



Preliminary research amongst carers to inform and shape a new expert carers-type programme

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Executive Summary

This report details market research commissioned by the Expert Patients Programme Community Interest Company (EPP CIC) to inform the development of Caring with Confidence. A survey of 1,084 carers and six detailed group discussions was conducted with carers by Waves, an independent research consultancy, during February, March and April 2008.

The findings set out in this report begin by describing the current issues facing carers (Section 2) and then exploring the opportunity of a new programme for carers in terms of what information carers want to know more about (Section 3), and what they have experienced in the past (Section 4). Reaction to the idea of Caring with Confidence is explored (Section 5) followed by ideas and strategies for maximising its success (Section 6). Finally, we set out the key conclusions and implications of implementing a programme (Section 7).

Overall the data challenges many assumptions about carers. In particular, it should not be assumed carers:

- see themselves as carers
- have an interest in the umbrella notion of carers' issues
- want information or believe they need help
- are open to the general notion of support
- are seeking or respond to the broad concept of kinship from other carers
- are familiar with existing carers organisations (national or local)

This research has also shown that much of the vocabulary in this arena is extremely loaded. This includes both key words (eg 'carer', 'training' and 'skills') and providers of carer support (eg social services). As a result, how we communicate to carers will need careful consideration.

Strong interest in the idea of caring with Confidence is evident from almost one in five of all carers increasing to one in four for those caring 21-49 hours and one in three for 50+ hours. Further, the research tested nineteen topics and all were thought very or extremely useful by at least one in five carers (21%). This demonstrates that a programme offering a relatively wide portfolio of topics should be sustainable.

Interestingly, the perceived usefulness of possible topics is different to past provision and considerable opportunity exists for both general topics (eg confidence building & dealing with benefits/healthcare systems; looking after yourself & balancing with family/work) and specifics (eg dealing with loss & caring near the end of life; dealing with psychiatric/mental illness). Appeal for most topics was strongest among those caring 21-49 hours. Furthermore, past participation in some kind of training, self awareness and acceptance of their own caring situation, all lead to greater interest from carers. All of this highlights that precise targeting and focus will be critical.

There is considerable evidence in the research that the initiative should be set up on the basis of a 'hot spot model'. A series of local events (not based in town centres), covering a range of topics (c10-15) and repeated on several occasions (run 3 times) is necessary for this initiative to be successful. It is critically important that Caring with Confidence is not spread too thin to be effective. Without local critical mass, any provision would be seen as a series of one off events and will lack the cohesion of an overall initiative. The idea must be 'rolled out' on this basis; with the number of hot spots developed according to the overall number of carers intended to be reached.

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1. Introduction

1.1 Background

The Experts Patients Programme Community Interest Company (EPP CIC) is the lead administrative organisation in a consortium of collaborative organisations¹ who were awarded a contract by the Department of Health (DH) to deliver an expert carers programme (ecp) across England. In January 2008 Waves (an independent market research consultancy) were commissioned by the expert carers programme, now known as Caring with Confidence, to provide an independent objective assessment of carers' views so that strategy and planning for a skills and knowledge programme for carers would be based on robust understanding of their requirements.

1.2 Research Objectives

The overall objective of this research can be summarised as:

“to provide research and consultancy to EPP CIC and its collaborative organisations in order that all planning is based on objective input and a robust understanding of both carers and existing training provision.”

More specifically, the project sought to address the following:

- Understanding issues from a carers perspective
- Understanding a carers perspective on training
- Existing training provision from a carers perspective
- Future product definition from a carer's perspective
- Reaction to the proposed ecp proposition
- How to maximise appeal

1.3 Research Method

A mix of qualitative and quantitative methods were used to address the overall objectives.

Qualitative Research

Qualitative research was chosen to allow issues to be discussed in depth and with creativity. Group discussions allowed us to adopt an exploratory approach to issues of concern.

Six group discussions were held with a range of carers in late February/early March 2008; two each with full time carers (50+ hours per week), part time carers (20+ hours week) and occasional carers (up to 20 hours per week). These were conducted in London (Harrow), Oldham and Nottingham and led by an experienced moderator. Groups followed an unstructured open format according to an agreed topic guide. All groups were moderated by Andrew Vincent from Waves.

¹ Carers UK, Crossroads Caring for Carers, Partners UK and The Princess Royal Trust for Carers.

This report uses respondent verbatims to illustrate how views and opinions are expressed. Note that any quotes included are purely for illustrative purposes, key differences, where they exist, are highlighted in the main body text of this document.

Quantitative Research

To give numeric ranking and perspective, and a degree of statistical accuracy, quantitative research was used alongside the qualitative work. A survey of 1,084 carers was conducted on line to provide measurement of current behaviour, attitudes, beliefs and levels of interest.

Carers were recruited at random from a market research 'Access Panel'² and defined according to the question used in the census namely:

Q. Do you look after or give any help or support to family members, friends or neighbours or others because of: long term physical or mental ill health or disability or problems related to old age?

The research took place in England and was designed to be representative by regional population. Each survey took c15 minutes to complete.

² Access Panels are large databases of consumers (c100,000+) used by the market research industry to enable cost effective online surveys to be carried out

The sample achieved is summarised below.

Table 1: Sample Profile Achieved			
Gender:		Household Income	
Male	42%	Under £15,000	17%
Female	58%	£15-£19,999	17%
Total	100%	£20-£29,999	20%
		£30-£39,999	14%
		£40,000+	16%
		Total	84% (16% refused)
Age:		Ethnic Heritage	
18-35	15%	White	77%
35-44	20%	Asian	11%
45-54	25%	Black	4%
55-64	21%	Chinese	1%
65-74	17%	Mixed	3%
75+	3%	Total	96% (4% refused)
Total	100%		

2. Setting the Scene: What is the Current Situation

Before we could assess reaction to the ecp idea it was necessary to understand the perspective from which carers react. This section looks at carers current situation; what it is and what it feels like.

2.1 Overview of the Caring Role

Almost half (46%) those surveyed were caring for a parent (including in-laws), 21% a partner, 18% a friend, 12% another family member, 11% a child and 6% a sibling (including in-laws).

Not surprisingly, occasional carers are greater in number and 35% of our sample cared for up to 7 hours per week and 30% 8-20 hours. A further 14% cared for 21-34 hours and 7% 35-49 hours with 13% caring for 50+ hours.

Generally, those providing care for more hours were more likely to be women and less likely to be working. However, even among those providing 50+ hours care per week, one in five was working full time. Interestingly, occasional carers, those providing up to 7 hours per week, were a majority (60%) male. The table below gives more details.

The last column in the table indicates the average age of the person cared for. This analysis tells us that occasional carers are more likely to be caring for older people and that overall the average age decreases as the time commitment increases. Interestingly, those caring 35+ hours per week (whether 35-49 or 50+ hours) show the greatest similarity on all measures.

Time spent caring	% female	% working full time	Ave age of person cared for
50+ hours/week	63%	20%	54
35-49 hours/week	65%	26%	55
21-34 hours/week	58%	31%	62
8-20 hours/week	47%	40%	65
Up to 7 hours/week	40%	31%	70

There was a significant variation regarding the length of time people had been carers. Whilst the overall average was 5.3 years, 25% had been caring for at least 10 years and 10% for no more than one. In broad terms, the length of time spent caring increased in line with the weekly hours:

- Average of 6.3 years among those 50+ hours per week
- Average 6.7 years if 35-49 hours
- Average 5.5 years if 21-34 hours
- Average 5.0 years if 8-20 hours
- Average 4.8 years if up to 7 hours

Carers were asked the extent to which their health impacted their situation. Firstly, 60% said their own health impacted their ability to care; 15% said it impacted a lot and 45% a little.

Furthermore, across the total sample 62% felt that their caring affected their health; 16% 'a lot' and 46% 'a little'. This considerably increased with caring commitment rising to 84% if caring 21-49 hours per week (27% 'a lot' and 57% 'a little') and 85% if caring 50+ hours per week (41% 'a lot' and 44% 'a little').

2.2 What Does it Feel Like?

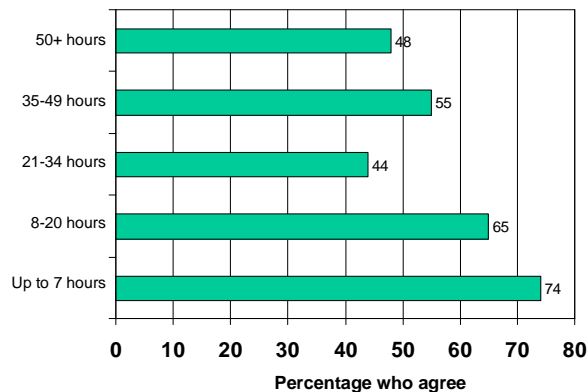
2.2.1 Underpinning Attitudes

The research has given great insight into how carers feel about being a carer. Firstly an examination of underpinning attitudes shows that **62% of all carers do not actually consider themselves a carer**. This is a highly significant finding and has major implications regarding how to communicate with this audience. Table 3 highlights the level of agreement with several statements presented to respondents in our online survey. This shows that whilst many carers accept they can't know everything, significant numbers admit to feeling poorly informed and feel the support available is not the right kind of help.

Table 3 Underpinning Attitudes	
Statement	% who agree
I don't really think of myself as a carer	62
There is so much to know carers can't know everything	61
I feel poorly informed about the person I care for	36
The support available is not the right kind of help	34
Support is available but I don't have time to access it	25
There is already a lot of support for those in my situation	24
Total	#
Base: 1084 carers	
# Multi-response possible	

The following chart illustrates how those who do not consider themselves a carer varies according to the hours spent caring each week. Significantly, almost half (48%) those caring 50+ hours per week do not consider themselves a carer.

Who Does Not Consider Themselves A Carer?



Base: All 1084 respondents

This issue is best summed up by the carer who said...

"How are you their carer? You are their daughter."

From the qualitative element it was clear that carers see themselves fulfilling many different roles as the example quotes below illustrate.

- Carer as Lover: *"I don't like to call it carer. I like to call it unconditional lover."*
- Carer as Free Labour: *"As long as you're doing your job the Government don't care or give you anything."*
- Carer as Prisoner: *"It's getting very difficult, he's getting very obsessed about me, he wants me to be with him 24 hours a day. I feel like a prisoner. He thinks I'm going to run off and leave him.....it's like a mental torture!"*
- Carer as PA: *"It's like you have to do a secretary's job to find out what you can do for them. You have to phone round so many places and you are passed on and passed on. So its tension for us."*
- Carer as Human Being: *"I don't think of myself as a carer I just help my mum."*
- Carers as No one: *"Yourself disappears into the caring role."*

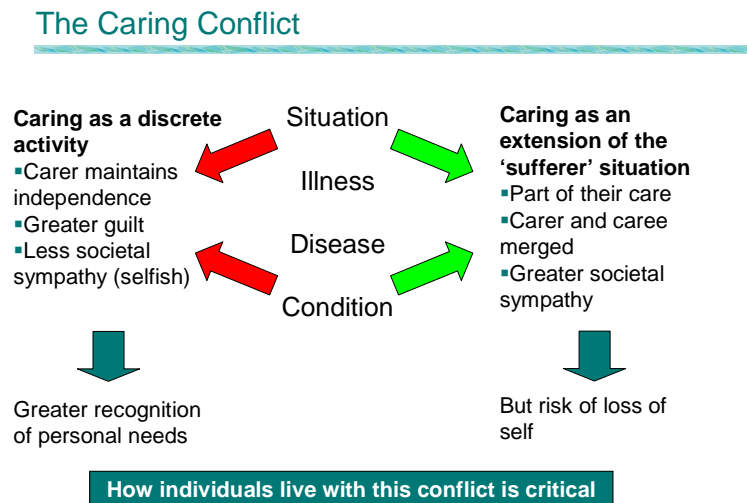
Further, because these carers are fulfilling a variety of roles they are experiencing considerable role strain.

2.2.2 The Caring Conflict

From the debate in the group discussions it was evident that carers have a conflict between the needs of the person they care for and also recognising their own needs as a separate individual. We would conclude that the carers' ability to separate these two roles determines both their current behaviour and their reaction to the new ideas that we tested.

The following chart illustrates the caring conflict. Those who can recognise their own needs (the left hand side) tend to be more emotionally independent from the person they care for and have a greater recognition of their own personal needs. However, they tend to articulate more guilt and experience less societal sympathy with their situation. In contrast, (the right hand side) there are those carers who see their caring almost as an extension of the 'caree' and their situation. Here the carer and caree become merged and there is a risk of loss of self for the carer. However there was greater societal sympathy evident for these people.

The reason why we believe this is such an important analysis is that those carers who see themselves as more discreet have a greater awareness of their own strengths and needs and were more open to the idea of ecp-type training. Hence how carers live with the conflict highlighted is critical. But this raises the issue as to how we reach those carers who see themselves as caring as an extension of the 'sufferer' situation.



2.2.3 Societal Image of the Situation

It was very clear from our discussions that how others relate to you and your situation as a carer is critical. From talking to carers in a diverse range of situations we could see that the level of sympathy they experience from society varies considerably.

The greatest sympathy is for what we would call the **classic medical conditions**. These diseases are not seen as part of the natural order and society views the impact of cancer, heart disease, stroke, etc as tragic. There are several features of these diseases that make the situation different for carers:

- They are medically easily defined
- They are more widespread and therefore more people the carer interacts with have experienced them (eg benefits agency staff)
- The support available is most highly rated (eg Macmillan nurses) so there is less interest in anything new

All of this means that carers experience is less negative and more sympathetic as this comment from someone whose partner had cancer illustrates:

“benefits staff were fantastic; they sat me down and I told them my story and they just filled it all in.”

The next carer group that was evident was those we term **part of the natural order**. These are situations where the caree is considered to be ageing, rather than ill although they may have an illness. Characteristics of this situation are:

- Caree is not thought to be ill, as one carer said: *“my mum is 91, she has to die of something.”*
- Less sympathy from society, this situation is sad but inevitable (and not tragic)
- Carers are more likely to be occasional
- Most carers in our survey in this situation (67%) did not see themselves as a carer; just looking after dad!

The greatest level of acceptance appeared to be from carers in these situations.

The third group identified were carers dealing with situations around **mental illness**. These carers encountered considerable problems with society and in many cases found it harder to be a carer than in either of the above groups. Here unique features were:

- These illnesses are not as well understood by society
- Medical care is not as good as for the ‘classic medical conditions’
- Considerable prejudice exists towards these illnesses

All of this makes the role of carer even more stressful.

Probably the toughest situation in which to be carer appears to be for what we have termed **socially nebulous situations**. This would include a wide range of conditions, syndromes and difficulties; for example ADHD, Aspergers, ME, etc. Here carers find that:

- The situation is less well known
- There is much less sympathy from society
- More of a fight to get an accurate diagnosis (and in some cases to even prove they are suffering from something)
- In our survey a greater proportion of carers in these situations were caring for a child

Unlike those in the ‘classic medical condition’ these carers feel a constant struggle to prove their situation valid and this can have a devastating impact on carers self esteem. A typical comment from a carer of someone with Aspergers or ME was that:

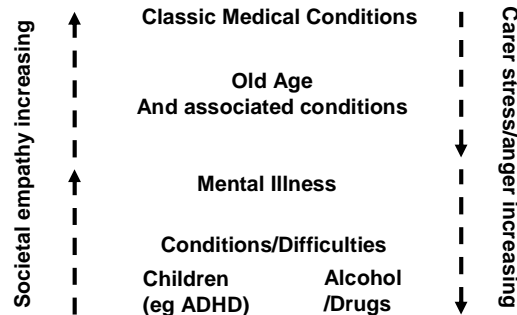
“we are constantly trying to get what we are entitled to.”

There are two key subgroups that are a subset of this last group. Some of the issues around children are particularly difficult. For example those caring for a child with ADHD talked about not being taken seriously and, even worse, could be seen by others as having a poorly behaved child who is assumed to be healthy. Similarly those caring for someone with alcohol or drug dependency felt that society did not take them as seriously. These conditions were often thought to be self-inflicted and again they encounter much less sympathy as a result.

In general, those carers in this latter group have a very different experience compared to those at the opposite end of our spectrum; the classic medical conditions. Any provision of services, such as the proposed ecp-type 'training' should take these differences into account.

The diagram below summarises the different situations we found.

Situation Impacts How Carers Feel/Are Treated



2.2.4 Carers Emotions

In listening to carers stories and discussing the issues in the group discussions we experienced many powerful emotions from carers. In particular, as the following illustrate, there was considerably negativity:

- Anger: *“I found myself getting really angry and went to an outreach team. I went to one of their meetings for carers and it was useless. I don’t want to sit and listen to other people’s stories. I don’t want to know about your 3 year old and how it is for you. I couldn’t care less. Tell me about autism, the spectrum and the illness. I haven’t got time to read all this.”*
- Despair: *“If you fill in forms without help (eg from the CAB) then you might as well piss in the wind.”*
- Drowning: *“At the age of 10 I had this diagnosis dropped on me like a brick”*

Whilst these emotions are not particularly unexpected it was very clear that they create significant barriers to considering any new concepts. Indeed for some carers, these barriers are insurmountable and while they feel so emotive they are unlikely to seriously consider any new idea.

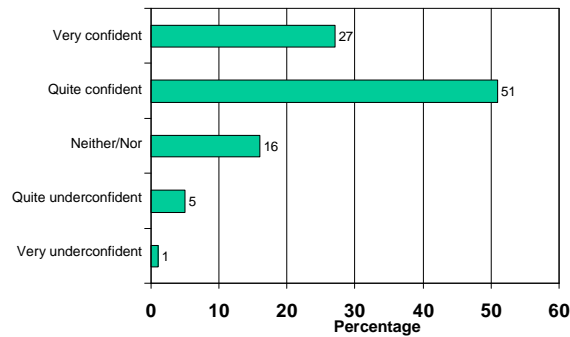
Interestingly, as carers move towards acceptance of their situation they appear more receptive to new ideas. As the examples below illustrate, carers can acknowledge when they have reached acceptance and we feel this is a key stage for them to become open to any new initiative.

- *“It takes two years to get up the learning curve.”*
- *“It (acceptance) is making the most of how she is at any given moment.”*
- *“I think it was four years into the illness that I really understood it and realised that we weren’t going to return to normal.”*

2.2.5 Carers Confidence and Knowledge

Respondents to our online survey were asked to rate how confident they felt in their caring activities and only 1 in 4 described themselves as 'very'.

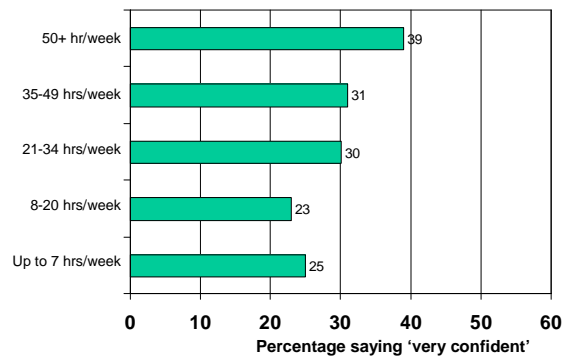
Overall Confidence



Base: All 1084 respondents

Interestingly, those caring 50+ hours per week were the most confident, although the differences between those providing up to 7 hours (25% very confident) and 35-49 hours (31%) were not particularly significant.

Overall Confidence: By Hours Spent Per Week

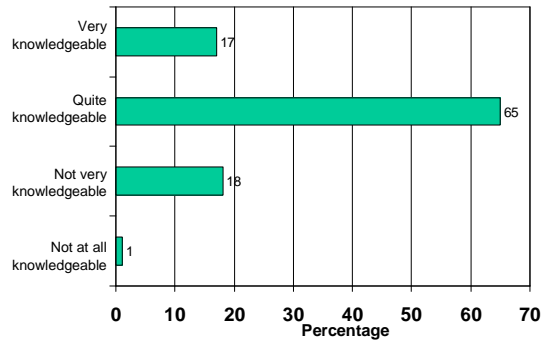


Base: All 1084 respondents

Confidence was highest among those aged 18-44 (44%) and lowest for those aged 45-54 (24%) and 65+ (23%). Most significantly, carer confidence showed no relationship to household income.

The survey also asked how knowledgeable carers felt about the support and care they gave; and even fewer carers described themselves as very knowledgeable.

Carers View Of Their Knowledge



Base: All 1084 respondents

We feel it is interesting that carers' confidence exceeds their knowledge and believe this difference is probably down to the fact that much caring is about a human response to someone you care for, and this is more important than necessarily being knowledgeable about the situation. Most of all, however, this data demonstrates the scope for carers to become both more confident and knowledgeable.

3. Information Needs: The Opportunity

3.1 Attitudes to Information

Qualitatively, attitudes towards information already available for carers which is already available appear polarised. A small minority felt quite happy with information but many more felt either under informed (or even uninformed) and many others felt overwhelmed; as these comments illustrate:

"It's difficult to have the time, the head and the space to read all there is."

"There is too much information. You can get too much. I say 'can you cut through the butter.'"

"I have a friend who has time and finds stuff out for me on the internet. I feel quite emotional about it. I don't know where I'd be without her; she has mentored me through all this."

Many carers talked about the need for sifting information and finding the relevant nuggets.

There was a strong desire for specific information and carers talked about how such information could make them feel more confident.

"It gave me confidence knowing that I had the specific information I needed regarding the wellbeing of the person, and how to react and deal with the anger which would sometimes be displayed."

However, as we explored this further it became clear that many carers want information, advice and support that is totally unique to them. Examples of this are as follows:

"(I would like) an interview to discuss the needs of the person I care for so they could structure a programme of training to suit my needs."

"I wish someone could come into our home and live with us and see where I'm going wrong and see what they could do to help."

This is a key finding as it highlights that although many carers are in similar situations their needs are actually very different. A good example of this might be those caring for someone who had a stroke. Two carers looking after someone who had a stroke 10 months ago might (on paper) seem to be in a similar situation and yet one may be caring for someone who can walk unaided but cannot speak while the other could be caring for someone living with a wheelchair but perfectly able to have a conversation. Any future provision must take into account such vastly different personal situations. Carers feel that currently they can be patronised by (well intentioned) communications that oversimplify their situation or draw unrealistic comparisons to others in the 'same situation'.

3.2 Timing of Information

In the group discussions we asked carers when information would be most helpful. Three distinct phases were identified.

Initial Phase

The initial period post diagnosis/realisation was thought very difficult. Here the carer is coming to terms with the situation. Often there is considerable contact with health care professionals and information focuses on critical information such as what is it, what are the implications, how to manage it, etc. Often carers talked about information overload during this phase; there is too much to absorb and often they feel left to flounder. Clearly, it would be inappropriate to target any new support during this time.

Accepted Phase

After a certain amount of time, carers achieve a degree of acceptance and enter what we have termed the acceptance phase. Typically this is after 1-5 years following initial diagnosis/realisation. Here carers become more confident; they talk about 'getting to grips' with the situation and 'having a hold on it'. Qualitatively carers appear more open during this phase. They are aware that they are on a learning curve and that even after a few years they are still learning and many feel their knowledge could be greater. We felt the interest in any support or service would be strongest at this time.

Confident Phase

After a certain amount of time, usually c5-8 years, carers become much more confident. They feel they know a lot about the situation (and in some cases everything). They rate their knowledge and confidence highly and many consider themselves experts, knowing more about their situation than any health care professional. At this stage, carers are less open to new support and any provision aimed at this group would need very careful targeting.

Although these three stages became evident it is important to appreciate that as circumstances change and new diagnoses emerge carers fluctuate between the different phases. In particular a carer from the confident phase could return to the initial phase when a new condition is diagnosed (eg because someone in old age develops Alzheimers).

3.3 Usefulness of Topics

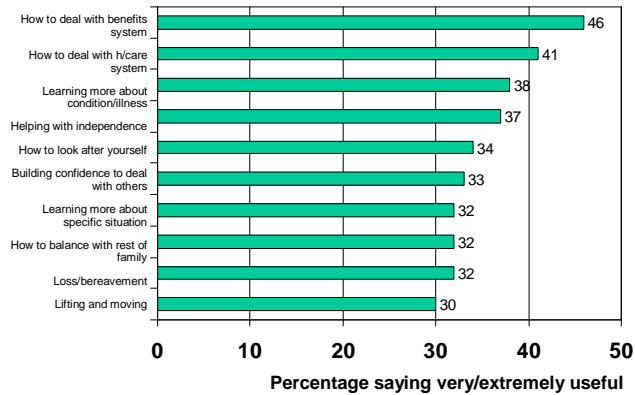
The most useful possible topics for any new support, guidance or advice to offer were thought to be how to deal with either the healthcare or benefits systems, described as very, or extremely useful for 46% and 41% of carers respectively.

Other potential topics thought at least 'very useful' by more than a third of carers were: learning more about the condition/illness (38%), helping with independence (37%) and how to look after yourself (34%).

The degree of interest with 19 different topics is shown on the following charts.

The most positively received topics were:

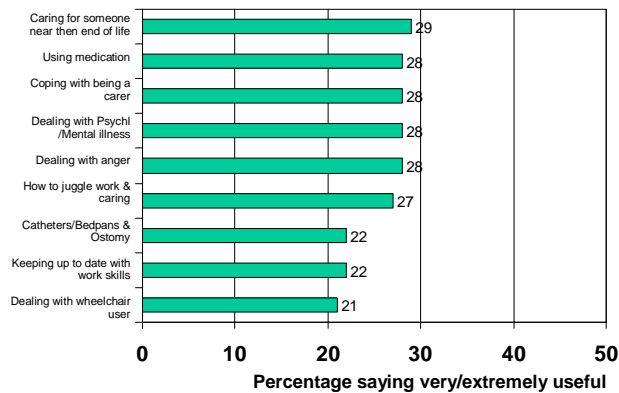
Usefulness of Potential Topics(1)



Base: All 1084 respondents

The topics with slightly less overall appeal are shown below (although all topics were of interest to at least one in five carers).

Usefulness of Potential Topics(2)

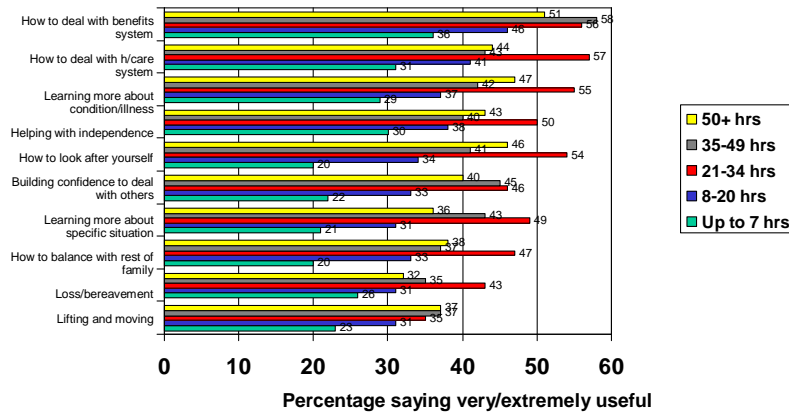


Base: All 1084 respondents

Interestingly, when we explored interest according to the number of hours cared for we found that those caring for 21-34 hours (often regarded as part time carers) expressed the most interest in almost all the topics. We feel this reflects the role strain for this group who are likely to be juggling caring with other activities and as a result appear more open to additional support and guidance. This is an important finding as it is often thought that those caring full time are most in need of support.

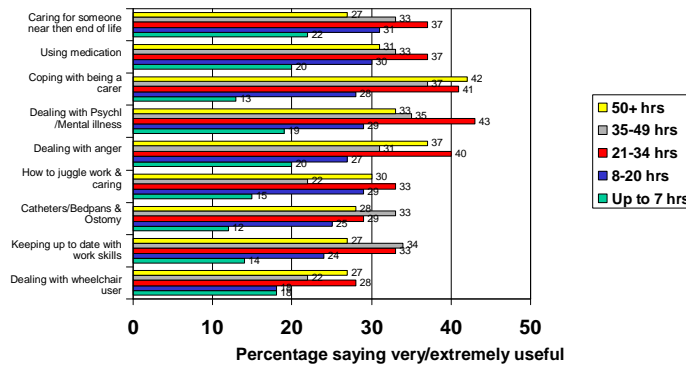
The charts below detail interest according to hours spent caring.

Usefulness of Potential Topics(1) According to how many hours caring



Base: All 1084 respondents

Usefulness of Potential Topics(2) According to how many hours caring



Base: All 1084 respondents

From this research we can, therefore, conclude that all the nineteen topics tested had appeal; all were thought very or extremely useful by at least one in five carers (21%). This demonstrates that a programme offering a relatively wide portfolio of topics could be sustainable. Finally, there was considerable variation in the appeal of topics according to the number of hours spent caring per week and appeal was greatest for those caring 21-34 hours. This suggests that any programme will need careful targeting and may need topics to be held at a range of different times of the day to maximise opportunities to attend

3.4 Past Experiences

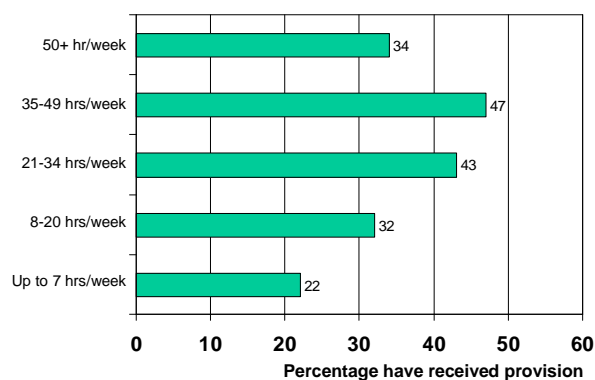
Participation Levels

In our survey, 31% of carers had in the past received advice, guidance or training to help them be better at caring; 21% in relation to the current caree and 10% for someone else. Interestingly this figure was higher for those caring for children (48%) and also for respondents who are of black and minority ethnic heritage (48%). Also, this figure was lowest for those caring for someone in old age (23%).

Interestingly, of all these people, over half (58%) felt that this provision could be called training. Thus training can be relevant terminology once a carer has experienced provision (although as subsequent findings from this survey show, it is not thought appropriate in advance of taking part).

As the chart below shows, past participation was highest for those currently caring 21-49 hours per week.

Past Participation Greater If Caring 21-49 hrs/week

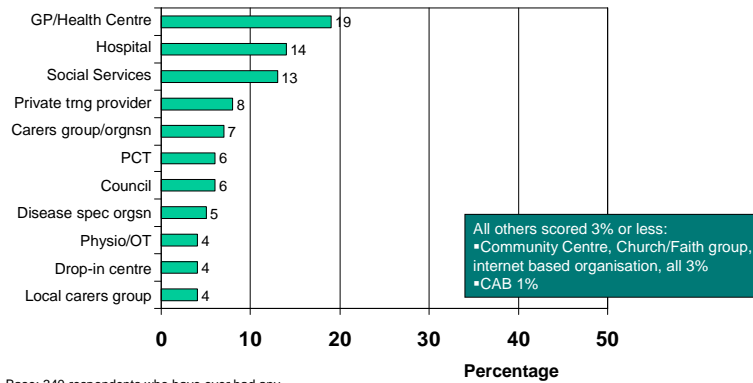


Base: All 1084 respondents

Providers of Past Provision

The chart below details what organisations provided past provision. Most commonly, provision came from healthcare providers eg GPs, health centres and hospitals.

Providers Of Past Provision

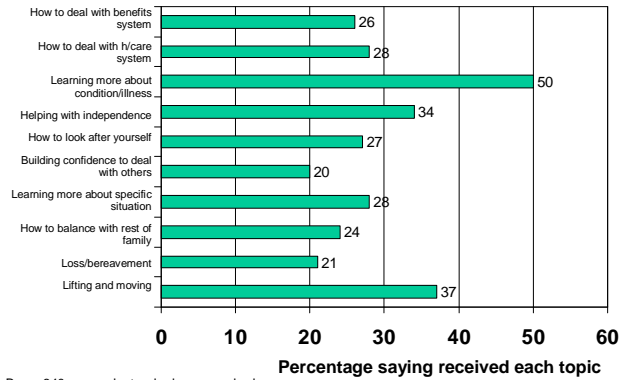


Base: 340 respondents who have ever had any advice/guidance/training about being a carer

Topics Covered

The following two charts set out which broad topics were covered by past provision. On these charts, topics are ordered according to perceived usefulness (as above). Significantly, the most commonly provided topics in the past were not those of most interest currently.

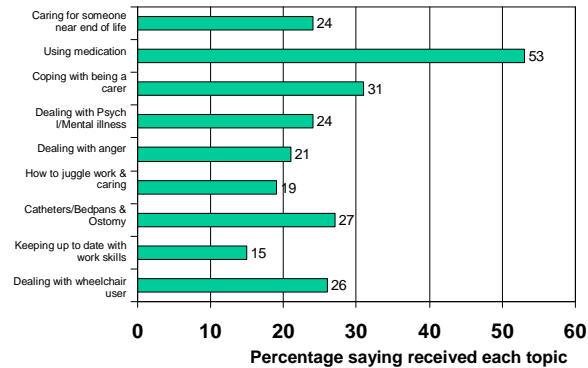
Advice, Guidance or Training Received(1)



Base: 340 respondents who have ever had any guidance/training about being a carer

Note: order above is same as 'usefulness' from earlier

Advice, Guidance Or Training Received(2)

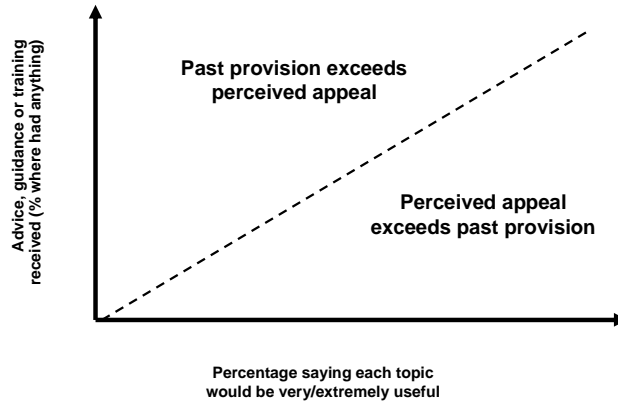


Base: 340 respondents who have ever had any guidance/training about being a carer

Note: order above is same as 'usefulness from earlier'

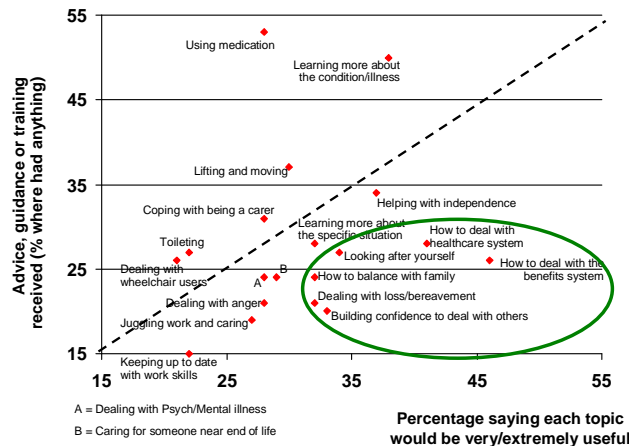
3.5 Appeal vs Past Provision

Appeal vs Past Provision



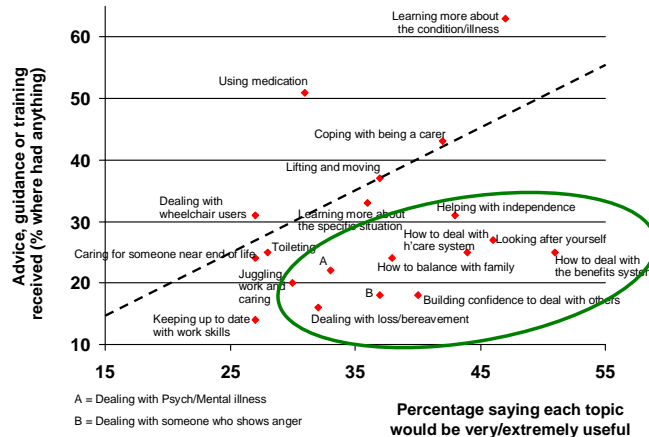
By comparing appeal of topics with past provision we were able to identify for which topics past provision exceeded current appeal and for which appeal exceeded provision. Thus, those topics in the lower half of the graph below would appear to offer greatest potential.

Appeal vs Past Provision (1) Total Sample

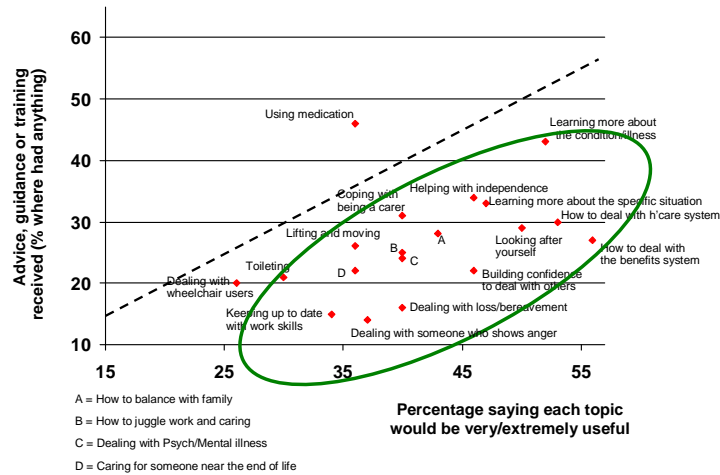


The next two charts show the same analysis according to hours spent caring per week, and, as the second graph shows, there appears to be a greater opportunity among those caring 21-49 hours compared to those spending 50+ (as evidenced by there being more topics below the diagonal).

Appeal vs Past Provision (2) Those caring 50+ hours per week



Appeal vs Past Provision (3) Those caring 21-49 hours per week



4. Execution of Past Provision

Those carers who had experienced past provision of advice guidance or training about being a carer (340 respondents) were asked in detail about how it was delivered and what they thought of each component.

4.1 What was Delivered?

The most common delivery, all experienced by more than 20%, were informal discussions with experts, one off events and courses with several sessions. Interestingly, only 8% had participated in a course run by other carers. The full list is as follows:

- Informal discussions with experts 27%
- One off event/session 26%
- A course with several sessions 21%
- Advice by telephone 18%
- Talks from experts 16%
- Regular meetings with others in a similar situation 16%
- Materials on the internet 12%
- A course run by experts 11%
- A work book to work through at home 10%
- Role playing 9%
- A course run by carers 8%

4.2 Rating of Provision

Provision that was given the highest performance rating was not necessarily those that were most commonly experienced. Indeed courses run by experts and by carers (both experienced by no more than one in ten) achieved the highest satisfaction ratings, with over half very satisfied. The full list in descending order of satisfaction was:

- A course run by experts 54% very satisfied
- A course run by carers 50%
- Regular meetings with others in a similar situation 50%
- Talks from experts 48%
- A course with several sessions 41%
- Informal discussions with experts 34%
- Advice by telephone 28%
- Role playing 28%
- Materials on the internet 27%
- A work book to work through at home 24%
- A one off event/session 18%

5. The Future Idea

In this section we report carers' reaction to the future idea for carer 'training'.

5.1 Reaction to the Proposition

All respondents, both quantitatively and qualitatively were shown the following neutral description of the core idea and asked their opinion.

A local free programme for carers across a range of subject areas such as financial and health issues and caring skills

In the group discussions, there was a reserved response. The words 'local' and 'free' were thought particularly interesting. Overall, however, carers thought the devil would be in the detail and typical responses were "*sounds promising*" and "*need to know more*".

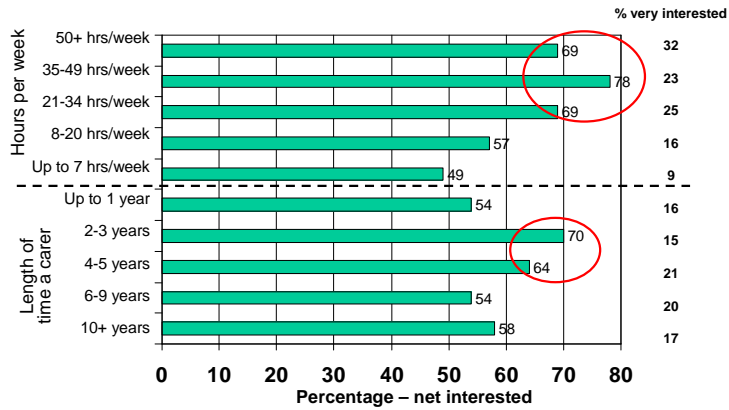
In our survey, 59% of carers said they were interested to find out more but only 18% described themselves as very interested (and 41% quite interested). One quarter (25%) described themselves as neither interested or uninterested and 15% uninterested to know more (8% quite and 7% very).

The overall level of interest increased significantly from 59% up to 78% for those caring 35-49 hours per week and 69% for those caring either 50+ or 21-34 hours. It was also higher for those who had been a carer for between 2 and 5 years (70% for 2-3 years and 64% for 4-5 years). The lowest level of interest was for those in their first year of being a carer and this confirms the qualitative phases of timing we identified in Section 3.2.

Level of interest to know more was also higher for carers aged 35-44 and those from households with an income of £40,000+. Finally, in our survey those carers describing themselves as of black and minority ethnic heritage also gave higher scores for interest (79% and 76% respectively).

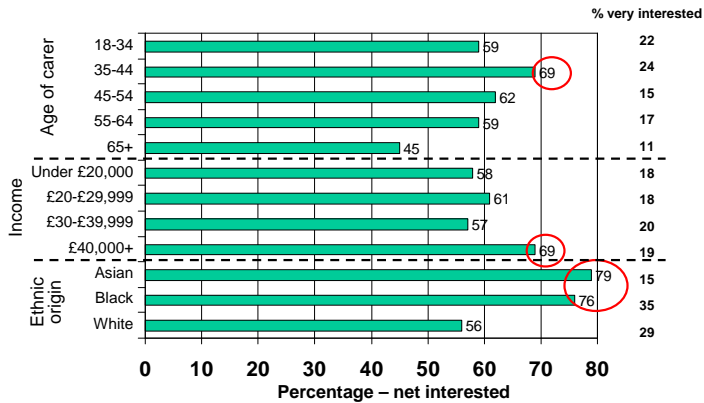
The charts overleaf give greater detail regarding the level of positive interest among different types of carers.

Reaction To The Core Proposition(1) Subgroups with most interest



Base: All 1084 respondents

Reaction To The Core Proposition(2) Subgroups with most interest



Base: All 1084 respondents

5.2 Positioning the Proposition

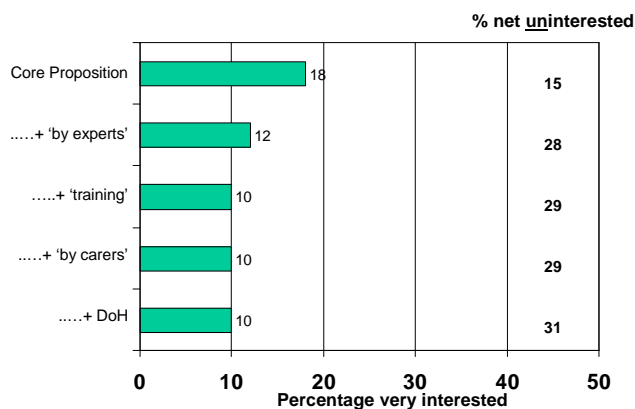
In our survey, the basic paragraph (see section 5.1) about a possible new service for carers was repeated but with several different enhancements as shown below. The purpose of this was to see if the appeal of the previous more neutral description could be enhanced by positioning the idea in a different way. The four enhanced statements were:

1. A local free training programme for carers across a wide range of subject areas such as financial and health issues and caring skills
2. A programme of support for carers delivered by carers. This will be a local free programme across a wide range of subject areas such as financial and health issues and caring skills
3. A national, Department of Health sponsored series of courses for carers. This will be a local free programme across a wide range of subject areas such as financial and health issues and caring skills
4. Help for carers from experts and specialist professionals. This will be a local free programme across a wide range of subject areas such as financial and health issues and caring skills

Thus, the different statements sought to position the idea as: 'training', 'for carers by carers', 'part of a national DH initiative' and 'involving experts and specialists'. The four different statements were randomised in the survey so each had an equal chance of being shown first etc.

In the group discussions these terms were explored qualitatively and it became very clear that each of these different terms was quite polarising. Some liked them more but others liked them less. This was confirmed in the survey and in each case when the new idea was described using any of the above statements, overall interest decreased with only around 1 in 10 now describing themselves as very interested. Furthermore the proportion describing themselves as uninterested doubled (from 15% previously to almost 30%). This is shown in the chart below.

Positioning The Overall Proposition



Base: All 1084 respondents

To further understand how the proposition should be developed we asked carers to imagine how they thought it would need to be described if they were to become interested. The verbatim responses below demonstrate how the concept would need to feel to participants.

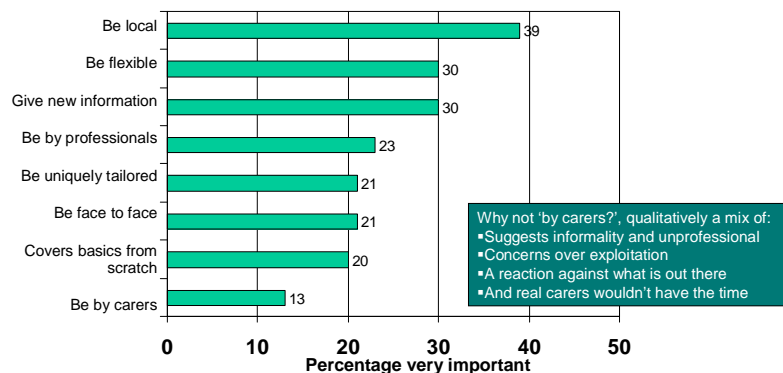
- *“informal”*
- *“not talked at”*
- *“for working people”*
- *“shared experiences”*
- *“someone my equal”*
- *“we need to feel valued”*
- *“learning from others not notes”*
- *“I don’t need comforting. I need me (and my situation) to be understood”*

Overall we believe there is a need for informed empathy; while generalised empathy is to be avoided.

Finally, in the quantitative survey we asked carers how important certain features were to any provision. As the chart below shows; being local, flexible and giving new information were thought most important of the features tested.

Being delivered by carers was only thought very important by 13%. This does not mean that this issue is viewed negatively, rather it demonstrates that this on its own is not enough and that fundamentally carers need to see the benefits of any provision (simply being run by carers does not make it valuable).

Developing The Proposition



Base: All 1084 respondents

6. Maximising Success

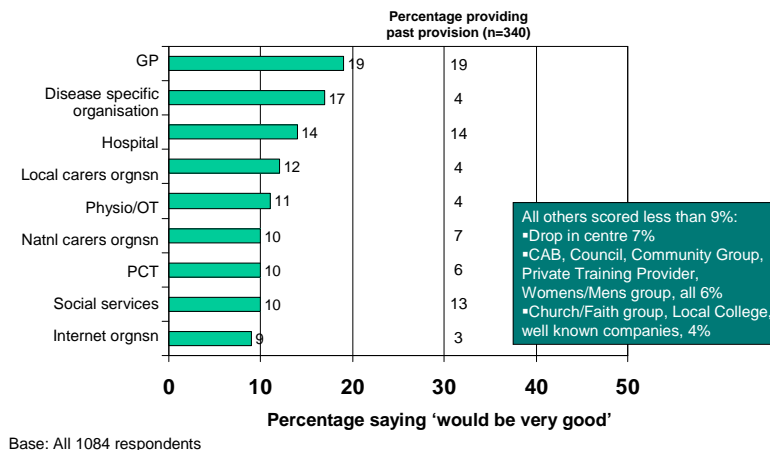
6.1 Delivery Credibility

In our research we explored the credibility of different delivery sources and respondents were asked how good they thought the idea would be if it were provided by certain organisations. Responses to our survey showed that provision via the GP/health centre was rated highest for 'would be very good' (19%); followed by a disease specific organisation (17%) and the hospital (14%).

We feel that this data does not necessarily suggest that the proposed new provision should be provided at a GP surgery or hospital. Rather, it indicates that carers become most engaged when the initiative is positioned as an extension of the overall care for the caree. Hence it is expected to be better, if at all related to GP or hospital care.

The chart below shows the full response to this question. In addition, it highlights where past provision was delivered (shown by the column of numbers on the right hand side). Significantly, this data suggests that both disease specific organisations and local carers organisations should have an enhanced role in the new initiative. Only 4% of past provision came from either of these sources yet the scores for 'would be very good' if provided by them, were 17% and 12%.

Credibility Of Who Might Deliver It



6.2 Bringing the Concept Alive: Other Organisations

Carers Organisations

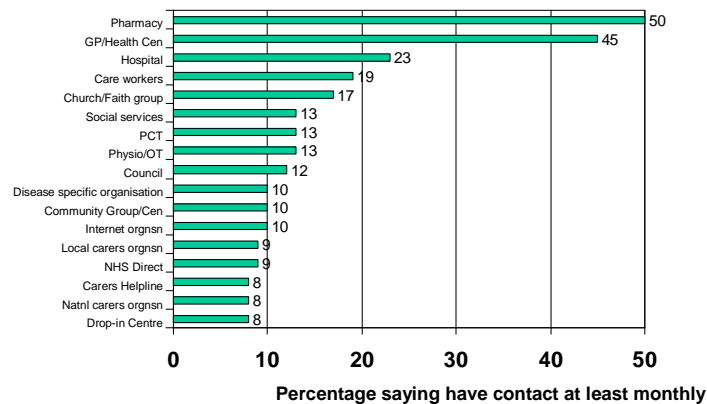
When asked about carers' organisations, respondents were more likely to name local organisations. However, when prompted in our survey, 48% of carers were aware of at least one of the national carers' organisations. Interestingly, this figure was highest for younger carers aged 18-34 (62%) and awareness decreased with age; 35-44 (55%), 45-54 (43%), 55-64 (45%) and 65+ (40%).

When asked specifically about key organisations, Crossroads was known by 26%, The Princess Royal Trust for Carers 23% and Carers UK 21%. Only 7% of this national sample said they were actively involved with any of these organisations.

Frequency of Interaction

In our survey we asked carers how often they interacted with a wide variety of organisations. Almost half of all carers had at least monthly contact with pharmacies and GP surgeries. These were followed by hospitals, care workers and church/faith groups. The full list of organisations contacted at least monthly is shown below.

Frequency Of Interaction With Organisations



An Interesting Analogy

Finally, in three of our group discussions the new concept was spontaneously likened to Weight Watchers or Slimming World. This was an interesting finding and we explored with these carers why they drew such a parallel. There were several key reasons; that it was a national initiative, provided very locally (my local church hall), the organisation behind it was clearly separate from the locations of delivery, these organisations make a sensitive issue relevant and those attending all have different situations to deal with. Finally, and perhaps most importantly, the local organiser is both a human face of the organisation and a lynchpin to execution.

6.3 The Hot Spot Model

In our groups we discussed with carers how they envisaged such an initiative might work; if it existed what would they expect it to be like? In the light of this discussion we believe the following is a realistic template:

- Provided in small groups (max c10-15) to encourage interaction
- Led by 'experts' with input from carers
- c10-15 topics provided locally (not in town centres) eg meeting space at a health centre, church hall, etc
- Each topic to be covered c3 times over 2 or 3 months so you can get to the most convenient date or catch up if you miss one (alternative dates can be a little further away geographically)
- Individuals would attend anything from 2 to 10
- Handouts to take home are valuable for some
- A coordinator very important (and for some critical)
 - A human face to the initiative
 - Someone running through the modules
 - Continuity from week to week and topic to topic
 - Someone to get back to with queries and follow up questions

All of this led us to conclude that this initiative should be set up within key hotspots in order that sufficient critical mass can be achieved at the local level. Without local critical mass, any provision would be seen as a series of one off events and will lack the cohesion of an overall initiative. The number of hotspots should be determined based on the number of carers the initiative is seeking to reach. What is critically important, however, is that it is not spread too thin to be effective.

7. Key Conclusions and Implications

Based on our research we drew the following key conclusions

Challenge Assumptions

Overall we feel the data challenges many assumptions about carers. In particular it should not be assumed that carers:

- See themselves as carers
- Have an interest in the *umbrella notion* of carers' issues
- Want information or believe they need help
- Are open to the *general notion* of support
- Are seeking or respond to the *broad concept* of kinship from other carers
- Are familiar with existing carers organisations (national or local)

Defining 'Full Time'

Those caring 35-49 hours per week, are in our opinion, more similar to those caring 50+ hours (than 21-34). Thus we don't feel it is fair to categorise those caring 21-49 hours per week as a 'part time' group. Further, it is clear that the emotional cost of caring is clearly not related to hours per week. Indeed for many, the more individuals have to juggle multiple roles (caring, work, family, etc) the greater their stress.

Loaded Vocabulary

Much of the vocabulary in this arena is extremely loaded. This includes both key words (eg 'carer', 'training' and 'skills') and possible providers (eg social services).

Appeal of the New Idea/Proposition

Strong interest in the core proposition is evident from almost one in five of all carers increasing to one in four for those caring 21-49 hours and one in three for 50+ hours.

The perceived usefulness of possible topics is different to past provision and considerable opportunity exists for:

General:

- Confidence building & dealing with benefits/healthcare systems
- Looking after yourself & balancing with family/work

Specifics:

- Dealing with loss & caring near the end of life
- Dealing with psychiatric/mental illness

Appeal for most topics is strongest among those caring 21-49 hours. Furthermore, past participation, self awareness and acceptance of the caring situation all predispose greater interest. All of this highlights that precise targeting and focus will be critical

A Hot Spot Model

In the light of the research we believed very strongly that the initiative should be set up on the basis of a 'hot spot model'. A series of local events (not held in town centres), covering a range of topics (c10-15) and repeated on several occasions (run 3 times) is necessary for this initiative to be successful. Thus, sufficient critical mass at the local level must be created and to succeed, the idea must be 'rolled out' on this basis; with the number of hot spots developed according to the overall number of carers intended to be reached.