on he rang the police nine times insisting the neighbours were trying to kill me. It was petrifying. We’d never had to confront anything like it before. He was a star student at school and was in the air cadets. One day his behaviour got out of control and he was sectioned. Later on he came home for ‘home treatment’ but the hospital discharge was unclear and we didn’t seem to have a clear care plan. His medication was up and down and the care support workers seemed to say different things. Our son wasn’t responding well and he seemed exhausted by the situation. Still hearing voices and being paranoid we were at our wits end and didn’t know who to reach out to. Looking back I just wish the support had been clearer and more joined-up. If you’re totally new to local services, having given up work to care, everything seems so unclear and in different places.”

“You have to sign-up to a newsletter first to know where anything is. If you’re up to your eyeballs caring all day and don’t have time to go online what do you do. No one gives you a carer handbook with a checklist of what you are entitled to and where to go. No one ever says carers matter. We are made to feel we are at the bottom of the heap.”

Influencing

- Involve carers in a clear 'decision process' that is shared and consistent to enable carer-led influence of the Health Wellbeing Board, CCG and council executive
- Develop and expand the Carer Champion project in order that it remains at the forefront of local change
- Give carers and their families an open source web platform to share stories about life as a carer, both good and bad. In order that practitioners and professionals can learn about and solve problems encountered by carers in real time
- Agree new methods to measure how services to carers are monitored and evaluated, by carers themselves
- Be clear how carers can complain if their rights are not met
- Ensure a genuine and innovative co-production approach between carers and agencies providing carer services

"Carers are remarkable people and we can learn a great deal from their experiences. Once you are a carer you're made to feel like you're supposed to fade into the background but the council and others should be learning from our lives. We share a special spirit that keeps us going, it's about: friendship, being valued and respected and being able to share what we've learned along the way. Our systems don't work to achieve these things and it makes everything much harder and very sad."

"You don't feel like the council and NHS are listening. The system is complicated and confusing so you don't come forward with new ideas. I've been in close contact with services, for many years, since my daughter was born. She's now 35, but the council doesn't have a way, that I know about, to share what I've learnt about how things can improve for carers. Going along to coffee mornings won't mean carers will have better services. We need to find new ways to influence the council where we are listened to and things change."

"I don't call myself a carer. I am a Mum first and it is my job to care. I receive no help, no guidance and certainly no support. I feel I have to beg to get anyone to listen. Is there a way to influence the council? I am screaming inside and no one is listening. My situation varies from day to day depending on what kind of day my children are having. I would like to know where to go and who to ask for help without begging. When my kids needed specialist equipment I was told no."

Harrow's Health & Wellbeing Board

has carers as a priority but it hasn't yet identified engagement and listening to carers as significant. There is little evidence of the Board yet being creative in reaching out to local communities. Carers believe they have an instrumental role to play as champions reaching out to the community and helping the council design future care and carer support solutions. Carers should also have a prominent influencing voice through the HWBB, HealthWatch and CCG.

Awareness and Identification of Carers

- Ensure council staff and councillors participate in training which would involve ‘walking in the shoes of a carer’ so they can experience their lives, including how carers interact with services
- Deliver a borough wide campaign to target hidden carers who don’t recognise themselves as carers. (possible campaign title, “Who Cares?”)
- Support carers to have a loud voice in Harrow, one that is not only listened to but is valued and respected in order to raise awareness and remove the barriers to adequate support
- Hold regular ‘thank you’ events for carers, not to patronise but to heighten awareness, highlighting carer stories to enhance decision maker understanding of what it’s like to be a carer

“The pain and depression can swallow you up. I’ve given up my job, friends and social life to care. My life has been completely turned upside down. There’s one world where everyone else is going out to work and being busy and there’s another world where you only see four walls for weeks on end. How this feels and the impact it has isn’t understood by the council or politicians. When you call the council you get passed from one department to the other and in the end you give up. If you could pick up the phone and I say ‘I am a carer’ and felt the person on the end of the phone understood what that meant it would make a massive difference to how I felt about the council and asking for help.”

“I don’t feel I have any choices as a carer or that I’m respected for what I do. Most people with problems have some sort of family and friends support system around them but I don’t have that so everything is raw, hurts a bit more and feels more extreme.”

“The biggest problem is the assumption that actually there’s little capacity within the carer community for self-support. We want the council to look at that. Yes, carers are pushed and time poor but we want to share our skills and experience to help other carers – including identifying hidden carers and giving them our support.”

“You constantly have to justify why you deserve support. When you haven’t been out of the house for weeks on end, and have been surviving on less than 2 or 3 hours sleep a night for years, you end up living in a trance. You are just surviving. On one occasion, when my son was in hospital, I broke down in tears, but I was told by health professionals we aren’t here to look after you.”

“For the first 12 years I didn’t even know I was a carer. Caring is hidden and no two carers have the same experience. Many groups in Harrow don’t understand the label. We have to change that by sharing stories about the experience.”

“The carer experience isn’t understood. I never wanted to ask for help but the strain on every aspect of my life has been enormous. I’m terrified of talking about it because in my community it’s not acceptable to ask for outside help.”

It is really important ways to raise awareness about carers and identify more carers are designed around the ideas of carers – and ideally led by carers through Carer Champion projects. Carers are more likely to share their story and come forward for advice and support if they are receiving the advice from other carers who’ve walked in their shoes.

Support, training & enterprise

- Establish a carer learning and development service for carers so that carers have the opportunity to develop new skills, make new friends, and support carer earning and enterprise
- Support carers with business ideas so these can flourish and grow, which in turn will help expand Harrow's care market place
- Introduce confidence and assertiveness training to enable carers to know their rights so that they are able to ask for what they need to assist them in their care needs
- Introduce more carer befriending schemes in localities with greater carer populations in order to be able to offer emotional support, empathy and practical advice
- Existing resources such as the Housebound Library Service and Harrow Samaritans should be harnessed for carers
- Support carers in the provision of a Carer Café to support carer wellbeing
- Introduce short respite breaks for carers

"Supporting carers should be a priority. Our services need to change and carers need to be utilised and listened to by the council so that more carers can be identified. My passion is seeing carers come together in groups supporting one another to improve wellbeing and share coping strategies. There isn't a way for carers to bring forward new ideas and secure funding to run local projects that will actually help the council. A buddy system is another idea that would cost very little to set up but could help tackle some of the isolation. There isn't a body where carers can influence decision makers and put forward new ideas. Networks are everything and we are not going anywhere if we don't help carers connect with each other to get support when the council and other services are closed."

"The hardest thing is realising you won't work again. I've had gruelling conversations with Human Resources trying to get time off to care. You feel like you're being written off. At work, you have to prove your case over and over again until you're job security hits rock bottom. In the end you just give up. I couldn't put my family into a care home."

"The council needs to trust carers to deliver self-support. Carers haven't got time to do battle with the council, getting passed from pillar to post. I just want to meet others who get it and can help me cope with a situation that will never change. I can't go into central Harrow for a coffee group when there's no parking. We need more local groups with a bit start-up funding to help get us going."

"You are just surviving. My son was born with downs syndrome and autism and for the first five years of his life my only priorities were eating, sleeping and keeping my son alive. You live in a trance. The only time you have conversations is when you're having to justify why you deserve benefits. It wasn't until my son started school, and I became a parent ambassador, that my life began to change. Now I run my own parents forum and I want to empower other carers to get more involved in improving the services we have in Harrow."

"I'm part of a coffee group that started through a dementia training course. It's a lifeline. Not enough attention is given to the huge difference informal groups make. Meeting other carers helps me feel less isolated. I've now started my own dementia awareness training course. I want to show other carers how they can do the same in their area."

Social enterprise has an important role to play in developing Harrow's care sector. Carers with ideas with the potential to become viable projects should be supported through training where they can secure investment. Good care can be a stimulus to the local economy and supporting carers to unleash their ideas can bring value to the local care economy.

“The Carer Champion Project report really brings to life what it can be like caring for a loved one. It highlights the challenges, loneliness and desperation of trying to get the support carers need and the value of peer support which is sometimes the only lifeline carers have. Carers must be heard and listened to if we are to make the most of this invaluable resource in our community. We cannot afford to fail.”

Mike Coker | Chief Executive | Harrow Carers | www.harrowcarers.org



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Unpaid carers save £119 billion a year
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Too old to care? The experiences of older grandparents raising their grandchildren
GrandparentsPlus
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Methodology

The Harrow Carer Champion project spoke to 50 carers between 2012 and 2013. All interviews were transcribed and stored. In total, Harrow Carer Champions collated more than 20,000 words of first person accounts from carers. Once the stories were collated each were analysed in search of themes, trends and issues to identify ideas to help alleviate some of the problems carers encounter every day.

The Harrow Carer Champion Project hopes to develop its impact in the coming months to make new carer rights a reality in Harrow.

Good practice resources

Brent Carers Centre
www.brentcarerscentre.org.uk

Staffordshire Cares
www.staffordshirecares.info/pages/i-care-for-young-carers/young-carers.aspx

Carers in Hertfordshire
www.carersinherts.org.uk

Southwark Carers
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Carers talk about isolation

Council leader says how exhausting it was looking after partner

By John Shumaker
 Carers across the borough have come together to discuss how isolation that often stems from their dedication to the role.

The leader of Harrow Council, Councillor Helen Hogg, has expressed her sympathy for carers who have to look after a partner with a long-term health condition. She said: "It is members of the Harrow Council Carers' Forum who have helped me to understand the challenges carers face. I have been involved in many projects and have seen first-hand how difficult it can be to look after someone with a long-term health condition. It is often a 24-hour job and can be very tiring. I am proud to be a member of the Harrow Council Carers' Forum and to support the work they do. I will continue to work with them to ensure that carers in Harrow have the support they need to look after their loved ones."

Carers' Revivals - This is a free event for unpaid carers, supporting a vulnerable person living in Harrow. It takes place at St Peter's Church, West Harrow, on the first Friday of every month from 12.30-2.30pm. Contact Alice Brice on 020 8901 2680 or email alison.brice@harrow.gov.uk

Views in print and online

Council must make carers the priority

The Harrow Council Carers' Forum has urged the council to make carers the priority in its budget and service plans. The forum, which represents over 1,000 unpaid carers in Harrow, said that carers were often overlooked in council decisions. It called for a "war of action" to ensure that carers' needs were met. The forum also urged the council to provide more support for carers, including respite care and counselling services.

councillor up for Age UK award

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A Harrow councillor has been nominated for a local government award. Councillor Victoria Silver has been nominated for the Age UK Award for Local Government. The award recognizes individuals who have made a significant contribution to their community. Councillor Silver has been praised for her work in supporting carers and vulnerable people in Harrow.

Muni Bhachau, 50, cares for her 28 year old son.

"Being a carer has changed my life completely. I used to work in an office full-time, but four years ago I had to give up everything and devote all of my time to my son."

"My 28-year-old son was diagnosed with a rare condition and I had to learn how to care for him. It's been a challenge, but I've found a lot of support from the Harrow Council Carers' Forum. They've helped me to manage my son's care and to find a balance between my own life and my son's needs."

Chandu Shah, 72, cares for his 46 year old son.

"My wife Kanta and I care for our son, Chandu, who has a learning disability. It's been a journey, but we've found a lot of support from the Harrow Council Carers' Forum. They've helped us to find a balance between our own lives and our son's needs."

Manish Savjani cares for his 90 year old mum

"She gets a care package which means that we receive support from a professional carer on a daily basis. It's been a relief to have that support, as it allows me to continue with my work and my own life. The Harrow Council Carers' Forum has been a great source of support for me, and I would recommend it to other carers."

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