

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



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

A report by Healthwatch Kent

September 2020

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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. It is estimated that during Covid there could be 280,000 people providing care and support for family, friends and neighbours in Kent.

Working in partnership with the commissioned carers organisations in Kent, we designed a series of social media adverts. These adverts reached over 50,000 people but only 10 people actually asked for a carers organisation to contact them. These 10 people were caring for a range of family and neighbours, some providing 24 hour care on a range of practical support needs and some offering personal care.

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 Kent Carers Matter as a result of the social media activity
- A literature review of help seeking behaviour
- Focus groups to explore the issues 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.

Recommendations

1. Carers organisations, and any other organisation wishing to reach unpaid carers, should use the insights and identified barriers in this report to inform their future advertising and promotional materials. Organisations should be brave in talking about barriers and stress points that carers experience, using emotive and contextualised content, and highlighting what support could be available.
2. Carers organisations continue the great work they are doing in developing relationships with other professionals and raising awareness of the need to recognise carers and be a proactive first point of contact for people who may never have considered themselves a carer. In particular, to review GP practices use of Carers Registers, create material for GPs to raise awareness of what a good conversation with a Carer should look like and key trigger points to consider initiating a carer focused conversation with patients and their loved ones.
3. Carers organisations to revisit and refresh previous work done to encourage large employers in Kent to consider carers within their workforce but to also explore opportunities to open up routes of employment for carers.
4. Carers organisations to offer people a ‘no strings’ awareness session, exploring the known pressures on carers and myth busting the barriers to help seeking behaviour. This could be an information session to empower people to ask for help as and when they feel they need it. This could be in the form of webinars, chat rooms or face to face sessions delivered in GP surgeries, or community centres.
5. Healthwatch and Carers Organisations to work together and share this report with national Carer's organisations and the Regional Carer Manager at NHS England and NHS Improvement. Working from within GP surgeries, use the report to raise awareness of the barriers faced by carers and the impact that GPs can have in identifying and helping to support a hidden carer.



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 in April reported that one-third (33%) of people who were already supporting another person were now giving more help. In Kent there are 4 commissioned carers organisations (Carers Support East Kent, Involve, Imago, and Crossroads Care.) These organisations were already working to understand any change in the needs of and support Carers during the pandemic.

Every week during lockdown, we have been gathering the feedback that we've heard from people about how they are coping. We've been sharing that feedback directly with decision makers to ensure they can hear how people are coping and plan support accordingly. During this exercise, we have been hearing from a number of people who have been looking after themselves. Some, but not all, don't see themselves as a Carer and aren't currently getting any support from the carer organisations.

'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.



Throughout May we heard growing evidence of the role “hidden carers” have been playing in supporting people. Some people have been unable to offer the level of support they previously did, and others have found themselves offering care support where previously they didn’t.

- ‘family members who normally help them out cannot do so now as they won’t visit anymore due to worries at passing on infection’.
- “I moved in with my mum for lockdown, she has Alzheimer’s. I’m finding it hard because I’ve lived on my own for so long and now I’m sharing a house with someone that I can’t even have a conversation with. This covid is definitely accelerating the Alzheimer’s. Mum knows there’s something scary out there, but doesn’t quite understand what so she comes looking for me in the house if she hasn’t seen me for an hour. She’s 89 with Alzheimer’s, leukaemia and arthritis”
- “I like to think of myself of sound mind but I am at home looking after my 89 year old Mum and 87 year old Aunt and it’s driving me crackers. I have to get out and walk the dog to get away”
- Although my father is her carer, they still depended on other family members to get bits of shopping and help out with household tasks. However, since lockdown began, the family have not been able to help out at all and it has been left to my father to do all the usual tasks in the house

It was agreed that we would work in partnership with the carer organisations to reach people who didn’t see themselves as carers, but who may be in need of additional support.

The aims of the project

- To reach unpaid carers and make them aware of the support that could be available to them from the commissioned carers organisations. We wanted to facilitate, where possible, a direct contact with the relevant commissioned carer organisation.
- 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 did we do?

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 Kent Carers Matter website, where they were able to complete a short set of questions about their situation and request a call back from their relevant carer organisation. An automated email alert was then sent to the appropriate carer organisation with all 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: health care provider, helping behaviour, personal care, caregiver, neighbourhood, neighbourhood watch, local area network, home care, long-term care or elderly care, volunteer.

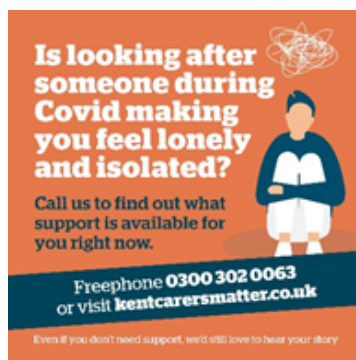


Phase 1 Adverts ran from 4th - 14th May 2020. Paid adverts ran for a 10 day period.

Phase 2

Phase 2 adverts were designed to be more emotive, reaching people's feeling 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.



Phase 2 Adverts, ran from 5th - 15th June 2020. Paid adverts ran for a 10 day period.

Phase 3

Phase 3 adverts were designed around Covid and lockdown specific situations and used 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.



Phase 3 Adverts, ran from 5th - 15th June 2020. Paid adverts ran for a 10 day period.

Phase 4

As well as social media adverts, we also used partner newsletters to extend our reach into the wider community. One of these target audiences were NHS employees, through NHS Hospital Trust staff newsletters. 5 NHS staff contacted us after reading that newsletter.

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 completed the survey	Number of people who asked for a call back
Phase 1	2,738	8-9 times	103	0	0
Phase 2	24,762	1-2 times	320	5	1
Phase 3	23,072	1-2 times	394	0	0
TOTAL	50,572		817 1% of people who saw the advert	5 Less than 1% of people who reacted	1 20% of people who completed the survey

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		26	4%	0	35%	65%
		7	14%	29%	57%	14%
		23	9%	9%	43%	48%
		38	8%	8%	21%	71%

Phase 1 adverts attracted 103 clicks, of whom 95% were female.







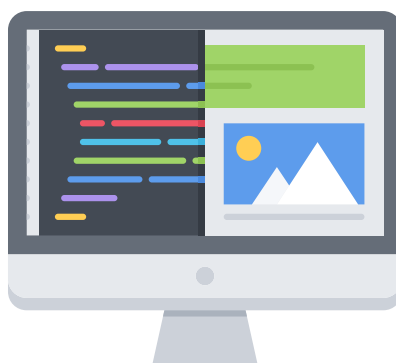
Phase 2	 <p>Who supports you, while you look after someone? Call us to find out what support is available for you right now. Freephone 0300 302 0063 or visit kentcarersmatter.co.uk</p>	117	18%	>1%	13%	86%
	 <p>Is looking after someone during Covid making you feel lonely and isolated? Call us to find out what support is available for you right now. Freephone 0300 302 0063 or visit kentcarersmatter.co.uk</p>	110	27%	3%	22%	75%
	 <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 302 0063 or visit kentcarersmatter.co.uk</p>	93	25%	0%	11%	89%
Phase 2 adverts attracted 302 clicks, of whom 81% 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 302 0063 or visit kentcarersmatter.co.uk</p>	190	6%	1%	36%	63%
	 <p>Do you know someone who is looking after someone during Covid? Are they getting the help that they need? Find out what support is available for you. Freephone 0300 302 0063 or visit kentcarersmatter.co.uk</p>	111	5%	5	27	68
	 <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 302 0063 or visit kentcarersmatter.co.uk</p>	93	38%	4	18	78
Phase 3 adverts attracted 394 clicks of whom 86% were female						

Table 2. Public reactions by individual Advert.

Analysis of website activity.

Analytics from the website show an increase in this website traffic with a significant 300% increase in new users and page views during the first three weeks of the campaign.

Once landing on this page there was a click through link to the survey.



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.

Gender differences

In all phases the social media adverts attracted more females than male responses, (phase 1, 95%, phase 2, 75% and phase 3, 71%). However, it is possible to draw some inferences from the adverts that attracted more men to click through for information. The top three adverts that attracted highest male click through rates were based on practical implications of caring for someone.



38% Males



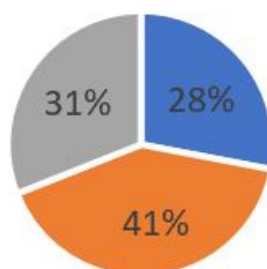
27% Males



25% Males

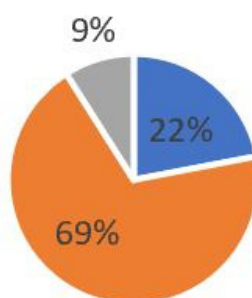
Examining this further to look at the reactions to adverts within gender group, of the total males that clicked through in phase 2, 41% of them clicked on the 'feeling lonely' advert as opposed to only 28% who clicked on the 'who is looking after you' creative. In phase 3 we found that 69% of the men that reacted to adverts, clicked on the advert asking 'has your care package stopped?'

Phase 2 Male click rates



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

Phase 3 male click rates



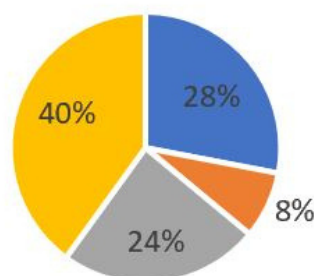
- Shielding
- Care Package stopped
- Know someone else who is caring

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. From phase 3, the significantly increased number of men clicking on the advert asking about a stopped care package, could suggest that the straightforward, practical nature of this advert attracted greater male responses.

When we looked at the female click rates for adverts within gender group, in phase 1, the most frequent response was shopping, which correlates with data from ONS highlighting that shopping was one of the most common activities that people undertook as part of their caring responsibilities (85%). This was also a significant area of growth activity during lockdown and support was available through the community hubs food parcel / delivery service put in place during the pandemic.

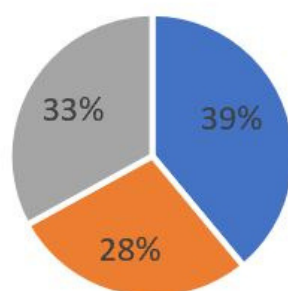
In phase 2, we designed the adverts to generate an emotional impact. We found all three adverts attracted broadly similar levels of activity. In phase 3 we found over 50% of activity related to our advert around shielding.

Phase 1 Female click rates



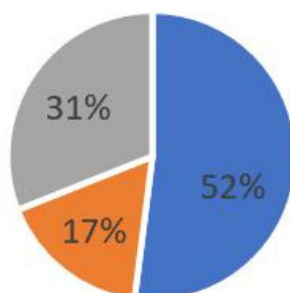
- Cooking
- Collecting Prescriptions
- Looking after someone
- Shopping

Phase 2 Female click rate



■ Who looking after you? ■ Given up work ■ Feeling lonley

Phase 3 female click rate



■ Sheilding ■ Care Package stopped ■ Know someone else

Social media adverts versus staff newsletter.

In total 5 people completed questions on the Kent Carers Matter website after having clicked on a social media advert and 5 people completed after clicking on a link in a staff newsletter, distributed by the NHS. Of the social media generated contacts only 1 in 5 requested a carers organisation contact them to discuss their situation. Of the newsletter generated contacts 3 in 5 requested a follow up call. In terms of reach, social media reached a greater number of people but the response rate was significantly lower than the response rate generated by the staff newsletter.

What can we learn about hidden carers?

Upon landing on the webform people were asked a few basic questions about their circumstances. These 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 5 people completed these questions after having clicked on a social media advert, and 5 people completed after clicking on a link in a staff newsletter, distributed by the NHS.

We have analysed these two groups separately

Tasks and responsibilities undertaken

All of the social media group reported supporting people with shopping, cleaning and cooking. In addition, people said they were taking on a range of support tasks including:

- Laundry
- Paperwork
- Making medical appointments and taking people to appointments or for treatment
- Emotional support
- Getting medication
- Telephone support and social contact

The five people who answered the questions after following the link within an NHS staff newsletter, all reported undertaking shopping, cooking, feeding and cleaning related tasks. Four people also reported undertaking some personal care tasks, such as washing. Three people said they undertook paperwork for the person they cared for, two people told us they did gardening and taking people to medical appointments and social services.

Amount of time given as unpaid carer

From the social media cohort, four of the five people said that they were caring at least daily and the final person said that they did weekly shopping and other chores when needed. Two people said that these tasks were undertaken 24 hrs a day, with 3 others saying that the amount of time they supported others varied each week.

From the NHS staff newsletter cohort, four people said that they cared for their loved one on a daily basis with one saying that they undertook these tasks several times a week. One person stated that 'I work for the NHS and I am currently working from home 4 days a week'. We cannot be certain that the others are still working while caring, but the contacts came as a result of the staff newsletter so we can assume that they are working at least part time. One person said they are providing 24 hour care, whilst the other 4 reported that their caring role took a variable number of hours each day.

Exploring the low conversion rate

Scale of potential Hidden Unpaid Carers in Kent

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 Kent this suggests that there could be over 280,000 people providing unpaid care during Covid. This is nearly 1 in 7 people.

Given that our social media adverts reached a total of over 50,000 people we could reasonably expect that just over 7,000 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?

Seven women caring for their parents joined the focus group. Of these, one person had paid for private carers to undertake personal care needs. Carers spoke about providing practical support with shopping, laundry, cleaning, paperwork and personal care, but also about the emotional and social support they provided. The time that people found they were needed to care for their parents varied, from some people popping in a day or two a week, to others who were living with their parents and caring full time.

- ‘I do my Mum’s personal care and give my Dad a break, I am the respite for my Dad. It’s too much for them. How much longer can they cope like they are? It’s a balancing act. It has a massive impact on my life and I don’t know how it will go on.’
- ‘They discharged her from hospital, on the condition that she lived with me. She sold her bungalow and I took her in. That was 7 years ago.’

Six of the people in the focus group told us that Covid 19 had had an impact on the care they provide:

- ‘At the moment due to Covid, Mum has moved in with me and my partner. She won’t be able to live on her own anymore now.’
- ‘I have been shielding during this so its been difficult to see her as often’.
- ‘Until the pandemic they have been managing with private care, someone who comes and sits with Mum 2/3 times a week, but due to lockdown the care stopped. I was furloughed so I went there to look after her’.

- ‘He has arthritis... he is waiting for a hip replacement... he was due a pre assessment in April but Covid happened so surgery has been delayed’
- ‘Only recently, during Covid, she has allowed us to support her more, her mental health is getting worse as she hasn’t been able to go out to see friends. It has affected her substantially.’
- ‘Covid has made it a lot harder and worse for me, respite for my daughter has stopped. It has been just us with my Mum who wasn’t getting any support before this as she had just had the stroke. It has just been us on our own’

Carers talked about their expectations of a ‘carer’ and how they didn’t identify with this term. Carers were felt to be ‘paid or unpaid ... someone doing a specific profession, role, job title, somebody external to come in and help look after Mum and take the responsibility away from me’. Carers talked about giving ‘unconditional love, help and care’ to their parents.

Carers all felt a degree of inevitability and resignation at becoming a carer for their parents.

- ‘What I have now learnt from experience is that being a carer doesn’t come with a wage, it comes with a circumstance, it just happens how your life turns out.’
- ‘I had my Mum and my own life, and I tried to be happy, but it eroded and eroded and I became just a carer trying to maintain some level of me in the middle of it. What happens with that is you lose yourself and you just become a tool to look after people’.
- ‘I know this is a long time scenario for me and they are in their late 70’s and I don’t know if I will ever be able to work full time again. I’m so exhausted, I can’t recoup my energy.’
- ‘It is something you just fall into and you don’t realise you have started becoming a carer’.
- ‘You think your Mum looked after you, so you have to look after her and the roles change and that’s what you do. You aren’t you anymore’.
- ‘I think the speed at which this role reversal has happened has taken me by surprise a bit, almost over night. I’m the parent and she’s is the child’.
- ‘I’m just getting on with it because I have to. She’s my mother so I want to look after her. I don’t want her in a care home, she doesn’t want to be in a care home... I love her very much. I could choose to leave but this is my situation. I want to look after her, so I accept it.’

Throughout the focus group people talked about a number of hurdles and barriers they had faced in seeking help. The most frequently mentioned barrier was that information was hard to find, some carers had a sense that information was ‘hidden’ making it difficult for carers to find what they are entitled to. Carers frequently used the word ‘consequences’, in terms of needing to understand what might happen next in their parents health or care journey, but also in terms of how decisions the carer makes may impact on available options and finance later.

Not knowing what was available or where to look for help.

- ‘No one has sat down and asked if you are getting this or that. Everything seems to be buried under massive menus’
- ‘There doesn’t seem to be a joined up approach. There should be a checklist of all the benefits that are available and all the appliances that can come into your house’.
- ‘There used to be a shop in Maidstone that did disabled aids, but it closed. Everything seems to be online. You really need to see these things, not just look online’.
- ‘There is help out there, but it is knowing where to go, you kind of pick things up by word of mouth’.
- ‘When you are in the middle of it, it is very hard to get your head around everything and things are so well hidden. If you don’t have a connection or know who to talk to you are left floundering and it makes the carer role so much more difficult’

The cared for ‘don’t like it’

- ‘My Dad sent people away the whole time. We had a different person everyday coming in to wash mum but because she didn’t like strangers in the house it didn’t help’.
- ‘My mother will not have a respite carer in the house. She won’t have stranger look after her. She is anti carer, anti taking tablet, she is resistant’.
- ‘I think most of the time I’m doing ok but when I get back home, when I’m just hearing her negativity and anxiety and the depression, the fact that it doesn’t matter what you suggest there is always a reason that it can’t be done... that’s the bit that is getting to me, you try to put things in place to make her life easier and you just get knocked back, in the nicest way’
- ‘The consequence about asking for help is I wouldn’t know how my Dad would react. He is very independent, and I think he would be resistant. I feel like he is a burden but actually I feel like I should be doing more for him.’
- ‘Consequences are you get pushed back; the person you care for thinks you don’t want to look after them... it is the fear of the unknown. You have to manage the expectations of who you care for.’
- ‘How would she react if I took a break? I don’t think she would be amused. I get excited to go out and do something for myself but I don’t want to get too excited because it might not happen’



A sense of 'coping' and guilt

- 'We cope as carers. We don't like to ask for help and we muddle through... You cope on a day to day basis, as everything gets thrown at you on a day to day basis.'
- 'I think it is hard to ask for help. The longer you go without help, the more difficult it becomes... there is so much guilt around being a carer, the fact we are hidden makes us feel guilty. If that guilt was taken away maybe we could ask for help and not be afraid of asking'.
- 'Sometimes it feels like failing so you don't want to ask as that is admitting that you have failed. You are your own worst enemy, you make yourself feel like you are not doing enough and that is really hard as well. You can't see it because you are in it.'
- 'I think it's my duty to help that is what stops me asking for help. Your parents spent so much of their lives looking after you, that you kind of feel that it should be you doing it. So setting up another agency to do that is quite difficult'.

A sense of not being in control

- 'I came home and found these massive hand rails in the bath and the toilets, no one asked if that was ok. They just came in when I was at work; luckily I was pleased with it'.

Finance

- 'Mum is worried about money. She is classed as self supporting... as soon as they know you are self supporting they say off you go you can sort it out for yourself.'

Carers talked openly about the emotional impact of being a carer and the range of emotions they experienced.

- 'I feel guilty going to work'
- 'For me personally it was a case of I didn't realise how much it had affected me both mentally and physically and eroded my feeling of self worth. My ability to do my day job had collapsed around me, but I had to focus on the two people. I nearly had a breakdown, that is when the support started to come in, but before that there was no signpost for me, there was nowhere for me to go. I just felt shattered trying to grab anything to help me'.
- 'My life feels like it is shrinking. It goes through thinking, when is the next crisis going to hit and keeping that balancing act'.
- 'I am still in that place where you are torn all the time, because when the phone rings you think oh gosh what has happened, I have to go somewhere, anxiety, I have employers who will let me do that but if that intensifies how much longer will they let me do that'.
- 'I don't feel strong enough to cope with it all the time. That worries me. The uncertainty of how long it will go on. My life at the moment feels like one big void; I have no job and I'm stuck in this bizarre situation'.
- 'The seven years leading up to now is where I earned all my battle scars and learnt the system, I had to reach a crisis point to know that'.
- 'It's a foreign idea to think I could go out and have a break. By the time I sit down it's about 9pm. With her health declining, I don't want to sleep too deeply in case you miss her call during the night. I need to make sure that everything is in place all the time'.
- 'When I look at her she is a little old lady, not the mother I knew. It's heart breaking.'

When exploring peoples' experiences of asking for help from friends and family, or from organisations, we heard about the barriers that stopped people communicating about their needs and the emotional impact of being a carer.

Some people felt that they would like more support and help from their immediate social circles, while others said they found it difficult to talk to friends and family about the challenges and frustrations they found in caring for their parents. These experiences of asking for, and receiving, help and support had informed how they felt about asking for further help.

- 'It is hard to know who to share what you are going through with'
- 'It's hard trying to speak with anyone from social services'.
- 'The process of identifying what an individual needs in the care package felt impersonal. It felt like following a process, 'we will try this and if not move to the next tick list'.'
- 'My mum has two neighbours that call in on her, they are my eyes and ears and alert me if something is wrong. One is very nosey but that works well for me'.
- 'I think admitting how you feel to someone is hard, especially as your friends aren't going through it so they don't understand so you don't talk about it'
- 'I keep trying to find out what is available, people tell you about things but then I spend a morning ringing around and I end up back at square one'

All of the carers that asked for help in recent weeks, talked about reaching a 'crisis point'. This crisis point was the catalyst to a third party helping make the introduction to a carers organisation.

- 'You tell yourself you are ok, but you realise you aren't. I went to the doctor saying I needed help for my Mum as her dementia is getting worse. But it came to a crisis point for me. Carers don't realise how much they are doing'.
- 'During Covid we were all ill. Luckily I developed a good relationship with my parents GP and she realised how desperate times were so she alerted an emergency respite team'
- 'Until my GP got involved, I found it very stressful. Once you get the support, then you get into the system. You can be lead through the whole team, frailty team, mental health team and all the others.'

Carers were able to reflect on the barriers that they had faced, and suggest some ways to overcome them.

- 'The professionals need to be prepared for this. They should be telling you all this and have a list. They need to make sure that they are prepared to identify true carers within the community and they can signpost people to the right place.
- 'Just knowing what is available and how you can go down certain routes. People say you can do this and that, but it's finding the time to sit down and find what is available... if there was just one resource that is fairly easy to use like flow charts or bullet points. If you could follow the flow chart and then ask questions'
- 'I think information for employers about if you are a carer how that impacts you as a member of staff. I think that would be beneficial. I think employers should be given information about supporting staff members who are carers'.

What did we learn from staff working with carers?

We spoke to five staff who worked for the commissioned carers organisations in Kent. We wanted to explore from their perspective what barriers they felt carers had in asking for help.

Concern about how the Cared for will react

This was the most frequently mentioned reason that put carers off asking for help. The cared for may be unwilling to accept that they have an illness or that they need any sort of help and support, and the carer can then worry that bringing in support will cause arguments and / or distress.

- ‘I found with some clients that they will accept the help. They have a 3 hour visit. But then the cared for spends the next 24 hours being very awkward, getting upset and throwing a tantrum. So carers won’t then accept another break as the cared for makes it so hard for them.’

The second most common barrier that staff found was that carers felt like they should be able to cope. That they felt guilty about not being able to cope and this prevented them admitting to needing help. There is a fear of being judged.

- ‘You feel guilty asking for help even if you work in the business, you give help to other people but not yourself. I got to the end of it and was exhausted coming to work and yet I still didn’t ask for help, I felt like I was wasting someone else’s opportunity’
- ‘I think it is a privacy thing sometimes. They don’t want people coming into their homes and finding intimate details about them. Sometimes they are independent and don’t want people to know that side of their lives’.

The third common issue is that carers worry they will lose control. Their loved ones might be taken from them and put into full time care, or that they will lose control of what happens next and people coming and going in their homes and the loss of privacy.

- ‘There is some embarrassment as well. They apologise and say sorry it’s not ‘him’. Or they are embarrassed about their house, because it might not be clean, they didn’t have time to Hoover so that can put up a barrier.’

Financial concerns

Many carers worry about the financial impact of having care provided.

- ‘People worry that if they need local authority support, they may have to sell their home to pay for the care fees. Also when an adult child is living with a parent, fear over where they will live if their parent goes into full time care and that they will be forced to move out so the house can be sold’.

A range of other barriers were also suggested

- ‘The longer they are carers, the less they recognise it. You don’t think of being a carer and until someone sits you down and ask how you are feeling. Then they click that they don’t have any time for themselves. Need to give people acknowledgement that they are important’
- ‘Sometimes I think that people in the older generation are worried about having services in especially if they haven’t had good services before, or their friends have had a bad experience. They feel quite vulnerable’.
- ‘Not knowing who to ask for help or what help they can ask for’

Staff talked about the emotional impact they see for carers when they first get a chance to talk to someone about what they have been coping with.

- ‘During the carer assessment, the majority of carers cry as it is the first time that they have spoken about the impact it is having on them. The realisation that they have suppressed for so long the feelings they have and feared were wrong. They feel like they have lost their husband, mother or father, and they are no longer a wife or a daughter, just a carer.’

Staff suggested some ideas that could help to overcome some of these barriers:

- All staff talked about doing activities within the community. There were mixed views as to whether this approach really worked with some saying that ‘usually the only ones who come up are the ones who already have got support from you already’
- ‘Being clear that the aim is to make life as easy as possible for both the carer, and person they care for, to continuing living how they want to live and that the support is just to help them to maintain this’.
- ‘Greater recognition of Carers and the support they provide amongst professionals’
- ‘Local GP surgeries advertising the services of the carer organisations works well for us’
- ‘I think the terminology of carer needs to be reviewed. When you do the assessment people don’t realise that they are a carer. I think terminology is a big barrier.’
- ‘We have done talks in hospitals and we come along and talk to people. People do come up to us and ask for information and guidance’.
- ‘We do a lot of local radio stations, especially during Carers Week’.



Conclusions

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

- Analysis of social media activity
- Data from a survey of people who contacted Kent Carers Matter 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. The staff newsletter, although still a faceless contact, was possibly seen as a trusted link from an employer and thus elicited a greater response than the social media posts.

2. The design and wording of social media adverts can be tailored to resonate with target groups. Emotive language elicited greater reactions in both males and females and all age groups. Men are more likely to react to a task based approach.

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 Kent. 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:

- Carers feel a sense of duty, resignation, and endurance about finding themselves a carer for a family member.
- People do not identify themselves 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.
- People have low expectations of what care is available based on previous experience of looking for help, or on the experience of friends.

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.

Once in the ‘system’ people said “I know everyone has said speaking to the right people is vital but very difficult to achieve. But once you have the route and access in, I have nothing but applause for them. But getting to the right person is the key’.

What are we recommending?

1. Carers organisations, and any other organisation wishing to reach unpaid carers, should use the insights and identified barriers in this report to inform their future advertising and promotional materials. Organisations should be brave in talking about barriers and stress points that carers experience, using emotive and contextualised content, and highlighting what support could be available.
2. Carers organisations continue the great work they are doing in developing relationships with other professionals and raising awareness of the need to recognise carers and be a proactive first point of contact for people who may never have considered themselves a carer. In particular, to review GP practices use of Carers Registers, create material for GPs to raise awareness of what a good conversation with a Carer should look like and key trigger points to consider initiating a carer focused conversation with patients and their loved ones.
3. Carers organisations to revisit and refresh previous work done to encourage large employers in Kent to consider carers within their workforce but to also explore opportunities to open up routes of employment for carers.
4. Carers organisations to offer people a ‘no strings’ awareness session, exploring the known pressures on carers and myth busting the barriers to help seeking behaviour. This could be an information session to empower people to ask for help as and when they feel they need it. This could be in the form of webinars, chat rooms or face to face sessions delivered in GP surgeries, or community centres.
5. Healthwatch and Carers Organisations to work together and share this report with national Carer’s organisations and the Regional Carer Manager at NHS England and NHS Improvement. Working from within GP surgeries, use the report to raise awareness of the barriers faced by carers and the impact that GPs can have in identifying and helping to support a hidden carer.

Thank you



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