

Looking for those that don't know they need to be found



Finding and understanding the needs of 'hidden unpaid carers' in Medway

September 2020

In partnership with



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The COVID 19 pandemic and subsequent lockdown and shielding programme, meant that more people were looking after people at home than ever before. Many of them were not known to the regular services and so are known as hidden carers.

For local authorities it brought the need to understand the implications of how much 'hidden' care is provided by families and friends within the community sharply into focus. However, this is not an easy task, especially during a lockdown. The very nature of the relationships offering this 'hidden' care and support, makes it very difficult to identify people who may be caring for someone. Many of these individuals wouldn't necessarily class themselves as a carer.

Working in partnership with Carers First, and the Medway Better Together Consortium, we designed a series of social media adverts encouraging people to get in touch and see what support was available to them. Our adverts reached over 50,000 people but only 10 people asked for Carers First to contact them. These 10 people were caring for a range of family and neighbours, some providing 24 hour care and undertaking a range of practical and personal care tasks.

Given that the Office of National Statistics reported that an estimated 15% of the population were offering care and support in April 2020, we wanted to explore why less than 1% of the people that saw our social media advert made contact with us. We used different methods to examine this from a range of perspectives:

- Analysis of the social media activity
- Data from a survey of people who contacted Carers First as a result of social media
- A literature review of help seeking behaviour
- Focus groups with 'hidden' unpaid carers

Triangulating these insights we have concluded:

- Social media has the ability to reach a large number of people, but it lacks the personal and face to face interaction needed to help overcome the barriers around starting a conversation.
- The design and wording of social media adverts can be tailored to resonate with target groups.
- Key barriers to help seeking behaviours for unpaid carers in Medway are:
 - People have low expectations of what care is available based on previous experience of looking for help, or on the experience of friends.
 - Carers feel a sense of duty, resignation and endurance
 - People do not identify themselves as Carers.
 - People don't know where to go to find information.
 - The person who is cared for, and sometimes the carer, wish to stay independent and maintain control of their situation.
- The single most effective way to overcome these barriers is a trusting relationship with a professional, who can reflect back to the individual that they are a carer, offer information, an invitation to talk about the experience of being a carer and signpost them to the appropriate carers support.

What are we recommending?

- Organisations wishing to reach unpaid carers, should use the insights and identified barriers to help seeking behaviour to inform their future advertising and promotional materials.
- To explore extending the work of embedding carer awareness amongst health and social care professionals with employers as an alternative trusted first point of contact for carers.
- To explore the possibility of creating a flow chart/ pathway for carers based on a 'well trodden path' concept. Giving people a sense of what they may need to consider next and how to find information to help inform this.
- For Medway Council to review how carer assessments are undertaken.



Context

People across the UK pulled together during the coronavirus (COVID-19) pandemic and in particular during the lockdown period, in ways that may have a lasting legacy for communities. People looked out for neighbours, friends and family with almost half (48%) of people in the UK providing help or support to someone outside of their household in the first month of lockdown in April 2020. (ONS report May 2020). This is a substantial increase as figures from ONS before the pandemic showed that just over 1 in 10 (11%) adults reported providing some regular service or help for a sick, disabled, or elderly person not living with them during 2017 to 2018.

In April, a joint statement from Carers UK and Carers Trust highlighted the urgency in understanding and supporting the needs of people who were providing unpaid care during the pandemic. Data from ONS (Office of National Statistics) in April reported that one-third (33%) of people who were already supporting another person were now giving more help. In Medway, Carers First is commissioned by Medway Council to provide support for unpaid carers.

Carers First were already working hard to understand any change in the needs of and support for unpaid carers during the pandemic. Healthwatch Medway offered to work in partnership with them and other members of the Medway Better Together Consortium (Medway Voluntary Action, Citizen's Advice and Kent Association for the Blind) to focus on reaching hidden carers and further the work of the Medway Joint Carers Strategy.

Hidden carers' is a term that refers to informal carers who may not recognise themselves as a carer, and who are not already in contact with a carers support organisation. During the pandemic there was a concern that an increasing number of people may find themselves looking after a loved one, friend or neighbour, or conversely find that they are unable to provide the level of support and care that they had previously, due to practical issues of self isolating or shielding.

This project therefore wanted to reach people who didn't see themselves as carers, but who may be in need of additional support.

What were we trying to achieve?

- To reach unpaid carers and make them aware of the support that could be available to them from Carers First, facilitating where possible a direct contact for people requesting information.
- To learn from the advertising and promotion activities to inform future activities to reach hidden carers.
- To create an anonymised data set illustrating the scope and scale of hidden carers activity and needs to inform future services and commissioning.



What we did?

Given that we were operating during a lockdown, we used social media to reach people and raise awareness of the fact that there was support available to people who may be caring for others. We designed the project in stages to enable us to experiment with different style of social media so that we could test and tailor our approach at each stage. We wanted to learn and test what worked best to reach this target audience.

People who clicked on the advert were taken to the Healthwatch Medway website, where they were able to complete a short set of questions about their situation and request a call back from Carers First. An automated email alert was then sent to Carers First with relevant information to enable them to make a follow up phone call.



Image 1. Designed process flow

Phase 1

Phase 1 of the advertising campaign used task based adverts, highlighting tasks that people might recognise that they undertake. We deliberately avoided using the term ‘carer’ as we felt that not everyone would necessarily associate themselves as a carer.

Adverts were placed on Facebook as a paid campaign, using targeted demographics. The campaign used budget optimisation from Facebook, an option that works in real time to identify who is reacting to adverts and then adjust how this advert is promoted to similar demographic groups or target audiences.

Facebook offers an option to target adverts to identified groups of people according to algorithms about their likes and interest areas. Target groups identified within this first phase included: community issues, helping behaviour, volunteering, family care givers, care in the community, caregiver, neighbourhood, self care, compassion.



Phase 1 Adverts ran from 12th - 22nd May 2020. Paid adverts ran for 10 day period.

Phase 2

Our Phase 2 adverts were designed to be more emotive; reaching people’s feelings about being a carer. These adverts were inspired by a Carers Trust report that identified the impacts and pressures that carers were reporting being under during lockdown. Adverts were placed on Facebook as a paid campaign, but didn’t use targeted demographics or the budget optimisation options from Facebook.



Who supports you, while you look after someone?

Call us to find out what support is available for you right now.

Freephone **0300 3031555**
or visit **healthwatchmedway.com**

Even if you don't need support, we'd still love to hear your story



Is looking after someone during Covid making you feel lonely and isolated?

Call us to find out what support is available for you right now.

Freephone **0300 3031555**
or visit **healthwatchmedway.com**

Even if you don't need support, we'd still love to hear your story



Have you had to give up work to look after someone during Covid?

Call us to find out what support is available for you right now.

Freephone **0300 3031555**
or visit **healthwatchmedway.com**

Even if you don't need support, we'd still love to hear your story

Phase 2 Adverts ran from 11th - 21st June 2020. Paid adverts ran for 10 day period.

Phase 3

Phase 3 adverts were designed around Covid and lockdown specific situations and use of new terminology such as ‘shielding’. These adverts were placed on Facebook as a paid campaign, but didn’t use targeted demographics or the budget optimisation options from Facebook.



Do you know someone who is looking after someone during Covid?

Are they getting the help that they need?

Tag them below so they can find out what support is available to them.

Freephone **0300 3031555**
or visit **healthwatchmedway.com**

Even if you don't need support, we'd still love to hear your story



Are you shielding someone right now?

Call us to find out what support is available for you right now.

Freephone **0300 3031555**
or visit **healthwatchmedway.com**

Even if you don't need support, we'd still love to hear your story



Has your normal Care package stopped due to Covid?

Call us to find out what support is available for you right now.

Freephone **0300 3031555**
or visit **healthwatchmedway.com**

Even if you don't need support, we'd still love to hear your story

Phase 2 Adverts ran from 11th - 21st June 2020. Paid adverts ran for 10 day period.





What did we find?

Number of people that interacted with paid adverts in Phase 1, 2 and 3

	Number of unique people who saw the advert	Average number of times they saw the advert	Number of people who clicked on the advert	Number of people who landed on website page	Number of people who completed the survey	Number of people who asked for a call back
Phase 1	12,024	2	214	192	5	2
Phase 2	22,041	1-2	182	301	4	1
Phase 3	19,335	1-2	212			
TOTAL	52,400		608 1% of those that saw the advert		9 1.5% of those that clicked advert	3

Table 1. Public reactions to paid advert by phase.

Breakdown of reactions to different Adverts

		Number of people who clicked	% males who reacted	Under 34yrs old	35-54 yrs. old	55yrs +
Phase 1		8	25%	1	4	3
		3	33%	0	0	3
		135	11%	7	36	92
		68	10%	6	24	38

Phase 1 adverts attracted 214 clicks, of whom 88% were female.







Phase 2	 <p>Who supports you, while you look after someone? Call us to find out what support is available for you right now. FreePhone 0300 3031555 or visit healthwatchmedway.com</p>	51	33%	4	4	41
	 <p>Is looking after someone during Covid making you feel lonely and isolated? Call us to find out what support is available for you right now. FreePhone 0300 3031555 or visit healthwatchmedway.com</p>	66	32%	3	20	43
	 <p>Have you had to give up work to look after someone during Covid? Call us to find out what support is available for you right now. FreePhone 0300 3031555 or visit healthwatchmedway.com</p>	65	46%	5	18	42
Phase 2 adverts attracted 182 clicks, of whom 62% were female.						
Phase 3	 <p>Are you shielding someone right now? Call us to find out what support is available for you right now. FreePhone 0300 3031555 or visit healthwatchmedway.com</p>	95	4%	1	33	61
	 <p>Do you know someone who is looking after someone during Covid? Are they getting the help that they need? The Good Neighbourly help that they need is available to find. FreePhone 0300 3031555 or visit healthwatchmedway.com</p>	67	23%	1	9	57
	 <p>Has your normal Care package stopped due to Covid? Call us to find out what support is available for you right now. FreePhone 0300 3031555 or visit healthwatchmedway.com</p>	50	22%	8	7	35
Phase 3 adverts attracted 212 clicks of whom 85% were female						

Table 2. Public reactions by individual advert.

Analysis of website activity

192 people in phase 1, and 301 in phase 2 and 3 followed the link through to Healthwatch Medway website. Analytics from the website show an increase in this website traffic with a significant 200% increase in new users and page views during the first three weeks of the campaign.



What can we learn from analysis of adverts?

Timing of adverts

An analysis of the time of day people reacted to or saw an advert on Facebook revealed no significant patterns.

Age differences

70% of those that clicked on an advert were aged over 55 years and just 7% were under 35 years of age.

Gender differences

In all phases the social media adverts attracted more females than male responses, (phase 1, 88%, phase 2, 62% and phase 3, 85%). However, it is possible to draw some inferences from the adverts that attracted more men to click through for information.

The top advert that attracted the highest male click through rates (46%) was based on practical implications of caring for someone:



A second cluster of adverts attracted a significant proportion of male reactions:



33% Male



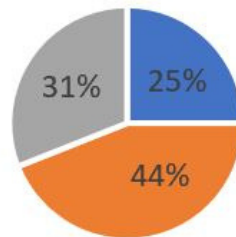
32% Male



33% Male

Examining this further to look at the reactions to adverts within gender group, of the total males that clicked through in phase 2, 44% of them clicked on feeling lonely as oppose to only 25% who clicked on who looking after you.

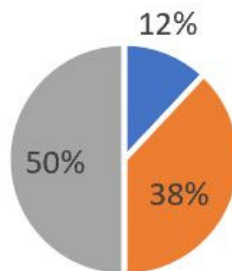
Phase 2 Male click rates



- Who looking after you?
- Feeling lonley
- Give up work

In phase 3, we found that 50% of the men that reacted to adverts, clicked on advert asking if they knew someone who was caring.

Phase 3 male click rates

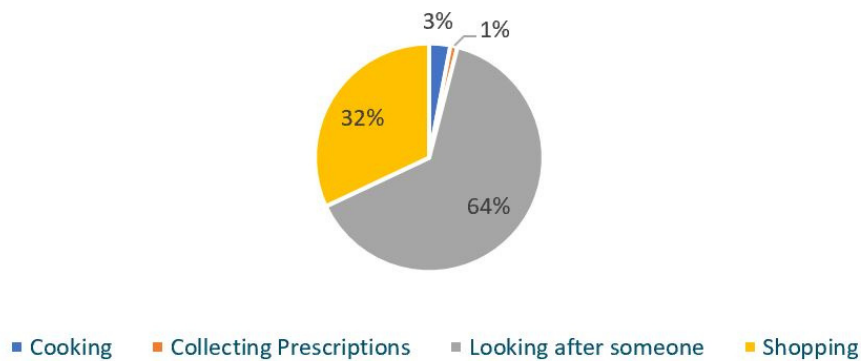


- Shielding
- Care Package stopped
- Know someone else who is caring

Drilling further into this difference, we can see that more males within all age groups reacted to the advert about feeling loneliness and isolation than the advert that asked ‘who is looking after you, whilst you look after someone’. We can infer from this that feeling looked after was not something that resonated as much as acknowledging feelings of loneliness and isolation. All the adverts in Phase 2 attracted significantly more interest from males than adverts from phase 3.

When we looked at the female click rates for adverts within gender group, in phase 1, the most frequent response was caring for someone.

Phase 1 Female click rates



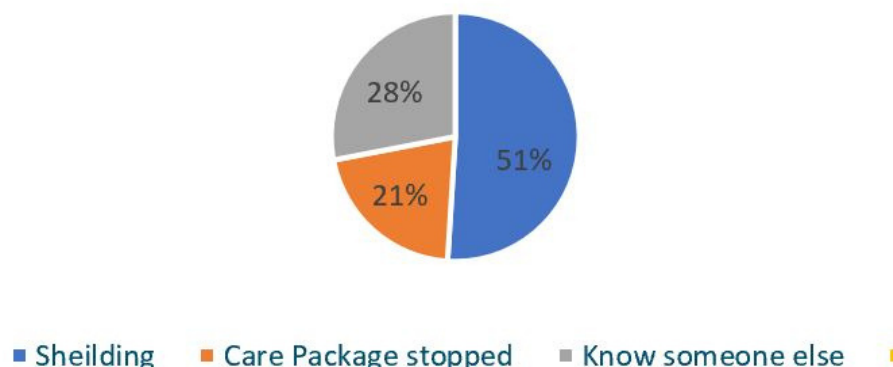
In phase 2 adverts, designed to create an emotional impact we found that the greatest reaction was to the advert asking if people felt lonely.

Phase 2 Female click rate



In Phase 3, we found over 50% of activity related to the advert around shielding.

Phase 3 female click rate



What can we learn about hidden carers?

Upon landing on the webform people were asked a few basic questions about their circumstances. The questions were designed to gain an insight into the type of caring tasks that they were undertaking and the frequency with which they did these tasks.

In total 9 people completed these questions after having clicked on a social media advert.

Tasks and responsibilities undertaken

All of the social media group reported supporting people with shopping, cleaning and cooking. Three people said they offered personal care.

In addition, people said they were taking on a range of support tasks including:

- Laundry
- Paperwork and banking
- Making medical appointments and taking them to follow up treatment / appointments
- Emotional support
- Getting medication
- Telephone support and social contact
- 'Visiting to read post as visually impaired twice weekly'
- 'Some gardening'
- 'Its really difficult to know what to do. It's trying to get out of him what he actually needs'

Amount of time given as unpaid carer

Eight of the nine people said that they were caring at least daily and the final person said that they spent some hours each week as needed. Three people said that these tasks were undertaken 24 hrs a day, with others saying that the amount of time they supported others varied each week



Exploring the low conversion rate

Scale of potential Hidden Unpaid Carers in Medway

Pre Covid figures suggest that 1 in 10 people are unpaid carers and a report published by Carers UK during Carers Week in June 2020 estimated a 150% increase in the number of unpaid carers as a result of the Covid-19 pandemic. For Medway this suggests that there could be 1 in 7 people who have been acting as an unpaid carer.

Given that our social media adverts reached a total of over 50,000 people we could reasonably expect that just over 7,500 of them could be unpaid carers during lockdown, so why did only 1% of the people that saw the advert click to find out more information?

Literature review of 'help seeking behaviour'

A review of literature around 'help seeking' behaviour highlighted:

- Carers in general, but older males in particular, are often reluctant to identify themselves as carers. C Milligan, H Morbey. *Older men who care: Understanding their support and support needs*. Lancaster University Centre for Ageing Research 2013.
- A number of studies looking at help seeking behaviour for health conditions such as cancer, conclude that two factors influence how and when people seek help, recognising and understanding the symptoms and overcoming the fear. (L K Smith, C Pope, J L Botha. *Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis*. *Lancet* 2005; 366: 825-31)
- Men increase their consultation rates with GPs when taking on a caring role. In contrast, women who look after someone in the same household and carry heavy caring responsibilities have relatively less contact with GPs than expected. (H Arksey and M Hirst. *Unpaid carers' access to and use of primary care services*. Cambridge University Press: 31 October 2006)
- Withdrawal from social contact with others, resignation of their situation and low expectations in terms of what could be available to help, are dominant themes in why older people with unmet needs do not seek help within primary care settings. (K Walters, S Iliffe, M Orrell. *An explanation of help seeking behaviour in older people with unmet needs*. *Family Practice* 2001.)
- A lack of information, and not knowing where to seek help, or what was available is a barrier. (K Walters, S Iliffe, M Orrell. *An explanation of help seeking behaviour in older people with unmet needs*. *Family Practice* 2001.)
- There is a fear of the consequences of asking for help, and particularly amongst carers is a sense of duty and endurance. (K Walters, S Iliffe, M Orrell. *An explanation of help seeking behaviour in older people with unmet needs*. *Family Practice* 2001.)
- People with dementia wish to stay independent and in control as long as possible, and early experiences of formal care, such as a few hours respite can increase uncertainty, affect self perception and disturb relations between carer and cared for. (Stephan et al. *Barriers and facilitators to the access to and use of formal dementia care: findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries*. *BMC Geriatrics* 2018)

Literature review of 'help seeking behaviour' cont.

- A trusting relationship that provides information and is approachable can help overcome some barriers to help seeking behaviour (Stephan et al. Barriers and facilitators to the access to and use of formal dementia care: findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries. BMC Geriatrics 2018)
- Male carers are committed to their caring role but are ambivalent about seeking help and are less likely than females to access support services. (N Greenwood, R Smith. Barriers and facilitators for male carers in accessing formal and informal support: A systematic review. Maturitas 2015)
- Males are reported to adopt more independent attitudes and to take a more task focused approach to caring compared to females who use more emotion based strategies. (N Greenwood, R Smith. Barriers and facilitators for male carers in accessing formal and informal support: A systematic review. Maturitas 2015)
- Professionals can create barriers including lack of recognition of the caring role and awareness of the needs and issues involved; professional uncertainty about roles and boundaries; reactive rather than proactive approaches; prioritising the care recipient at the expense of the carer. (H Arksey, K Jackson, A Wallace, S Baldwin, S Golder, E Newbronner, P Hare, A. Shapiro. Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D. December 2003)
- As carers often don't identify themselves as carers, GP surgeries identifying and recording carers and being the intermediaries, for example receptionists offering information can help people overcome their lack of assertiveness. (H Arksey, K Jackson, A Wallace, S Baldwin, S Golder, E Newbronner, P Hare, A. Shapiro. Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D. December 2003)
- A need to address carers needs and concerns away from those they care for, which may require one-to-one time with healthcare and social-care professionals which is sometimes not prioritised as its seen as an additional resource / time constraint and time is often focused on the cared for. (P Hudson. Improving support for family carers: Key implications fo research, policy and practice. Palliative Medicine, June 18, 2013)

To further understand hidden unpaid carer's issues around 'help seeking' behaviour we invited women, aged between 50 and 70, who were caring for their parents, and who we knew had seen our adverts, but had not asked for help, to join a focus group. The focus group was promoted as 'Exploring the issues around asking for help when you are supporting your parent to live independently at home'.

We also held a focus group for staff from commissioned carers organisations to explore the issues from their perspectives.

Help seeking behaviour focus group methodology

The focus group was based on a conversation method developed by the Institute of Cultural Affairs (ICA), that creates a structured discussion exploring things on a rational and emotional level. Questions were designed to facilitate the participants journey from a conversational first response, to deeper reflection and then move to a sense of action and personal control.

The objectives of the focus group were to try and understand:

- How do people feel about the term Carer and does it relate to how they view the care and support they are giving?
- How do people feel about asking for help with the care and support they currently offer?
- What might help change how people look for help and information about the care and support they give?

A £20 Amazon voucher was offered to incentivise participation.

What did we learn from the help seeking behaviour focus groups?

Three women caring for their parents joined our focus groups. One person cares for her mother, one is carer for mother, father and husband, and the other is carer for father and husband.

All carers took on practical tasks such as shopping, cleaning, laundry, gardening and paperwork, but not personal care. One person has now started to get some paid carer support around personal care.

- ‘I run her life and manage two households. If I didn’t run her household completely nothing would happen, she would just sit in a chair 24/7. Nothing would happen if I didn’t organise everything for her. ‘
- ‘It doesn’t take all of my time. I do have time to myself because I put things in place for other people to do what I think I should be doing, but I can’t do everything for her.’
- ‘I am very blessed in some respect that mum and dad can do a lot for themselves. Mum is always in the garden, Dad is cooking meals from fresh. I don’t need those services, but I’m not saying I won’t need them eventually’.

The women talked about their expectations of a ‘carer’ and how they didn’t identify with this term.

- ‘A carer is someone who pops in and checks that they are ok. Especially if they are on their own, it gives them a bit of time for company, you don’t need someone there all the time’.
- ‘Before I became a carer, I would never of even considered the term. But if I had thought about it then I would have thought of a professional carer, someone who goes in every day to look after someone. I would never have considered it as someone who didn’t do it professionally.’
- ‘I would never consider becoming a carer; it’s not in my nature which is why I resent it so much. I don’t have the patience or tolerance.’

But during the focus group discussions, carers were able to identify that others were clearly a carer and would benefit from support and respite away from the ‘responsibility’ of caring. It seems that it is easier to see a carer in someone else than it is in oneself!

All the carers saw the support they gave as a natural progression in the mother-parent relationship.

‘I’m still the daughter going round and doing little bits. I don’t class myself as a carer, I’m just a daughter’.

‘I don’t consider myself to be a carer. I still separate it and think of a carer as a professional carer. I wouldn’t know how to define what I do’.

‘To be honest it is a natural thing you do together anyway, me and my husband helping.’

‘I don’t feel like myself, you feel like you do it because you are a daughter and you have a duty of care. Sometimes it takes over your life and you don’t realise how much you get sucked into it and when it will end.’

When asked about what support they received from other people, both women said that they relied on family members and friends. However, both women had mixed experiences of asking for, and receiving, help and support from health, social services and the voluntary sector and this experience informed how they felt about asking for further help.

- ‘It was when mum was in hospital after her second stroke and she could do very little for herself, so I contacted social services for help but I didn’t receive any help’.
- ‘I have tried to get her into residential in the past but she didn’t want to. Social services don’t listen to me, they listen to her. They have no regard for me whatsoever.’
- ‘When my husband came out of hospital, I got six weeks of help. A carer was coming in to help with his daily clean up, then came in at lunch time. My husband got uptight about a young girl giving him a wash. The girl said, I’m coming for 6 weeks, if he won’t let me wash him, is there anything I can do to help you? She said I’m here to help YOU. So her hanging my washing was what I needed. I personally feel that they don’t give her enough time to come in and do things. She only really gets twenty minutes.’
- ‘To get any support she has to re-assessed and it is so frustrating. In the end it’s ‘we will phone you back’, but they don’t and we end up sorting it independently because you never get to where you need to be. It isn’t worth asking for help’.
- ‘We use to go to the Stroke Association, that was handy, but again he was the youngest in the group as he was 50, everyone there was late 70’s. It didn’t feel right for him, they were talking about things in the war.’
- ‘Normally our church offers support, some people in the church pop round. Some pop round now for a cup of coffee.’
- ‘Medway AGE UK is very useful, they have clubs, if I can persuade her to go. It has been a big help’.
- ‘If you go somewhere like the Gateway you have to tell them what is going on and all they want is proof and to see your bank accounts, it feels like you are being judged’.

Carers talked about the challenges of caring for their parents and said that coping with their confusion and lack of understanding alongside maintaining personal hygiene were the hardest aspects of caring.

‘I just get on with it, you don’t think about it, you just do it. It’s just your mum and dad. You might get tetchy. But you can’t just leave them’.

The emotional impact of caring was felt, not only during the time they spent with the loved one, but at all times.

‘As soon as I step outside my front door I’m already angry and anxious about what I will find when I get back’.

Carers spoke about being resigned to the fact that the situation would continue to worsen and their concerns for the future reflected this inevitability:

- ‘In future, as they get older and dementia sets in, I worry about leaving my Dad alone with her. On some days she is nasty. Long term issue is something happening to my Dad and everything spiralling downwards. My concern is then trying to put two people into a home.’
- ‘I am concerned that I will never manage to get her into residential care because at the moment I am not at the end of my tether, but I have been in the past. So, if she gets much worse then I think I will be more concerned for me. She is pretty much oblivious.’

The single biggest factor that carers said would make a difference in overcoming the barrier of seeking help was a personal contact. Other suggestions were to use case studies or stories to help illustrate what support could be available, review use of the word Carer, as it isn’t a word that people relate to and create a simple flow chart of frequently asked questions and options.

- ‘When he was in hospital, the stroke team just gave me a load of numbers, they said someone will get back to you but no one ever did. I was on the ward one day and a lady from the stroke team was there and she said come along on the Thursday and that’s what we did. That’s when I heard about Carers First. Rather than getting bombarded with loads of numbers and paperwork, we need people to sit down and go through it and help you get through the red tape... someone to actually sit and speak with you.’
- ‘Someone who can actually do something constructive, not someone to give you another list of numbers. Someone on the end of the phone.’
- ‘Someone to take you through from start to finish. Initially in the hospital someone on the ward just gave me a number, she was busy but gave us the number to get us invited. Initially after doing that phone call, I wasn’t sure, but she followed it up and called me. She promised something and then followed through.’
- ‘Make it more obvious about what they provide rather than just say contact us to find out what we do. Advertise more about specific things that they can do, or what they have done, maybe a case study. It would possibly draw me in if it was clearer what they could offer’.

- ‘Certainly the name Carers First didn’t mean much to me, I wouldn’t consider it for me. The name doesn’t identify to me, I would think it was more for a professional carer.
- ‘Some positive stories showing that some people actually get help rather than hearing stories of constant frustration’.
- ‘A public fair with different stands, like Citizens Advice, Stroke Association, talk to different carers and find out information and how you can access things. Also able to give information about financial advice’.
- ‘I would like a flow chart that is quick easy for your parent. Can they do this, can they do that. It leads to the next question. There are a lot of questions on an attendance allowance form, ‘can they button their clothes?’ But you need someone who can tell you the consequences of answering ‘yes’ and ‘no’. No one gives you the consequences of all these forms that you fill in. Are they trying to guide you away from solutions?’

What did we learn from staff working with carers?

We spoke to two people who work within the commissioned carers organisations to explore from their perspective what barriers they felt carers had in asking for help and they identified three barriers.

They told us:

- People don’t identify themselves as carers
- The cared for does not want a stranger in the house, ‘they can feel judged’.
- ‘A lot of people say to us that they don’t ask for help because they can’t guarantee what time paid carers are going to turn up. They don’t like that people can come in and out of the house. For a lot of people it would turn their lives upside down’.
- The Carers Assessment is undertaken by the Council.
‘That is a huge issue because they work differently to how we work. It is a huge barrier for people seeking help. People do not want to get involved with social services... when you ask if someone has had a carers assessment and people will say I don’t know, and it is because the assessment gets linked with other things on the back of a needs questionnaire.’

Conclusions

We have been able to look at the issues around reaching people supporting parents or others within the community from a range of perspectives:

- Analysis of social media activity
- Data from a survey of people who contacted Carers First as a result of the social media activity
- A literature review of help seeking behaviour
- Focus groups of ‘hidden’ unpaid carers

Triangulating these insights we have concluded:

1. Social media has the ability to reach a large number of people but it lacks the personal touch that people have said they need, to help them overcome the barriers around starting a conversation about their personal situations and the stresses and concerns they have around caring for someone.
2. The design and wording of social media advert can be tailored to resonate with target groups. Emotive language elicited greater reactions in both males and females and all age groups.
3. From the focus groups and literature review we were able to identify the following key barriers to help seeking behaviours for unpaid carers in Medway. Some of these will not be surprising, but the insights can help to tailor future approaches to reach and engage with people.

List in order of relative impact:

- People have low expectations of what care is available based on previous experience of looking for help or on the experience of friends.
- Carers feel a sense of duty, resignation and endurance about finding themselves a carer for a family member.
- People do not identify as Carers.
- People don't know where to go to find information.
- The Cared for, and sometimes the carer, wish to stay independent and maintain control of their situation.

4. We found that the single most effective way to overcome these barriers is a trusting relationship with a professional, who can reflect back to the individual that they are a carer, offer information, an invitation to talk about the experience of being a carer and signpost them to the appropriate carers support.

What are we recommending?

- Organisations wishing to reach unpaid carers should use the insights and identified barriers to help seeking behaviour to inform their future advertising and promotional materials. We encourage them to be brave in tackling the issues carers have raised head on, using emotive and contextualised content, and highlighting what support could be available.
- To extend the work to embed carer awareness with health and social care professionals, with employers as an alternative trusted first point of contact for carers.
- To explore the possibility of creating a flow chart/ pathway for carers based on a 'well trodden path' concept. Giving people a sense of what they may need to consider next and how to find information to help inform this.
- For the Council to review how carer assessments are undertaken.

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Thank you



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 **Carers FIRST**
FIRST Choice for Carers