



Hillingdon Carers Partnership

Working together for unpaid carers




The essential guide to supporting unpaid family carers in primary care

Working in partnership with Hillingdon Clinical Commissioning Group
and Hillingdon Primary Care Confederation



Hillingdon Primary Care
Confederation





“I am very happy with my GP, they are very effective and can always help. The fact that my GP offers a regular monthly slot for carers to have a basic health check works really well for me as I can drop in when it is convenient.”

I care for my daughter with learning disabilities

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It is easy to refer a carer, just call 01895 811206 and the HCP will do the rest.

Foreword

Carers are vital to society and to the health and social care economy. The state cannot afford to provide the current level of community care and health services without this unpaid army of volunteers. It is therefore critical that support is provided to carers to help to mitigate the sometimes negative impacts of caring, particularly when it comes to managing their own health needs.

Not identifying and supporting carers will lead to an increased demand for costly health and care services in the future.

In 2016, NHS England published its Integrated Approach to Identifying and Assessing Carer Health and Wellbeing. This has impacted locally with a multi-agency Memorandum of Understanding for carer support in Hillingdon. A multi-agency Carers Strategy group has signed the MOU and oversees the Carers Strategy Delivery Plan and reports annually to the Health and Wellbeing Board.

With good support for carers a requirement of the Care Quality Commission, having arrangements for carer support in place can have a positive impact on CQC reports, as well as making good economic sense.

Hillingdon has an extensive range of services for carers thanks to generous financial support provided by the Council to the Hillingdon Carers Partnership, which has also been very successful at bringing in new funding and resources.

This guide is intended to help primary care staff to: better understand the needs of carers; recognise the benefits to identifying and supporting them; identify a few simple steps that will improve the carer's experience of primary care, and; inform practice staff of the help that is available and how to access it.



“As a carer with my own health issues, it is great that my practice offers us a double appointment so that I can discuss my needs at the same time as my sons. Flexibility in appointments like this makes all the difference.”

I am a carer for my son who has a long-term congenital disability and communication difficulties

(1) Identifying carers – the economic case

Identifying and supporting carers makes good economic sense

Carers provide unpaid support to people who are frail, disabled, living with long-term conditions, suffering from mental ill-health or who misuse substances. Without their help, the care recipient might not manage to live independently and would certainly need more support from health and social care services.

Additionally, without the right recognition and support, it is very likely that the carer will develop their own physical or mental health needs and almost certainly become a patient themselves.

72%


**of carers in the UK
said they had
suffered mental ill
health as a result
of caring.**



The economic case for supporting carers

- There are around 7 million carers in the UK saving the state an estimated **£132 billion per year**
- By 2030, the number of carers will **increase by 3.4 million** (close to a 50% increase)
- In the London Borough of Hillingdon carers save the local health and care economy **£554 million per year**, conservatively calculated at a replacement care cost of £18 per hour

Research consistently demonstrates that caring can have a pronounced adverse effect on health. Carers are less likely to access regular health checks or medical advice until their condition has significantly deteriorated.



“As a long-term carer for both my mum and dad, communication about their conditions and treatment with their GP was a challenge. However, my parents’ GP always made time to speak to me, which made life easier.”

I cared for both of my parents for many years, my mum had dementia and dad had emphysema and diabetes.

(2) Who are carers?

Over 60% of us will become a carer at some point in our lives

Anyone can be a carer and caring can be short-term and intense or can be a lifelong commitment. The advent of caring can be gradual or sudden and can happen at any point in a person's life.

The 2011 census data showed that around 10% of the population of Hillingdon was a carer (26,000 people), although population growth in the borough indicates this is now likely to be closer to 30,000.

The following reflect just some of the diversity of carers that you might see in your practice:

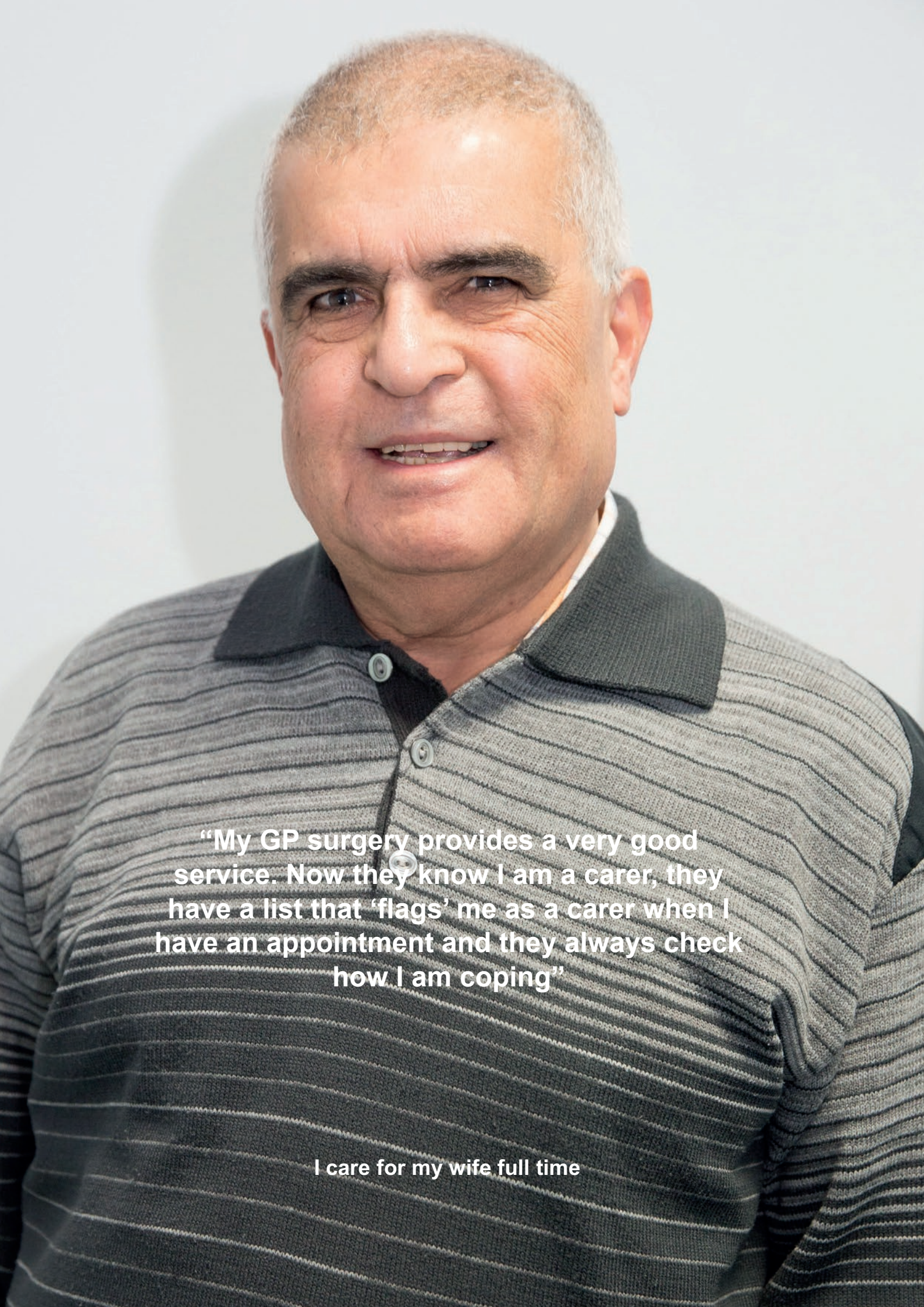
- **Pavel** is 22 years old and lives with his mum who has schizophrenia. He is presenting at your practice with low-level mental health problems, such as anxiety, sleeplessness and depression. He is not in education, employment or training.
- **Ava** is 84. She has congestive cardiac failure and is looking after her husband who has dementia. She has attended your surgery 7 times in the last two months with non-specific symptoms, although her CCF is well-controlled.
- **Amy** is 53 and has diabetes. She cares for her mum who has multiple sclerosis and a daughter who has severe ADHD. She gave up work 6 months ago to care. She attends your practice regularly for monitoring of her blood sugar. Your practice nurse tells you she is showing signs of self-neglect and is withdrawn and uncommunicative.

See page 18 for the help available to Pavel, Ava and Amy

People often don't think of themselves as carers, they are simply looking after a loved one who needs their support. This means that they are unlikely to seek help for themselves, even though Hillingdon has one of the best ranges of carer support services in Greater London.

Being a carer is not a chosen path, although for many caring can be very positive and a self-actualising experience. However, for thousands of carers it is a path that can have a serious implications for their future health, wealth and wellbeing.

Carers are more likely to come forward if some practical help is being offered; Hillingdon Carers Partnership can help.



“My GP surgery provides a very good service. Now they know I am a carer, they have a list that ‘flags’ me as a carer when I have an appointment and they always check how I am coping”

I care for my wife full time

(3) The effects of caring on health

Research consistently demonstrates that caring has a pronounced adverse effect on health and wellbeing

Finding time to keep regular medical appointments, meet up with friends or simply relaxing can feel like an impossibility when you are caring for someone. Added to this, nearly half of people caring juggle their caring role with working or volunteering either full- or part-time. Looking after yourself when caring for somebody who may need care 24 hours a day, seven days a week is no easy task, especially if you already have - or develop - your own health condition.


Carers have increased mortality, a greater risk of stroke and more chronic back problems than non-carers. They are significantly more likely to be socially-isolated or lonely than non-carers. Caring can also cause a deterioration in relationships and even family breakdown.

It is important to give carers access to time out, preventative and self-management techniques and respite from their caring role as soon as possible to mitigate the negative impacts of caring. Early identification, recognition and onward referral to sources of support is therefore extremely important.

What does research tell us?

- **65%** of older carers (aged 60–94) and **53%** under 60s have **long-term health problems** or a disability themselves
- Caring has a negative impact on **physical health (83%)** and **mental health (72%)**
- **39%** of carers have **put off medical treatment** because of caring. For **53%** this made their problem **significantly worse**
- **52%** of carers are **exercising a lot less** as a result of caring
- Carers are affected in the following ways:
 - Anxiety or stress (**91%**)
 - Injury such as back pain (**36%**)
 - High blood pressure (**22%**)
 - Deterioration of an existing condition (**26%**)
 - Disturbed sleep (**50%**)

(‘In Sickness and in Health’, Carers UK)



“My husband has multiple health conditions and I care full time. My own health has a significant impact on my ability to care, so having more time with the GP through the practice’s flexible appointments means I have more time to express our needs and definitely means I don’t have to keep coming back to get what I need.”

I care for my husband who has multiple health conditions and now requires 24 hour supervision

(4) The costs of caring

The more care that is provided, the more likely a carer is to be in financial difficulty.

The financial effects of caring:


- **52%** carers have had to **cut back** on **buying food**
- **65%** carers surveyed were experiencing **fuel poverty**
- **74%** carers have **difficulty** paying **essential bills**
- **55%** were **in debt** as a result of their caring responsibilities
- **75%** were **worse off financially** as a direct result of caring
- Nationally, nearly half a million people have given up work to care in the last 2 years: **more than 600 people a day**
- In **87% households** with working-age carers looking after their partner, **no-one** in the household **is in paid employment**
- On average, **carers retire eight years earlier** than their peers without caring commitments

(State of Caring, Carers UK)

The effects of caring can also be more subtle. Caring can hinder promotion prospects, affect the amount of hours a carer can work or affect the times of day they can work, therefore dictating the types of jobs they can access. They might also have to take time off at short notice if there is an emergency or a breakdown in their alternative care arrangements.

Despite the adverse financial effects of being a carer, many carers do not claim all the benefits that they are eligible for, such as Carers' Allowance. Carers UK research found that 81% of carers had been caring for over a year before they received an assessment and financial support; just under half of these had been caring for five years or more before getting support.

Hillingdon Carers' Advice team has secured over £3 million in carer-related benefits in the past three years



“I am very happy with the overall care from my GP surgery. It is particularly helpful that my surgery has a referral process for carer support services and a display of up-to-date information about what help there is. This has made a big difference to me.”

I care for my two sons who have a learning disability and autism.

(5) The Top Ten Tips for carer support

By looking after carers, they are better able to look after the person they care for so there will be fewer appointments needed for the patient.

The right support can also prevent (or delay) carers from becoming patients and therefore reduce the need for appointments for carers in their own right.

The **Top Ten Tips** for supporting carers are:

- (1) Provide information about local carer support services in the practice
- (2) Refer carers to the Hillingdon Carers Partnership (HCP) so they can access relevant training that supports them in their caring role – call the **single point of access on 01895 811206**
- (3) A referral will automatically trigger the offer of a Carers Assessment
- (4) Recognise carers as ‘expert partners’ in care; they live the caring situation 24/7
- (5) Provide flexible/short notice/double appointments
- (6) Broach confidentiality issues with the patient and secure permission to share relevant information with the carer
- (7) Use GP Read/SNOMED Codes on records to record caring status
- (8) Ensure, as far as possible, that the carer and care recipient are registered with the same GP practice
- (9) Flag the patient *is* a carer or *has* a carer and maintain a Carers’ Register
- (10) Provide access to annual flu vaccinations and health checks

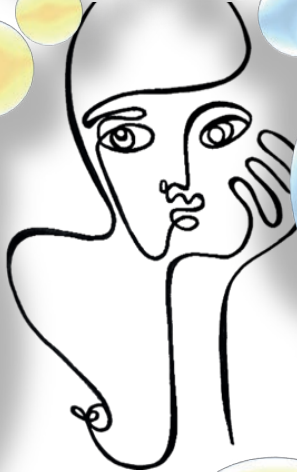
Practices can also:

- Consider how else the practice might facilitate improved carer-health – monthly **Carer Health checks** for example
- Have a **carer tab** on the GP **practice website**
- Consider how they support **staff who are carers**
- **Evidence** work with carers as it will **help with CQC inspections**

(6) So what works well?

Hillingdon Carers Partnership receives and collates regular feedback from the carers it supports. The comments in this guide have all been made by carers in Hillingdon and are intended to help you think through what might change by learning about the impact of practice procedures on carers' lives.

There is also a lot of support for practices that are doing some great things. Here are just some comments from carers about what really helps them:



"I really appreciate the repeat prescription service and the delivery service. It's so valuable to us, like a small gift of time."

"I am very happy with my GP, nurses and reception staff. They could not be more helpful – if there is no space they will always fit me in if it is an emergency."

"Flu jabs are a difficult time of year, especially if you have the jab together as the side effects kick in at the same time making caring very difficult."

Fortunately my surgery offers Flu clinics specifically for those with dementia, which is a godsend."

"As a carer for my adult son with learning disabilities, I can always speak to my GP about my concerns without my son present."

"My GP surgery gets support right! Their help is what keeps me caring when I feel I can't go on. Thank you from the bottom of my heart."

(7) Recognising carers

Reception staff, GPs, Practice Managers and nurses all have a part to play. Remember anyone can be a carer, including young children and non-family members...

At registration or diagnosis:

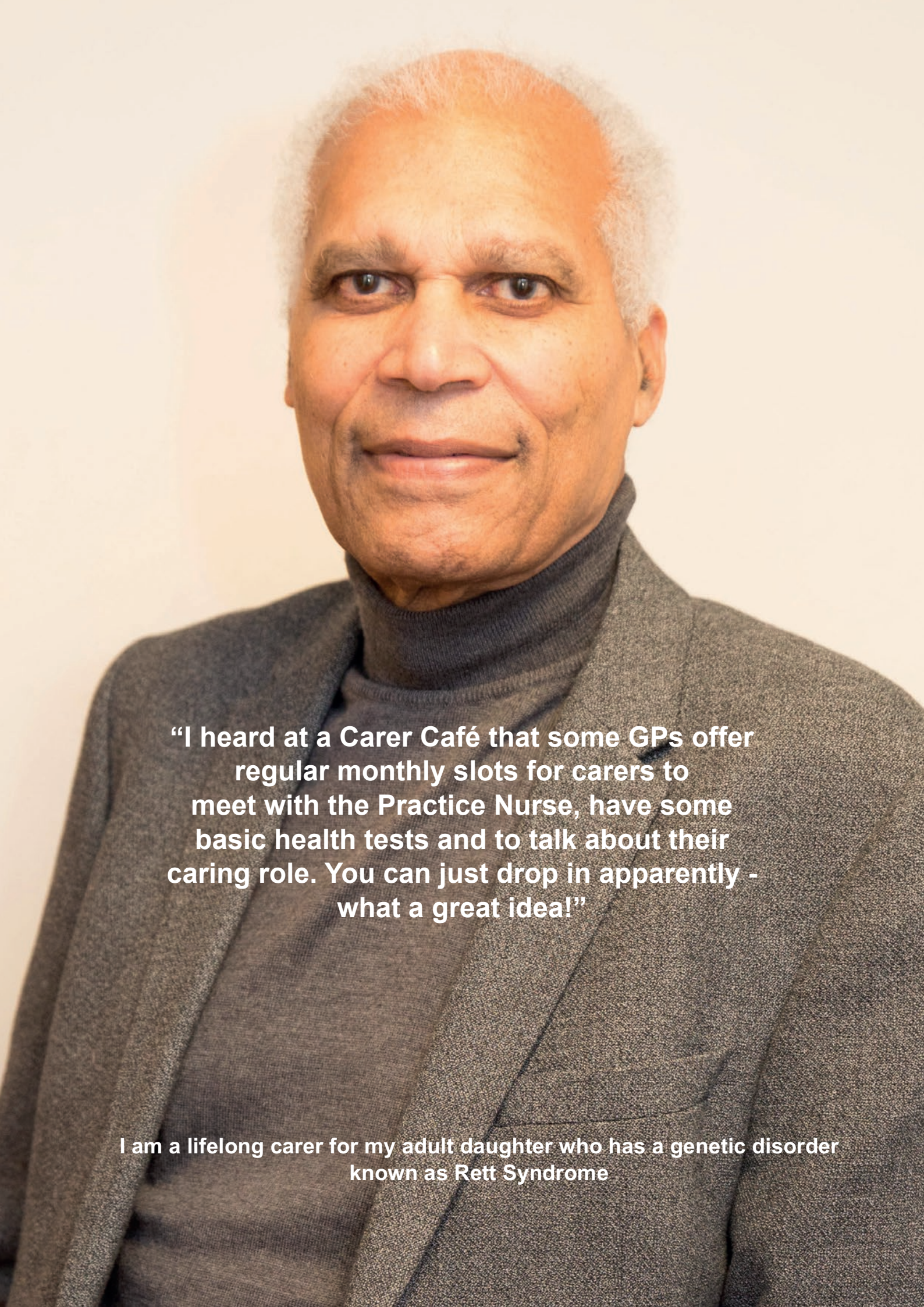
- Ask new patients if a **family member** or friend **provides** them with **support**
- Establish **who** else **lives** at the **same address** or lives nearby
- Ask **new patients** if they are **looking after someone** else
- Ask new patients if there is a **child or young person** in the family **who helps provide care or support** to someone else
- If a patient receives a new diagnosis of an acute or long-term condition, ask them if there is **anyone** that **can provide** them with **ongoing care and support**
- **Flag the patient's notes** so other professionals are aware of caring responsibilities
- Check that your practice has a **Carer Register** and it is **regularly updated**

Help carers to identify themselves:

- Promote **carer awareness** and services for carers in your practice
- **Remind families** about the **role of carers** and services for carers in **routine letters**
- **Note who** else is **present at home visits**. Are they carers?

Opportunistically:

- Are **some patients** **always accompanied** by a family member or friend **at appointments**?
- Does **someone other than the patient** routinely **book appointments**, request home visits or **request repeat prescriptions**?
- Does a **young person** **attend appointments** with a parent or sibling **during school hours**?

A portrait of an older man with short, white hair, looking directly at the camera with a slight smile. He is wearing a dark grey turtleneck sweater under a textured grey jacket. The background is a plain, light-colored wall.

“I heard at a Carer Café that some GPs offer regular monthly slots for carers to meet with the Practice Nurse, have some basic health tests and to talk about their caring role. You can just drop in apparently - what a great idea!”

I am a lifelong carer for my adult daughter who has a genetic disorder known as Rett Syndrome

(8) How can Hillingdon Carers Partnership (HCP) help?

Carers are more likely to come forward if some practical help is being offered

The partner organisations work closely together - and with others - to improve support and to expand the range of services available. They collectively offer over 50 services. All you need is the **carer's permission** to share their phone number. One phone call to the single point of access gives the carer many opportunities:

Adults:

- Carer assessments, with home visiting service
- Welfare benefits checks and help to claim entitlements
- Specialist BME support, four Asian languages spoken
- Onward referral to broad range of specialist services
- Extensive range of information and advice, High Street Advice Centre,
- Health and wellbeing services, including exercise for all abilities, Carer Cafes across the borough, trips, arts and cultural activities
- Carer training in all aspects of caring
- Access to employment support after caring finishes
- Free counselling and access to bespoke Talking Therapies
- Specialist dementia services
- Dementia Cafes
- Specialist dementia advice, with home visiting
- Caring with Confidence dementia training programme
- Complementary therapies
- Replacement (respite) care
- Free nail-cutting service for older carers
- Mental Health Carer Social group
- Mental Health Carer Cafes

Young carers:

- Weekly Young Carers' Clubs (Mon, Tues, Wed, Sat)
- Supported transition for young adult carers
- Specialist support for young carers affected by parental substance misuse
- Family Support Service for complex families
- Full school holiday activities programme in all school holidays
- Training, CBT, emotional support and personal development
- Schools liaison

**Remember, there is only one number to access this support:
01895 811206**

We introduced Pavel, Ava and Amy on Page 7 here's how Hillingdon Carers Partnership (HCP) can help them:

Pavel (presenting problems: anxiety, sleeplessness and depression, NEET)

HCP picked up Pavel's support via Hillingdon Carer's Supported Transition programme. They have provided him with a course of CBT under the Headquarters programme and he reports feeling less anxious and that his sleep is improving. He regularly accesses the social club for Young Adult Carers and has made new friends, whom he sees outside of Club.

To enhance his employability he has accessed workshops to develop his CV and has had mock interviews. He has applied for a local apprenticeship and is awaiting an interview. His support worker accessed a small 'hardship grant' for him to purchase a new suit for interviews.

Through the partnership with Hillingdon Mind, Pavel has attended a workshop on schizophrenia and better understands his mum's condition.

Ava (presenting problems: non-specific, frequent attendance)

Hillingdon Carers' Advice team conducted a Carers' Assessment and were able to secure higher-rate Attendance Allowance for Ava. She has also enjoyed a course of complementary therapies and a day trip with other carers of people with dementia and their loved ones.

Through the partnership, Ava is now supported by the Alzheimer's Society's Dementia Support Service and regularly attends a Dementia Café with her husband. She also receives four free hours of replacement care from the Partnership so that she can have a break, meet a friend and occasionally get her hair done. She now only attends your practice for routine appointments for managing her CCF.

Amy (presenting problems: withdrawn, early self-neglect, double carer)

Amy also had a Carers' Assessment, which led Hillingdon Carers to refer her on for a Social Service review of her home situation and to HACS (Hillingdon Autistic Care and Support) for help managing her daughter.

She has attended a series of health and wellbeing workshops, delivered specifically for carers by the Hillingdon IAPT Service and is receiving a free counselling service from Hillingdon Carers. Her mood is slowly improving

(9) Introducing your practice's Carer Champion – do you know who yours is?

In response to NHSE directives and the local Memorandum of Understanding for carer support, Hillingdon Carers Partnership has been working closely with the GP Confederation and Hillingdon CCG

In order to raise awareness of carers across practice staff, the Confederation is encouraging all GP practices in Hillingdon to have a Carers' lead.

Each practice should be committed to supporting carers and, having a Carers' lead will enable implementation of standardised ways of working which will help to identify carers and provide them with the level of support required to meet their needs and the needs of the person they care for. Their key tasks are to:

- Proactively **identify** and **support carers**
- Ensure that a **Carer Register** is maintained and updated regularly utilising agreed Read/SNOMED Codes appropriately
- Provide **active referral** to the **Hillingdon Carers Partnership**
- Work alongside the **Health Champions** in each GP practice to coordinate activity across the two roles
- Feed into the Confederation and its partners (Hillingdon Carers Partnership and Hillingdon CCG) and identify any **gaps in provision** or **requirements to help practices** to support carers further
- **Review** what the practice **offers carers** and suggest relevant changes
- Be willing to attend and disseminate any **training and information sessions** that relate to the support of carers within General Practice
- Keep **information on carer support** up-to-date in practices
- Be the point of contact for the **Hillingdon Carers' Health Development Officer** and receive regular updates on services
- Update practice staff on activity detailed in the multi-agency **Hillingdon Carers Strategy** and respond to emerging indicators from NHSE.

Carer Champions will have access to bespoke training and regular support from the Hillingdon Carers Partnership

Please contact The Primary Care Confederation if you require more information

Hillingdon Carers Partnership

Working together to improve help and support for all unpaid carers in the London Borough of Hillingdon

"Our vision is for a single, integrated, borough-wide service that provides high quality, specialist and consistent support to carers of all ages through the Hillingdon Carers Partnership (HCP)"

Single point of access: 01895 811206

Email: office@hillingdoncarers.org.uk

We will do the rest!

Please remember that we are not an emergency or frontline service. If a carer is in crisis, here are some useful contacts:

Hillingdon Social Care Direct: 01895 556633

Hillingdon Social Care out-of-hours: 01895 250111

Alzheimer's Society National Dementia helpline: 0300 222 1122

CNWL Mental Health Crisis line: 0800 023 4650

Urgent medical problems: NHS 111



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