



Support for carers campaign

Focus groups report

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Executive summary

The Communications Service plans to run a campaign to encourage carers to access the support available to them. The Corporate Research and Intelligence Team was commissioned by the Communications Service to help understand how to promote the support available. Focus groups were held with carers who are in contact with local carers' centres. The groups were held in Preston, Accrington and Garstang in July 2012.

Key findings

The main findings from the focus groups were:

- Getting people to identify themselves as a carer is important in getting people to access the support available to them. Most participants didn't immediately see themselves as a carer, and so weren't looking for support, because they felt that looking after their loved ones was just part of being a family.
- There was concern that there is a stigma for some people in accessing support for carers for a number of reasons. Participants felt that some people are too proud to ask for support, are afraid that they will have to reveal a lot of personal information, or think that asking for support will mean they then have to involve social services for example.
- Participants found out about the support available to them as carers through a number of sources. Several participants had seen leaflets or posters for their local carers' centre, and a couple of participants said they had been contacted directly by their local carers' centre. Many participants found out about support available through word of mouth.
- Participants felt that finding information about support available to carers is currently difficult and participants' knowledge of the support available, even though they are in contact with the carers' centres, was not good in all cases.
- Participants pointed out that, as carers, they come into contact with a number of professionals, for example GPs and social workers, who would be ideally placed to signpost carers to support. Most participants found that the professionals were focused only on the cared for person and didn't make the link to offer support for the carers.
- Participants agreed that sessions where they could get together with other carers at the carers' centres are very important to them with some saying it is the most important support they receive.

- Once participants had accessed the carers' centres, they then got further information about support available to them through, for example, the centre newsletter or through talking to other carers.
- A number of participants noted that extra resource may be needed to support any extra carers that this campaign identified.
- Participants felt that the campaign should help people identify themselves as carers by, for example, listing the sort of activities that carers may do for the person they care for or the sorts of issues that the cared for person may have.
- Participants felt the campaign would be most useful if it directed people to a central hub of information about the support available for carers.
- Participants suggested using local radio and television if possible, as well as posters and leaflets for the campaign. They felt that visual materials should be placed where many people are likely to go on a regular basis, for example supermarkets or GPs surgeries.
- A number of participants suggested promoting the campaign through schools and colleges to target young carers.
- Participants pointed out that the word 'carer' can be confusing as some people think it refers only to paid carers. Some participants suggested that using the terms 'support' or 'look after' rather than 'care for' or 'carer' would help to avoid this confusion.

Recommendations

- If it is not already available, look into the possibility of creating a central hub of information about the support available to carers. Investigate the possibility of using Help Direct to deliver this.
- Work with professionals, for example GPs, hospitals, social workers, to see if there are ways to target carers directly and signpost them to the support available for them as soon as possible once they become carers.
- Consider developing a campaign that helps people identify themselves as a carer and then directs them to information on the support available to them.
- Consider running two campaigns, one specifically for young carers.
- Ensure that the resources are available to support the extra carers that this campaign might identify.
- Consider doing some further research with carers that aren't in touch with carers' centres.

Introduction

The Communications Service plans to run a campaign to encourage carers to access the support that is available to them.

This research was commissioned by the Communications Service to help it understand which aspects of support are most important to carers and to gain a greater insight into effective channels and messages to promote the support available to carers.

Research objectives

The objectives of the research were to understand:

- how carers currently receiving help found out about the help available;
- what aspects of the help available are most important to carers; and
- how we could promote the help available to other carers.

Methodology

To satisfy the objectives, three focus groups were held with carers currently accessing support through carers' centres. Focus groups are effective in exploring perceptions, feelings and motivations, making them ideally suited to this project. In addition, focus groups, by their very nature, encourage discussion and debate among participants.

Participants were recruited directly by the carers' centres. Focus groups took place at:

- Preston Carers' centre, Preston – 12 July
- Carers Link, Accrington – 17 July
- Croston House, Garstang – 19 July

Between eight and thirteen participants attended each session. Participants represented a broad mix of demographics and included male and female participants, a range of ages (from around 35 upwards), and white and BME participants. Participants also had a variety of caring responsibilities including: couples who care for each other, people who care for their partner, people who care

for their teenage or adult children, people who care for other family members or friends.

Limitations

The nature of focus groups, and indeed qualitative research in general, means that only a small number of respondents from the population in Lancashire can participate. This means that the focus groups do not offer results that are statistically representative for all carers in Lancashire; they only offer indicative or illustrative results. Results are therefore attributed to participants only and not the wider public.

The advantage, however, of focus groups is that they can explore issues and perceptions in detail, so a wealth of quality, descriptive information can be obtained, which was ideally suited to the needs of this research.

All participants were recruited through the carers' centres. The views of carers who wouldn't want to engage with carers' centres, but may be interested in other forms of support available, are therefore missing from this report.

Main research findings

Finding out about support for carers

Almost without exception, participants said they now realised they had been a carer for a time before they identified themselves as a 'carer'. Many felt that, because they were caring for members of their family, they didn't count as a carer and were just doing their family duty.

"It's highlighting that because it's your husband or your parents, you are still a carer. It's not just your responsibility to look after them. That's how I felt – he's my husband, I've been married for 40 years, he's my responsibility" – Accrington

"I was looking after her [daughter], making sure she took her meds, taking her to the hospital when she self-harmed. I considered this a normal looking after somebody, I didn't think of myself as a carer" – Garstang

Participants found out about the support available to them as carers through a number of sources. Several participants had seen leaflets or posters for their local

carers' centre, and a couple of participants said they had been contacted directly by their local carers' centre although they were unclear how the centre had got their contact details. Many participants had found out about support available through word of mouth. There was general agreement in the groups that finding information about support for carers is not easy.

"This is how we find these things out [by talking to each other]" – Accrington

"It's lacking between finding that you are a carer and finding the support" – Preston

A small number of participants had been signposted to the support available to them by professionals, for example their GP, a social worker, advisers at Jobcentre Plus. However, most participants felt that professionals could do more to let carers know about the support available. A number of participants felt that often the carer's needs are forgotten about, as many professionals are focused on the needs of the person who needs care, and it is not until the carer becomes ill that they are told that support is available. In particular, participants felt that social workers should carry leaflets about the support available to carers in order to pass this information on when they come into contact with carers.

"Every social worker, when they go see somebody, should have cards for the carers' centres" – Preston

"The professional people should be able to pass that on" – Preston

"There are carers packs in hospitals but often they're not well promoted" – Accrington

Participants suggested that, when someone has been diagnosed with a condition that may mean they need extra care at home, an effort should be made by professionals to see if someone is providing care for them and to signpost the carer to support available.

"Really you need it as soon as the person is diagnosed" – Preston

"I think you need to start with the medical profession who are supposed to be caring for their patients – they do not pass anything on" – Garstang

Importance of available support for carers

Participants were asked what support for carers they are aware of. The list given by each group was extensive but knowledge of each type of support by individuals was variable with many participants saying they hadn't previously heard of something mentioned by someone else.

All participants felt that being able to attend sessions at their local carers' centre was the most important support they received.

"It's nice just to be able to talk to other people. A lot of time you come out and think 'what am I worried about? It's hard but he has it a lot worse than me'. There's always somebody worse off than you" – Preston

"A centre like this is a respite for me. When I meet these people, I know I'm not alone....slowly we become friends....a centre like this is pivotal for the carers to come in and talk" – Preston

"I think one of the most important things that you're asking about is the support from each other. You're not on your own" – Accrington

Once they had accessed support at the carers' centres, most participants found out about other support available to them through the centre newsletter or through talking to other carers at the centre.

However, while participants feel the carers' centres are vital for their support, a number of participants said that they felt attending the centres is not appropriate for all carers, for example for carers that live in rural areas and would need to find someone to care for the person they care for in order for them to attend the carers' centre.

"For people who [don't have extra support], how can they go and make use of these things? There's a big gap" – Garstang

"You'll find as well that if you live like I do in [a rural area] the nearest centre is in [your nearest city]. A lot of the carers within our area won't travel...Nobody ever says 'we'll give you help towards looking after whoever it is and pay for a taxi'" – Accrington

Participants also pointed out that not everyone would be interested in attending sessions at the carers' centres because of worries about having to talk about their situations in more detail than they would like or fear that they would then be 'hassled' by social services. Participants also felt that there is stigma attached to asking for help and that some people may be too proud to look for support.

"Some carers may feel like you're prying on their ability to care for the person you're caring for...we hear it time and time again that 'are they looking at whether I'm capable of looking after that person'...especially with social services" – Accrington

"I was speaking to my neighbour and saying 'you know, you're a carer'....he goes 'oh I'm not being bothered with all that and social services'" – Garstang

"The cared for person thinks they're going to be taken away" – Accrington

In one of the groups, participants felt that promoting the financial support to carers would be useful as, while people may not want the more emotional support that groups at carers' centres could provide, they may be more interested in practical support such as claiming carers allowance, accessing various discounts and so on.

"Financial aid – that would draw people in wouldn't it? If you're going to have to give your job up you want to know what's out there for you" – Accrington

A number of participants made the point that the carers' centres would need increased resources to adequately support extra carers that may try to access the centres on the back of this promotional campaign.

"Will you be able to cope with all this influx if more people come?" – Accrington

How to promote support to carers

Messages to use

Participants were asked what messages should be used to promote the support available to carers and, in particular, to people that perhaps hadn't identified themselves as carers.

A number of participants said they felt that previous promotions that they had seen which used the phrase 'are you a carer?' wouldn't be effective as many people do not see themselves as carers. Suggestions of a better phrase to use were 'do you care for someone else?' or 'could this person survive without you?'

"At the moment it just says 'are you a carer?' and you say yes and walk past"
– Accrington

Participants pointed out that the word 'carer' can be confusing as some people think it refers only to paid carers. Some participants suggested that using the terms 'support' or 'look after' rather than 'care for' or 'carer' would help to avoid this confusion.

In order to help people see themselves as carers, participants suggested using a list of typical things that a carer may do for someone else, for example 'do you help someone to dress each day? Do you help someone out of bed each day?' Alternatively, participants felt that a list of conditions that the person cared for has might also be useful, for example 'do you look after someone with: mental health problems, mobility issues, Alzheimer's.....'

"Are you caring for someone who's ill? Somebody who has mental health problems or physical needs? Did you know there's help available?" – Garstang

"Find the points that identify exactly what a carer is – do you do this for somebody? Do you do this? Make it clear that it doesn't matter whether it's a relative or whatever" – Garstang

Participants felt that, for visual campaign items, it would be useful to show the lists as a series of images in order to make the poster/leaflet more eye-catching and to cut through language barriers.

A couple of participants pointed out that care must be taken with this approach as, if the list isn't exhaustive, it may mean people who are carers but don't happen to do an activity on the list think that they aren't entitled to the support. For example, one participant felt it was important to avoid using images of the cared for person in a wheelchair as this may exclude carers of people without mobility issues.

"The problem is when you have a lot of 'invisible carers' that you can't visibly see something, there's no wheelchair....people don't always see a disability if you're deaf for example...It's going to have to be something that is broader... otherwise you'll get people saying 'well am I a carer then? He [the person I care for] isn't in a wheelchair'" – Accrington

Participants felt it would be most useful to promote where carers could go to access information about support, for example encouraging them to contact their local carers' centre, rather than trying to promote specific examples of support.

"It needs concentrating where a carer can get at the information instead of a bit from there, a bit from there – it's bitty all over the place....need a hub of knowledge where you can go" – Garstang

In order to also meet the needs of people who wouldn't be able to or interested in accessing support through a carers' centre, a number of participants also felt it would be useful to promote financial support available to carers.

Participants felt that the campaign should make it clear to carers that they are entitled to support and to get in touch in order to access the support. Some participants felt it was important to include a website for information as well as an email address and telephone number as some people wouldn't want to take the step of making a call while others wouldn't have access to email.

"[You] need a website – I wouldn't ring a number, commit myself to a telephone call" – Accrington

A number of participants felt it would be useful to include a slip on any leaflets produced for people to provide their contact details and give permission for the carers' centres to contact them.

"Maybe there should be a form, an acknowledgement slip or something, that if you know they're a carer you get them to sign to say it's ok for Carers Link or LCC to contact them. That breaks the barrier down of them having to come in [to the centre]" – Accrington

In the Accrington group there was some discussion about how many hours a week you had to be caring for someone in order to be classed as a carer and be able to access support. This may be worth considering when deciding who the campaign is targeted at – is it just people who are doing a certain amount of caring?

Other messages that participants felt it would be useful to get across in the campaign are:

- that it doesn't matter if the person you look after is a family member, you are still a carer;
- that the person you are caring for doesn't have to be living with you;
- that you can be working and still be a carer;
- that you don't have to wait until you are at breaking point to get support; and
- that you are just as important as the person you care for.

One group felt that it was important to make clear (generally, not just in a campaign) which organisations were providing funding for support.

"That's another point – we don't actually know that it's Lancashire County Council that's doing them [funding/providing support]. We talk about the Time 4 Me fund and it's just the Time 4 Me fund. You'd look more favourably on social services if you knew that [LCC] were doing those things for you" – Accrington

Channels and locations

Participants felt that visual methods such as posters and leaflets should be used to promote the service. Using radio was also suggested although it was pointed out that

not all local stations covered the whole of the county and so a number of local stations should be used to make sure the message reached all districts.

Locations suggested for posters and leaflets were GP surgery waiting rooms, pharmacies, dental surgery waiting rooms, supermarket notice boards, libraries, on bus shelters and on the sides or backs of buses. Participants also suggested advertising in local papers, particularly in the free papers that are distributed to all houses.

"You'd either be taking the person you're caring for to the doctors or going to the doctors yourself" – Preston

"[They need to be] somewhere social which everybody uses at least once a week. Have big posters or leaflets in supermarkets" – Garstang

If funding allowed, participants felt that using television would be a good way of promoting the support available, perhaps using promotion on local news or making use of TVs in GP surgeries, post offices and pharmacies.

"Television has brought awareness with this 'When I'm 65' series ...perhaps televisions your best medium" – Accrington

Some participants also felt it would be useful to promote the support available to carers through the internet.

Other ways of promoting support for carers that were suggested were through Help Direct and through the job centre as people may have had to give up work in order to provide care and so may be seeking information on benefits available to them.

Some participants suggested that support for carers should also be promoted in schools and colleges to target young carers.

"Another thing is schools and colleges because we have young carers. They sometimes carry that burden for years and years and years before they manage to speak up to say they are a carer for parents" – Accrington

Conclusions and recommendations

Key findings

The main findings from the focus groups were:

- Getting people to identify themselves as a carer is important in getting people to access the support available to them. Most participants didn't immediately see themselves as a carer, and so weren't looking for support, because they felt that looking after their loved ones was just part of being a family.
- There was concern that there is a stigma for some people in accessing support for carers for a number of reasons. Participants felt that some people are too proud to ask for support, are afraid that they will have to reveal a lot of personal information, or think that asking for support will mean they then have to involve social services for example.
- Participants found out about the support available to them as carers through a number of sources. Several participants had seen leaflets or posters for their local carers' centre, and a couple of participants said they had been contacted directly by their local carers' centre. Many participants found out about support available through word of mouth.
- Participants felt that finding information about support available to carers is currently difficult and participants' knowledge of the support available, even though they are in contact with the carers' centres, was not good in all cases.
- Participants pointed out that, as carers, they come into contact with a number of professionals, for example GPs and social workers, who would be ideally placed to signpost carers to support. Most participants found that the professionals were focused only on the cared for person and didn't make the link to offer support for the carers.
- Participants agreed that sessions where they could get together with other carers at the carers' centres are very important to them with some saying it is the most important support they receive.
- Once participants had accessed the carers' centres, they then got further information about support available to them through, for example, the centre newsletter or through talking to other carers.
- A number of participants noted that extra resource may be needed to support any extra carers that this campaign identified.
- Participants felt that the campaign should help people identify themselves as carers by, for example, listing the sort of activities that carers may do for the person they care for or the sorts of issues that the cared for person may have.

- Participants felt the campaign would be most useful if it directed people to a central hub of information about the support available for carers.
- Participants suggested using local radio and television if possible, as well as posters and leaflets for the campaign. They felt that visual materials should be placed where many people are likely to go on a regular basis, for example supermarkets or GPs surgeries.
- A number of participants suggested promoting the campaign through schools and colleges to target young carers.
- Participants pointed out that the word 'carer' can be confusing as some people think it refers only to paid carers. Some participants suggested that using the terms 'support' or 'look after' rather than 'care for' or 'carer' would help to avoid this confusion.

Recommendations

- If it is not already available, look into the possibility of creating a central hub of information about the support available to carers. Investigate the possibility of using Help Direct to deliver this.
- Work with professionals, for example GPs, hospitals, social workers, to see if there are ways to target carers directly and signpost them to the support available for them as soon as possible once they become carers.
- Consider developing a campaign that helps people identify themselves as a carer and then directs them to information on the support available to them.
- Consider running two campaigns, one specifically for young carers.
- Ensure that the resources are available to support the extra carers that this campaign might identify.
- Consider doing some further research with carers that aren't in touch with carers' centres.