



# **Carer's Engagement Summary**

**Darren Kistnasamy – User Researcher**

**Hertfordshire County Council**

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# What we wanted to know

We wanted to find out about the experiences of unpaid carers (people who look after family members).

Where do these carers go when they need help?

How do they do this?

# Carers forms

This included the forms on our '[Carers – how to get help](#)' page.

- Do unpaid carers use these forms?
- Do these forms meet their needs?

## Carers - how to get help

Help is available from us, your GP and Carers in Herts. There are also local services and technology that could help - we can point you in the right direction.

[Get a Carer's assessment](#)



[Create a 'Carer's in Case of Emergency' plan](#)



[Tell your GP and Carers in Herts](#)



## **What we did**

We met with Co-production members from local organisations involved with carers to discuss what we wanted to find out, and how we would do this.

We drafted a discussion guide for carers and shared this with Co-production members for review and comment to ensure this was robust.

We then carried out some informal one-to-one sessions with carers from across Hertfordshire to learn about their experiences.

# How we ran the sessions

We spoke to 13 carers:

- 9 one-to-one sessions over MS Teams
- 2 one-to-one sessions by phone
- 2 users at a joint session over MS Teams

# Carers we spoke to

- 13 unpaid carers (7 male, 6 female)
- 8 (62%) caring full time
- Age range 30's - 70's  
**Average age: 55**
- Time caring 3 - 21 years  
**Average time caring: 10 years**

# Use of IT

All carers in this sample are comfortable with IT. Frequent tasks include web browsing, social media, email and video calls.

Devices they use:

- Laptop – 10 (77%)
- Mobile – 5 (38%)
- Tablet – 3 (23%)
- Desktop – 2 (15%)

## **Who they care for**

- Spouse – 6 (46%)
- Parent – 4 (31%)
- Son/Daughter – 3 (23%)

## **Conditions**

- Dementia/Alzheimer's/Memory loss – 5 (38%)
- ADHD/Autism – 3 (23%)
- Arthritis/mobility issues – 3 (23%)
- Depression – 1 (8%)
- Heart condition – 1 (8%)



## How they feel about the word 'carer'

- 10 users (77%) have no issues with being described as a 'carer.' It isn't something they've considered before. *'It's just what I do'*
- 3 (23%) users feel the word is 'too broad' and that it doesn't indicate the difficulties and levels of stress involved.  
*'No distinction between paid carer and unpaid carer. I do more than a paid carer.'*

# Reasons why carers look for help

From this group of users, we discovered that carers look for help when:

- the condition of the person they're caring for deteriorates
- they want an assessment for themselves or the person they're caring for (home assessment) to see if they're eligible for any additional help or support
- they want a break from caring
- equipment needs repair or replacement
- they want to make an accommodation request for the person they're caring for
- they're no longer a carer
- they want to make a complaint

## Reasons for last enquiry

- Carer's assessment request – 3 (23%)
- Home assessment request – 3 (23%)
- Supported living request – 1 (8%)
- Equipment request – 1 (8%)
- Respite care – 1 (8%)
- No longer a carer – 1 (8%)
- Complaint (supported living request) – 1 (8%)
  
- 2 users (16%) have not had any contact with us, both for funding enquiries – GOV.UK (carer's allowance) and CCG (Clinical Commissioning Group) (Primary Health needs funding).

Enquiry	Method of contact with Herts County Council (HCC)
Carer's assessment request – 3 (27%)	1) Jewish Care (phone)> <b>phoned HCC</b> > Carers In Herts (phone)> <b>phoned HCC</b> 2) <b>Phoned HCC</b> 3) Google>Carers 'How to get help' page> <b>Ask for social care help form</b>
Home assessment request – 3 (27%)	1) HCC website> <b>phoned HCC</b> 2) Carers In Herts (phone)> <b>phoned HCC</b> 3) Google> <b>Phoned HCC</b> >Emailed HCC>paper form
Supported living request – 1 (9%)	<b>Phoned HCC</b> after being signposted by another local authority
Equipment request – 1 (9%) Bath lift AC power adaptor broken	HCC website>couldn't find info> <b>phoned HCC</b>
Respite care – 1 (9%) Wanted to book a carer's break	HCC website>couldn't find info> <b>phoned HCC</b>
No longer a carer – 1 (9%)	HCC website>couldn't find info> <b>phoned HCC</b>
Complaint (supported living request) – 1 (9%)	HCC website>Online complaint form

## Method of contact with Hertfordshire County Council (HCC)

Of the 11 carers that made contact:

- 5 (45%) came to the HCC website first.
- 4 (36%) phoned first.
- 2 (18%) Googled first.
  
- 4 (36%) phoned after trying to use the website first.
- 9 (82%) phoned to resolve their enquiry.
  
- 2 (18%) used our online web forms (carer's assessment form, emergency plan form, and complaint form) first and had no issues with these. Swift responses for both users.

# Google Analytics – carers pages

From 01/01/21 to 30/06/21:

- [Adult care – how to get care and support from us](#): 12,741 visitors (linked to via the 'Ask for social care help' top task tile on the Adult social services landing page).
- [Carers](#): 4,347 visitors
- [Carers – how to get help](#): 1,941 visitors
  - Google – 38%
  - Direct/unspecified – 19%
  - Carers In Herts referral – 13%
  - HCC top task tiles – 10%
  - Bing – 8%

# Google Analytics – carers forms

From 01/01/21 to 30/06/21:

- [Ask for social care help](#): 6,449
  - 33% from Adult social services landing page
  - 29% directly (unspecified)
  - 13% from Adult care – ‘how to get care and support from us’
  - 5% from Adult social services ‘contact us’
  - 3% from Carer’s page
  - **1% from Carer’s ‘how to get help’ page**
- [Carers in Case of Emergency plan](#): 488
- [Tell us you’re a carer](#): 492

# Carers – how to get help page

## Carers - how to get help

Help is available from us, your GP and Carers in Herts. There are also local services and technology that could help - we can point you in the right direction.

- [Get a Carer's assessment](#) >
- [Create a 'Carer's in Case of Emergency' plan](#) >
- [Tell your GP and Carers in Herts](#) >
- [Other help with day to day caring](#) >

- Page has been seen by 5 users (38%) before. Comments:
- *Page seems clear and easy to navigate. I'd like to see a clear list of things a new carer needs to know about.*
- *Page seems basic and easy to navigate.*
- *I like the way the 3 forms are presented differently. Smaller bites are easy to chew.*
- *I'd prefer to see the 3 forms combined so all info in one place. Frustrated at duplication.*
- *Forms appear as expected - no surprises.*
- *Accessibility link in the footer is hard to find – needs to be near the top of the page as it's so important.*
- *I came to this page looking to tell about change of circumstance (no longer a carer), but nothing helpful.*
- *I came to this page looking to book respite care, couldn't see anything here to help me.*

**Recommendations** – include or link to 'Tell us you're no longer a carer' info (medium) and link to 'Get a break from caring' page (low).



# Ask for a Carer's assessment form (Ask for social care help)

Ask us for a Carer's assessment >

- 12 (92%) have never used this form.
- **1 (8%) has used it themselves – no issues – ‘Clear, easy, no problems.’**
- 2 (15%) arranged a carer's assessment by phone.

## Comments from those who haven't used it before:

- *I wouldn't know what to ask for. I need help, but don't know what I need.*
- *Makes me think it's to check my skills, not my need for help.*
- *This is a priority. You need to say why it's needed. I only know because Age UK told me.*
- *Get a carer's assessment' sounds like informal help (e.g. breaks), but 'social care' on p2 sounds more formal, so feels different.*
- *I'd like to know if I'll get a reference number.*
- *On P2: Communication methods should be a simple tick box.*
  
- *Form is clear – already done with North Herts District Council.*
- *Form is 'straightforward enough.'*
- *As expected – no surprises.*

# **Ask for a Carer's assessment form (Ask for social care help)**

No evidence from this sample of carers that any amendments are needed to this form.

The one carer who has used it themselves found it '*clear*' and '*easy*' to use with '*no problems.*'

Comments from users who haven't used it suggest that it could be clearer in the accompanying text what the form is for and why it should be used:

## **Get a Carer's assessment**

This is an opportunity to discuss how caring for someone affects your life, what's important to you and how we can help. This might include taking a break from caring, advice on local services, planning for the future or technology that could help.

You can have an assessment on your own or with the person you care for.

## **Recommendation (low)**

Amend this wording to more clearly state what the form is for, and why it should be used.

# Carer's in Case of Emergency plan form

Create a Carer's in Case of Emergency plan >

- 12 (92%) have never used this form.
- **1 (8%) has used it – no issues – ‘Seemed fine.’** (Same user that completed carer's assessment form online).

Frustration is user had to fill emergency form again with social worker over the phone during assessment, after having completed it themselves online. Issue with process, not the form.

- 1 (8%) has arranged this with North Herts District Council.
- 1 (8%) has completed a paper form with a County Council social worker.

## Comments from those who haven't used it before:

- *The person you're caring for might not be able to give their consent.*
- *Understand it, but feels like it's if the person I'm caring for had an emergency, not me*
- *Form is fine, but I think it's more for the person I'm caring for, not me.*
- *Needs to be simpler e.g. 'Should you fall ill or die this will help with support for the person you care for.'*
- *I think it's for when you can't cope anymore and need help.*
- *I had help completing a paper form from social worker – no issues.*
- *I like the phone number on the form. Good to have the option to call.*

# Carer's in Case of Emergency plan form

No evidence from this sample of carers that any amendments are needed to this form.

The one carer who has used it themselves said it '*seemed fine.*'

A couple of comments from users who haven't used the form suggest that it could be clearer in the accompanying text that the form is for the carer, not the person they care for:

## **Create a 'Carer's in Case of Emergency' plan**

Complete this simple form to let us know you care for someone. If there's an emergency and you're unwell or unavailable, we'll have all the information we need to quickly arrange care.

### **Recommendation (low)**

Amend this wording to more clearly state that the form is for when the **carer** has an emergency and is unable to look after the person they care for.

# Tell us you're a carer form

Tell us you're a carer >

- **None of these carers have used this form.**
- 8 (62%) have already informed their GP surgery directly.
- Comments indicate this form is easier to use than the one provided by GP's.

## Comments from those who haven't used it before:

- *Already done with Carer's Champion at GP surgery.*
- *Already done with surgery who sent me a letter.*
- *Layout of this form looks better than the GP form – clearer.*
- *Fine, much better than the GP's form.*
- *No issues.*
- *Explain why you need GP to put you down as main carer. It's better than just being a named contact.*
- *Would be really useful the tell the GP you're a carer.*

# Tell us you're a carer form

No evidence that any amendments are needed to this form. Comments indicate it's clearer and easier to use than forms provided by GPs.

Comments from users who haven't used the form suggest that it could be clearer in the accompanying text what the benefits of telling your GP are. The term 'Carer's Champion' was used by a couple of carers.

## **Tell your GP and Carers in Herts**

We'll let **Carers in Hertfordshire** and **your GP** know, so you can get advice and support.

[Tell us you're a carer >](#)

Your GP might be able to offer you flexible appointments, health checks and flu jabs.

## **Recommendation (low)**

Amend this wording to more clearly state the benefits of telling your GP/Carer's Champion.

# Quotes from carers (negative)

Unpaid carers are stressed, and often find it difficult to get help.

Key reasons are perception of fragmented information, complex/inefficient processes, slow responses, and lack of empathy.

- *There seems to be more info around for people caring for a parent or child. It's different when you're caring for your spouse. Everything has to be as simple as possible.*
- *I've had to go through brick wall after brick wall.*
- *Being a carer is the worst job I've ever had – I'm trying not to cry.*
- *Council services seem a lot more disjointed now – get passed round a lot.*
- *People on the phone are trying to help but too many steps now to get things done.*
- *The main problem is slowness. It can take the council 6 weeks to respond.*
- *It's taken a toll on my health. Sometimes it's hard not to breakdown.*
- *Forms are limited. You can't faff on a form. I need to talk to someone.*
- *I'm fed up of being signposted to services. Carers don't have time.*
- *Have enough with caring without looking at websites.*
- *I felt completely lost in the system and bureaucracy.*
- *Unless you use the correct language, you won't get help e.g. 'failed discharge.' Now I'm in the system I know what to say.*
- *The people you deal with need to show more empathy. Carers assessment from HCC over the phone which was very cold and emotionally distressing.*

# Quotes from carers (positive)

Some positive feedback when dealing with the County Council and with other local organisations.

Key components are empathy and timely responses:

- *Social workers (HCC) are great when they get in touch.*
- *It was refreshing. She (HCC social worker) actually listened to my needs. Very helpful.*
- *SASH (Specialist Adolescent Service Hertfordshire) worker always gets back to me and involves other professionals.*
- *Quite a smooth process once on the phone (booking respite care via HCC).*
  
- *Thankful the borough council and Age UK have been so helpful.*
- *Carers In Herts have been a 'Godsend.'*
- *Carers In Herts have been brilliant. I was emotional and they really listened to me.*



## Carers (x13)

Average age:  
55

Average length  
of time caring  
for family  
member:  
10 years

Comfortable  
with IT

No issues with  
being called a  
'carer'

## Enquiry

Assessment  
requests  
(carer's and  
home)

Funding

Supported  
living request  
(and a  
complaint  
about this)

Equipment

No longer a  
carer

## First actions

38% HCC  
website

31% Google

15% phone  
HCC

15% phone  
other orgs

53% come  
directly to HCC

## HCC carers forms

Carer's  
Assessment: 1  
user – 'clear  
and easy'

Emergency  
Plan: 1 user –  
'seemed fine'

Tell us: not  
used by any

92% haven't  
used any of  
these forms

## Carer needs

Simple process  
for getting  
help

Timely  
responses to  
enquiries

Empathy

# Conclusions

- When looking for help, 53% of experienced, unpaid carers come to HCC first (38% website, 15% phone).
- Top enquiries are requesting a carer's assessment and requesting a home assessment.
- 92% of this sample haven't used any of the forms on the Carers – 'how to get help' page.
- Only one user had previously used the forms on the 'Carers – how to get help' page – 'Get a carer's assessment' and 'Emergency plan.' They didn't have any issues completing these.
- No users have used the 'Tell us you're a carer' form. 62% tell their GP directly. User comments indicate this form is easier to use than the one provided by GPs.
- Users who haven't used the forms before found them to be as expected, but felt accompanying text could be simplified to show more clearly why each form should be used.
- Most (77%) have no issues with being called a 'carer.'
- Needs are being met via direct contact with social workers, GPs/Carer's Champions and local organisations such as Carers In Herts, Age UK, and care hub support groups. Carers In Herts in particular received praise from a number of carers.
- Frustration for carers who work full time is that support meetings for carers are held during working hours, so they can't attend these.
- Social worker attitudes vary. Some are very thoughtful and engaged, others lack empathy. Caring is a very stressful, 24/7 role and carers often feel they're on their own or not being listened to. Empathy and timely responses are key.

# Recommendations

No evidence from this sample of carers that any amendments are needed to the actual forms on the '**Carers – how to get help**' web page.

However, comments suggest that amendments to accompanying page content would make the purpose of these forms clearer.

- **Get a carer's assessment form (low)** - amend wording to more clearly state what this form is for, and why it should be used. Note only 1% get to this form from this page – 54% get to it from other HCC pages (33% alone from the Adult social care landing page). As it's a top enquiry mention and link to from Carer's page as not currently mentioned there.
- **Emergency plan form (low)** - amend wording to more clearly state that the form is for when the **carer** has an emergency and is unable to look after the person they care for. Note this is linked to from the Carer's page (higher traffic than the 'how to get help' page – 4,347 vs 1,941 unique views for the last 6 months).
- **Tell us you're a carer form (low)** – amend wording to more clearly state the benefits of telling your GP/Carer's Champion (low) – note most users tell their GP/surgery directly - could link to from Carer's page to help increase usage.
- **Tell us you're no longer a carer (medium)** - include or link to this info.
- **Respite care (low)** – link to our 'Get a break from caring' page.

# Next steps

- Findings to be shared and discussed with service leads and stakeholders. Are there any concerns or surprises about these findings?
- When service and stakeholders are happy to authorise changes, our content team will review and amend.
- We'll continue to monitor feedback and can also arrange follow up sessions with carers to ensure content is meeting needs.