Giving Carers a Voice

Identifying as a carer

Understanding how and why people identify or register as an unpaid carer, and the perceived or experienced benefits of registering.

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healthwatch
Surrey C.I.C

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Contents

Executive summary

Background and objectives:

Action for Carers estimates there are 115,000 unpaid carers in Surrey. Unpaid carers are the frontline NHS/social care workforce - Carers UK[1] estimated the value of unpaid care at £190 billion a year during the pandemic, a value roughly equivalent to the NHS budget.

Since April 2022, Healthwatch Surrey have been listening to the experiences of unpaid carers under the Giving Carers a Voice Contract. In the past year we have attended 172 events and heard from 649 people.

The issue of identification and registration as a carer is one we often hear about: we talk to people who are undertaking the responsibilities of an unpaid carer but who do not see themselves as a carer, or who have not registered as a carer with any organisations.

This project sets out to explore why people don't identify as carers, what triggers their realisation that they are an unpaid carer, and the value of identifying as a carer.

Key findings:

1) People can be slow to self-identify as carers. The people we spoke to talked of:
    a. Not feeling they do enough to count as a "carer", or not recognising how much they now do for the cared for person over and above the usual family expectations; belief that the support they offer is normal and expected in their family role.
    b. Emotional resistance – resisting the change in relationship and status; seeing "carer" and "cared for" as replacement for parent/spouse/child rather than an additional role.
    c. Cultural resistance – in some cultures being a carer is expected and does not deserve any special support or recognition.
    d. Infrequent signposting from frontline/clinical staff

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[1] Key facts and figures | Carers UK

2) Understanding of the support and benefits available to carers appears to be weak for those who do not identify as carers.
3) Different people have different needs and strengths and find value in different types of benefits or support. It can be helpful to consider a "value equation":
    - Overall, is the practical, emotional/intellectual or financial cost of accessing a service "paid off" by the benefits of that service?
4) The benefits/services we heard about most often were:
    - Action for Carers – a range of services including signposting, support groups, yoga and help accessing benefits.
    - Any form of respite – most mentioned being Crossroads and GP funded breaks.
    - GPs – clear call to action for registration and some had accessed carer breaks, but for most the benefits received were limited.

Recommendations

1. Recognise that new carers are unlikely to self-identify and self-present. Maximise "recruitment" through media such as the Action for Carers posters, GP surgery posters, ongoing engagement; by encouraging word-of-mouth among carers.
2. Ensure frontline staff "think carer" – recognise carers, are confident in starting conversations, and know where to signpost.
3. Review the accessibility of support and benefits: how easy are they for someone time-poor, overwhelmed or on a limited budget to find, apply for or use? How well are those "costs" balanced with the benefit to the carer and cared for person?

Main Report

Purpose

In light of the high numbers of hidden carers, our aim has been to understand barriers to identification as a carer. We hope to deliver insight that can provoke reflection and enrich development of strategies to encourage carers to come forward and take advantage of the support on offer.

Approach

Between January 2023 and March 2023, we focussed our regular engagement on "identification". While listening to the experiences of carers, we guided the conversations to include our area of interest:

- For those not previously recognising or registering as carers, we probed on their view of a carer, why they hadn't registered, and what might make them more interested in registering.
- For those who did identify or had registered, we probed on what had led to their identification and registration, and what the benefits of this (if any) had been.

We developed relevant discussion probes for the conversations but did not administer a questionnaire: our contractual role is to listen, and we respect the needs of carers to share what is important to them. This is therefore a qualitative, listening project. What we heard represents the themes that were shared with us, rather than the extent to which any one theme is present.

We listened to 77 carers in 27 different engagement sessions. Of these, 26 did not recognise themselves as carers before our conversation.

Of our 77 respondents:

- 20 were caring for more than one person.
- 29 were caring for their child (or children).
- 19 were caring for a spouse.
- 14 were caring for a parent.

- 6 were caring for an adult child.
- 4 were caring for someone else.

Respondents all consented to our inclusion of anonymised verbatims in our report. Our verbatims identify the relationship between carer and cared for person, and where they live. So (Parent, GU7) is a verbatim from someone caring for a parent and living in the postcode area GU7.

We used a thematic analysis approach to develop our findings and report.

Main Findings

What is a carer?

There was consistency in understanding of what a “carer” is, although people found it hard to articulate.

Spontaneously, people spoke of a carer as someone who routinely takes on tasks of daily living (including management of wellbeing) because the cared-for person cannot complete these tasks – tasks others in the same situation would be able to manage for themselves.

> I would say being a carer is helping someone with aspects of their life that they can't do on their own, not just shopping, but making sure they have their medical, financial and personal care that they need. (Other elderly, GU9)

> I think that the definition of a parent carer should be 'when your child can't do things that are age appropriate, and you have to support them in doing things e.g. making visual cue sheets to help them dress/undress. A child of the same age would know not to put pants over pyjama bottoms and know the sequence without prompting, but a child with ADHD/autism/OCD needs prompts and help still. (Child, KT18)

> For my other daughter - I realised I was her carer when I was going over and above what a parent of a teenager has to do. The emotional support, taking her to appointments, being there at 3am with her sobbing. (Child, KT11)

Why don’t people recognise themselves as carers?

Every carer’s story is unique, but we heard consistent (and often overlapping) themes:

It’s just what you do

Caring for your child, spouse or loved one is simply part of the relationship – it’s an expected responsibility:

> Parent and carer doesn’t go together. (Child, GU9)

> My husband has always had mental health issues, but it has got worse over the last 6 years. I'm not a carer. I'm his wife. I have never looked for any support - I just cope. I go to a book club, volunteer in a charity shop and go to a paint and sip group. (Spouse, GU9)

Cultural Resistance

In some cultures, taking on whatever responsibilities arise within the family, however demanding, is an expectation – there is no sense that the role deserves recognition or support. In many languages there is no word for "carer":

> We don't like to say that we are taking care of someone in the family. Disability is not a good word. When asking someone from my culture, if they might be a carer, you need to be sensitive and ask 'what support do you need' Ask what the person does to support the person you think they are caring for – what do you do? How can I help you?. Never use the word carer. (Parent, TW18)

> It's a big stigma within our culture [Sri Lankan]. There is no word for carer at all or mental health - you are just mad. I'm 24 now and it was only a couple of years ago that I realized that I was a young adult carer. I genuinely wouldn't have recognised that I am a carer. It was when I filled out a survey from my GP that the penny dropped. Mum never recognised it either. (Parent, KT16)

Gradual shift in relationship and needs

A frequently heard story – from those who had recognised their role as well as those who had not – was that the increase in needs had been gradual and incremental; the point at which it had shifted from a normal partnership to caring had not been noticed:

> In 2018 I realised I was a full-time carer as I became aware that I was just doing more and more caring and less being a husband. The caring role just became bigger and bigger, and I took on more and more. (Spouse, GU9)

> I've been caring for my husband for years without even realising it. (Spouse, KT18)

> I didn't think of myself as a carer as mum and dad live together and dad does most of the day to day caring for mum. It was only when he went into hospital to have an operation and I had to look after mum and then him, when he was discharged that I recognised that I was a carer. But it took a colleague pointing out that neither of them could manage without me, that I did accept that I was. (Parents, KT22)

Resistance to a perceived shift from care driven by love to a more functional relationship

“Carer” has functional connotations; there is a sense that it replaces and masks the loving relationships of mum, husband, daughter that is the foundation of the unpaid carer’s role.

> He was becoming more unkempt, his standard of care was deteriorating. I felt that he was placing himself at risk and I had to step in and try to control things and reduce his exposure to certain risks. Is that being a carer or just doing what any parent would do. (Adult child, GU2)

> I’m a husband carer, no I’m more of a carer than husband. (Spouse, GU9)

> I don't think of myself as a carer. I'm just a mum doing what a mum does. (Child, GU9)

Belittling the cared-for person

When one person becomes a carer, the other person – someone they love and may have had an equal partnership with – becomes a cared-for person. This dependence can be hard to bear:

> We were … frightened that the dynamic of our relationship would change if I said that I was his carer. He still wants to take care of me. He is a proud man and has always taken care of me. (Spouse, RH2)

> I also look after my daughter who has mental health problems. I know I am her carer but would I call myself that officially? No as it wouldn’t be beneficial to her. She would be so humiliated and ashamed if she heard me refer to myself as that even though it is true. Mental health is hard enough without feeling you need a carer. (Adult child, KT11)

> I guess you could say I'm a distance carer. But like I said that word isn't very positive or useful. And when the person you help is of sound mind it's quite derogatory to them in some cases. (Other adult, GU9)
>
> I won't ask or seek help as it's like saying that my mum is a burden. Action for Carers convinced me to apply for carers allowance. I am also on universal credit. (Parent, TW18)

Not doing enough to be a carer

Some felt that what they were doing for their loved ones was not enough (hours/effort/tasks) for them to count as a carer:

> No. Carer is a bit of a push. Mum does lives with me, I converted my home, so she has her own space. I support her by taking her to the GP and dentist (Parent, GU1)
>
> I don't think of myself or would say that I am a carer. Why? Because I don't live with my mum. She lives in Devon and I live in Epsom. I'm not there every week but I do call her regularly. When I visit once a month, I have to trouble shoot all the things that need doing. Like the mice she's just had, the drains being blocked and the fence blowing down. I organise people to come and sort all these things out. I have also organised the cleaner and gardener. I also deal with all the calls from the carers that she has, order her weekly food delivery, order her pads and deal with her repeat prescriptions for her medication. I also make her podiatry and dental appointments. (Parent, KT18)
>
> I help care for my Mum, we have a big family and spilt the care, taking her to appointments and helping at home. I think she looks after me too so I wouldn't say I'm her carer. (Parent, GU21)

Infrequent signposting/drive by frontline staff

We heard very few examples of people being recognised and signposted by directly by frontline staff, and more examples of people not being signposted directly:

> My mum was in hospital for 5 weeks recently and not once did any member of staff mention the 'Carer' word to me. Yes, there were posters and info in the stairwells but there was nothing on the ward. You don't tend to stop and read things in the communal areas as you are going to visit someone or then going out (and want to limit the parking charge!), so having something about carers actually in the ward would be more useful for both staff and carers. They could see that I was visiting my mum, but I guess just saw me as her daughter and not as her carer. It would have been nice to have been acknowledged as such (Adult, KT22)

What triggers the recognition you are a carer?

The people we spoke to split between those who realised for themselves that they were a carer, and those who had needed an external trigger.

External triggers we heard about included:

- Conversations with our engagement team[2], including some in the course of this project

  > Notes from team member: "she didn't recognise herself as a parent carer until I pointed it out to her. She knew she was going over and above the role of mum but had been thinking about how her role had been changing but hadn't used the term carer for herself."

- Posters at the GP; occasionally signposting by surgery staff or questionnaires

  > I genuinely wouldn't have recognised that I am a carer. It was when I filled out a survey from my GP that the penny dropped. Mum never recognised it either. (Parent, KT16)
  >
  > I registered as a carer as I work in a doctor's surgery and saw the info about what a carer is. I then registered with my own surgery (Parent, RH2)

- A friend or family member

  > It wasn't until my line manager at work told me that I was. I was in my mid 40's by then. The irony is that I was training people to identify carers and

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[2] All newly identified carers are signposted to carer support

> referring carers to action for carers but I didn't recognise myself as a carer. (Adult child, GU22)

- Contact with or signposting to organisations including Action for Carers or Family Voice, sometimes through third parties or at adjacent support events (e.g. autism support groups signposting to Action for Carers)

  > Other groups that I have engaged with and found useful are the NAS [National Autistic Society]… it was them that told me about action for carers and they told me I was a parent carer (Child, KT18)

For those reporting a more 'organic' realisation that they were a carer, this was often described as happening when their caring responsibilities started dominating their life:

> When I was driving two hours a day twice a day, I realised I was a carer and that I would never be able to get a job again. How can I fit in work around my children and their needs? (Child, KT18)

> When you stop being a wife first and your caring role takes over (Spouse, GU15)

"Registering" as a carer

It is hard to unpick the relationship between "recognition" and "registration". Many of those who had registered with services had recognised they were carers at the same time as being introduced to support or benefits:

> I sat in the doctor's surgery back in 2017 and read the poster on the wall describing a carer. It had 6 questions on it and if you answered yes to them, it said then you are a carer so register with us. I spoke to reception and I registered (Parent, KT11)

> I registered as his carer in 2014 because he had to give up work then due to his bipolar. Someone advised me to register with Action for Carers and the GP. (Spouse, KT20)

Among those who had not previously recognised they were carers, or registered with any support services, many were unaware or vague about the benefits on offer:

> Can I claim these? I hadn't thought of myself as their carer and certainly didn't know that there are certain benefits a carer can claim. It might help with the petrol when I do the shopping or have to take them to appointments. Useful to know. (Parent, Unknown location)
>
> I didn't realise that there are benefits as a carer. As I didn't know that I was one until today, this is something that I will look into. (Child, KT18)
>
> Will investigate further and will look for support through Action for Carers. I hadn't heard of Action for Carers. Don't know what's out there. (Spouse, GU4)

And there were assumptions or concerns about eligibility:

> I would love respite care for my younger one. My son has been out of school for two years. I don't get any benefits as I work full time. (Child, GU25)
>
> It's all a bit new and overwhelming at the moment. I have heard people talk about carers allowance but I wasn't sure what it was or if it applied to me as I'm his mum. Seems a bit odd to have money for looking after your child which is something I have to do as his mum. (Child, Waverley)

What support or benefits are the most valuable to carers?

The carer/benefit 'value equation' – one way people judge the value of a benefit to them.

Across all our conversations with carers we have seen that many core demands can be grouped into three broad overlapping themes:

1) Time (and for some, physical effort) – how much time the carer has to dedicate to their caring duties. For some caring is a 24/7 job; for others it takes up relatively little time. For some carers even a few hours of caring takes up a considerable proportion of their "free" time. Some carers are physically vulnerable or the cared-for person is physically demanding, so energy is another finite resource.

2) Mental load and responsibility – decision making, managing the cared-for person's physical and mental health needs, pursuing benefits and support, taking responsibility for household chores, living with grief, relationship changes and stress, isolation. Caring for someone can be emotionally draining and intellectually challenging.
3) Cost – loss of earnings potential for the carer is a key issue, but sometimes there are additional costs of living for the cared-for person (transport, specialist equipment, heating).

Every carer/cared-for situation is a unique combination of challenges, and different benefits/support aim to meet different needs. As such, there is no one-size-fits-all solution.

- every carer will measure the 'gain' of a benefit against the potential 'cost' to them in terms of time, mental load and/or money (and there may be other, individualised practicalities to consider)
- for some carers, the demands on them are so high that carer support will be able to do relatively little to alleviate the pressures they are facing.

What we heard about the benefits/support available

In some conversations we were able to show a list of benefits available to carers. (Appendix 1). In others we were able to ask what support had been accessed and found valuable.

The resources people talked about most often were:

Action for Carers - several of our engagements took place at A4C groups so it is not surprising that they were often cited as an important part of support networks.

Specifically mentioned were:
- Signposting to services and benefits
- Help with applications and "form filling"
- Carers Groups and events

> Action for Carers have been brilliant. I've been doing their zoom yoga for the past three years, it is the one thing I do in the week for myself. It's wonderful. It's only an hour but it's a break. (Child, KT21)

All forms of respite and breaks

- Crossroads carer support is a highly valued service:

> I now have the sitting service. Someone comes in for 10 weeks for 3.5 hours a week. They get him up and will wash and change him and put the washing on. It's such a help (Spouse, KT12)
>
> I get 3 ½ hours of respite through Crossroads care every week which is an absolute godsend. (Spouse, CR3)

- Although the new "10 week" provision is challenging:

> But what's the point of having 10 weeks care which is going to finish? The whole point of having someone in would be to prepare my mum for someone coming in regularly. (Parent, KT22)

GP carers breaks had also been accessed by some:

> I did eventually register with my GP and got a carer's break …. Booking a weekend away with the money gave me something to look forward to. I absolutely loved it. It was something then to reflect back on and talk with my friends. (Adult Child, KT22)
>
> Carer breaks money was great but that's stopped now which is a real shame. (Parent, KT23)

Support from GPs

Some had been given access to early flu and covid vaccinations, or appointments:

> Free flu jab, early/extra covid boosters from GP. (Child, unknown location)
>
> If I need an appointment with the GP, I can usually get one for the next day and my wife gets one usually the same day. I think I am prioritised as I am a carer. (Spouse, CR3)

And as we've seen above some had accessed Carer Breaks:

> I get carer break money from GP. (Child, KT18)

Unfortunately, more people told us registering with their GP had not led to additional help:

> When I went to the GP to register as a carer, the receptionist said how can you possibly be a carer, you're his mum. (Child, KT21)

> I am registered with my GP as a carer but you don't get anything from it. I would like more privileges. Prioritise me as a carer. Call me back immediately, not 2 weeks later. I'm caring for 2 people on my own. (Parent and sibling, KT12)

> Oct 22 I had a chest infection…The infection didn't go and on the 4th [round of antibiotics] I said that I needed to see a Doctor. I have now been referred to a consultant at The Royal Surrey for further investigations. I think that carers should have priority within the system. I should have seen a GP immediately. I'm a carer. I need to be well to be able to care for my husband. I also have a chronic health condition but none of this seems to matter. Carers shouldn't have to wait so long to see a GP or nurse. (Spouse, KT12)

Rejection of services

For some people no services or benefits were of interest:

Administrative overload

Several told us of the challenges associated with accessing benefits or support – for these people, the gain of the benefit was low when compared to the effort/added mental load required to find it or apply for it:

> Parents of children with additional needs don't have time to do extra forms. We have so many to do already. (Adult child, KT21)

> There is loads of support and funding out there but I don't know where it is or where to find it. No-one tells you anything. (Child, KT18)

Needing more than support and benefits

We also heard from those for whom the services on offer could never meet their needs:

> No. I just want someone to help us and our son [substance misuse]. No benefits can do that. (Adult child, KT22)
>
> None of these benefits are useful to me. I'd love to have some respite but how can I? My son will only speak to me. He's highly anxious so it just wouldn't work. (Child, KT23)
>
> What would help would be if I didn't have to do it but that is not an option. No one else is around to do the things I do for [Mum] so I am stuck doing the lot. The only benefit to being labelled a carer would be some help but that's not possible. (Parent, KT11)

System Intelligence – unique insight from some providers and VCSE organisations

While listening to carers we took the opportunity to ask key staff at organisations we work with for their perspective on identification as a carer.

Their perspectives closely reflected what we heard directly from people.

- people feeling the care they are giving is the norm
- denial, protection of the relationship
- lack of awareness of benefits and services; the value of focussed entry points to care and of clear signposting
- the challenges and complexities of accessing support
- the value of respite, peer support and protection of the mental health of carers.

However, we did hear of some challenges that had not been shared with us directly by carers:

- Mistrust of outside services, especially social services, among some communities, and to extent among young carers

> I think communities such as GRT not wanting to engage is because of their culture and the expectations within that culture. There is also a general

mistrust of outside services becoming involved and the misconception that social services will remove the person they care for and place them in an institution. (Communities and Prevention, SCC)

- Lack of staff awareness resulting in poor signposting from one service to another

  There's so much to be done within the organisation but we do need to highlight carers and I will look at some staff training to make sure that they are aware (HomeStart)

- The value of showing carers that the system does care

  Carers are just happy that I am around, and I call them to review the situation and see how they are. So "How are you?" is always beneficial (Carer practice advisor)

Summary and Thanks

This project set out to deliver insight into why people don't register as carers, and the value of registering as a carer.

Our key messages are twofold:

- for service providers, the definition of a carer is fairly black-and-white: for people living the experience of becoming a carer it is not. People need to be helped to recognise that they are delivering additional levels of care, and that support is available.
- People will judge the support they are offered in terms of how much time/mental load/cost it reduces or adds to their lives. Services that demand little and deliver most will always be most highly valued.

We would like to thank all the carers we spoke to for sharing their experiences with us. We recognise their hard work and dedication to those they care for, and they value they bring to our community.

We would also like to thank the following organisations who enabled this project by linking us with carers and hidden carers and sharing their experiences with us:

Churches for Horley foodbank	Action for Carers Surrey
Home-Start Surrey	Guildford College
The Hive Guildford	Eikon
East Surrey Domestic Abuse Services ESDAS	Camberley Nepalese women's group
Woking Ukrainian hub	National Autistic Society
Your Sanctuary	ATLAS young people's group
I Choose Freedom	St David's Family Practice
Preston Partner Network	Hale Community Centre
Surrey Coalition of Disabled People	Reigate dementia café
Family Voice	Milford Parkinson's group
Knaphill community fridge	Spelthorne mental health parent carers group
Farnham SEN parent carers group	Surrey Adult Social Care
Surrey carer substance misuse group	Specialist Mental Health team Surrey
	Alzheimer's UK

Appendix 1

Benefits of identifying as a carer include:

- Carers credit – tops up National Insurance contributions. Available if you care for someone at least 20 hrs per week. That person must also be claiming certain benefits.
- Disability Living Allowance (DLA) - available to parents/carers whose child is under 16 and needs extra care due to disability/health issues.
- Personal Independence Payment (PIP) – for aged 16 and over with long term physical/mental health condition/disability/difficulty doing certain everyday tasks/getting around. Tax free. Not affected by savings. Lower weekly (£61.85) and higher rates (£92.40). Mobility part - lower (£24.45) and higher (£64.50) Other benefits are available - see www.gov.uk
- Carer's Allowance – available if you care for someone for at least 35 hours a week. That person must also be claiming certain benefits.
- Attendance Allowance – If disability is severe enough that someone is needed to look after you. There are 2 different rates depending on level of care needed - £61.85 or £92.40 per week.
- Carer health budget – from GP if registered as a carer. Up to £300 for carer to use for their wellbeing.
- Blue badge
- Vehicle tax discount/exemption
- Motability scheme vehicle.
- Emotional – support groups/dementia navigators/memory cafes etc.
- Emergency planning (emergency care card through Crossroads care) – if carer is suddenly taken ill then care is provided for the cared for.
- Respite care – Crossroads care – 3.5 hours for 10 weeks.
- Carer's assessment – social services will assess the carers needs and then provide services to support carer.
- Carers discount card for certain services and shops – see Crossroads Care website. There is also the ODE card but it's a cashback card.
- Registering with GP.

These are just a few – CAB, Alzheimer's society, Age UK and Action for Carers can offer further advice on benefits.

Healthwatch Surrey – Contact us

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