GP Carers' Project

Final
Evaluation Report
May 2009

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CONTENTS

ACKNOWLEGEMENTS

EXECUTIVE SUMMARY

The executive summary provides a very condensed record of the principal aspects of the study, its findings, conclusions and recommendations. The full text which follows the summary provides more data and a wider, more comprehensive discussion of the issues which have emerged, set within contemporary research evidence.

SUMMARY INTRODUCTION
The evaluation of the GP Carer's Project was awarded to RE:search South-West at the University of Plymouth on 16th June 2008 by Westbank, in partnership with Devon County Council.   Ethical approval for the evaluation study was granted by the NHS Ethics Committee on 19th September 2008. The study was undertaken during the period from end of September 2008 to the end of February 2009.

SUMMARY STUDY DESIGN & METHODS
The study was in two stages, using mixed methods including questionnaires, interviews and focus groups, to gather quantitative and qualitative data from project surgery staff and registered carers as follows:

Stage I (**T1**) Data prior to project implementation   Sept/Oct 2008
Stage II (**T2**) Data following 6-months' implementation   Feb/March 2009

Data were collected via similar surveys undertaken at the start of project implementation (**T1**) in October 2008, and repeated six months later (**T2**) in March 2009 using the following instruments:

* **Surgery staff interviews**, using structured questionnaires.
* **Postal carers' questionnaire packs** as follows:
  General Health Questionnaire (GHQ), a 28-question validated tool
  Enhanced Carer Strain Index (CSI), a 13-question validated questionnaire
  Monitoring Form designed to gather demographic data
  Carers' Satisfaction Survey (CSS), a an 8-part locally-designed questionnaire
* **Carer focus groups** using a topic guide prepared in partnership with the evaluation project's Carers' Participation Group.

SUMMARY ACHIEVEMENTS
A more holistic approach
All sites have recognised the importance of taking a more holistic approach and have sought ways to develop a broader support and social focus to the interventions offered to carers, identified and presenting to the GP surgery.   A surgery-based champion for carers, the advice and support workers have continually reminded staff throughout the surgery to 'think carer'.

Systems links for carer and cared for
A major achievement of the advice and support workers in all pilot sites has been the establishment of robust 'read coded' systems for the identification and linking of carer and cared for. The needs of carers frequently lie in a 'grey area' where health and social care overlap. Their position is further complicated by the inter-

connectedness of the needs of the person they care for and their own needs. Some of the tensions inherent in this close inter-relationship are exemplified by the comments from the focus group participants who said that they 'felt invisible' and just wanted some recognition of their existence, which is facilitated by the electronic 'tags' now in use.

A face-to-face 'listener'.
GPs recognised the need for talking with carers but also acknowledged their limited appointment time for this more supportive intervention. In the focus groups, carers identified the importance of having a named person, such as the A&SW, with whom they could make direct contact, without having to 'bother' the GP. A personal contact, as opposed to a telephone call centre, was highly valued by those in the focus groups but did produce some concerns around the personal impact of the work for the A&SWs themselves and projects had begun to put arrangements in place for more support and clinical supervision.

Flexible consultations
All pilot sites had identified the need to provide a range of ways of accessing their services and the importance of offering a choice of times and location to carers, so that sensitivity to the needs of individuals and flexible ways of setting up a specific appointment or consultation was a priority for all A&SWs.

A local information 'hub'
The importance to carers of one central, easily accessible, 'hub' through which they can receive guidance, advice and information about what is available to them in their own locality cannot be over-stated. Carers felt most confidence and trust in services derived from the GP surgery and preferred this, as opposed to social services offices, as the conduit for access to sources of help. A particular strength of the A&SW role based in the GP surgery is the ability to deliver a flow of information and advice at times which are appropriate to individual needs and sufficient for the particular stage in the journey through caring.

Range of services
It was clear from even the few words that each carer used to introduce themselves at the beginning of the focus groups that carers cannot be regarded as an homogenous group. Carers need to be offered a wide range of different services which will not necessarily be taken up by all, but which might be needed by different people at different times. All project sites had established an 'information bank' about local resources for carers including those aiming to meet their needs in four specific ways:
- To relieve the pressures of care-giving, e.g. support groups and condition-specific information
- To assist with practical tasks e.g. aids and adaptations, laundry and domestic help
- To provide relief from caring e.g. sitting services, day care or respite
- To help carers get more from the care system eg. advice and information about benefits

Generally, sign-posing involved handing on a leaflet or telephone number to carers. Given more time, there is scope to develop the advocacy role of A&SWs included as one of the initial pilot project objectives.

SUMMARY RECOMMENDATIONS

Future developments to consolidate the services and ensure sustainability of the benefits are set out in the seven recommendations below:

Recommendation 1
Clarification of the role of the Advice and Support Worker, identifying a clear job description, linked to on-going training and support for the role.

Recommendation 2
Identification of a GP lead for carers' issues to develop a strategic 'whole team' approach in the surgery including reception as well as administrative and clinical staff.

Recommendation 3
Continuation of work to increase registrations by drawing on existing clinics, chronic disease registers and public health promotions to identify harder to reach individuals.

Recommendation 4
Prioritisation of carer and their role at an early stage, as part of the diagnosis in a cared-for patient's plan with three primary aims:
- to increase registrations
- to facilitate take-up of advice and information
- to target support services to those identified in the study as most at risk of experiencing damaging levels of stress i.e. women, aged 60 – 65, caring for a partner for 30 hours a week or more

Recommendation 5
Development of training and support for carers, particularly condition-specific information and groups

Recommendation 6
Improving information and communication between carers and the surgery through:
- Website updating to include a specific space for carers;
- Development and co-ordination of specific carer participation groups and forums to actively gather perceptions and views of carers for integration into surgery developments;
- Routine inclusion of carers issues on core group and practice meeting agendas.

Recommendation 7
Sustaining the A&SW posts and services in alternative ways:
- **Integrating the role into the workforce** by sharing the key tasks across a number of existing staff workloads and designing job descriptions to reflect opportunities for personal and professional development in leading and developing carers issues in the team.
- **Building on the success of co-located professionals** by creating a shared, jointly-funded post, for instance within a cluster group to reflect similar arrangements already in place for graduate mental health workers.
- **Adding specific elements of the additional carer checks to existing clinics or public health promotion appointments**

1.0 INTRODUCTION

The evaluation of the GP Carers' Project was awarded to RE:search South-West at the University of Plymouth on 16th June 2008 by Westbank, in partnership with Devon County Council. Ethical approval for the evaluation study was granted by the NHS Ethics Committee on 19th September 2008.

The study was undertaken during the period from end of September 2008 to the end of February 2009. It should be noted that there was late confirmation of an extension of the funding for project implementation from the end of March to the end of June 2009. However, due to contractual restrictions and reporting deadlines, the evaluation study was not extended beyond the period set out above. For the purposes of this report therefore, 'end of project' refers to the end of the period at which final data collections were undertaken, not the final closure date for projects at individual surgery sites.

An Interim Report was submitted by RE:search South West in January 2009 and this is the final project evaluation report, dated May 2009, prepared for the Implementation Group of the GP Carers' Project.

2.0 BACKGROUND

The background to the project lies in a range of government initiatives set out in Green and White Papers such as *Our Health, Our Care, Our Say*, *Every Child Matters*, *Independence, Well-being & Choice* and *Options for Excellence*, in which services should be person-centred; responsive to individual need; focussed on the maintenance of independence; and delivered at or near to home.

This evaluation forms part of a Devon-wide project, funded by the Department of Health for two years from 2007 - 2009, under the heading 'Partnerships for Older People'. The Devon project was delivered through a multi-agency partnership titled 'My Life, My Choice' (MLMC), including health and social care providers in both the statutory and voluntary sectors. The overarching objectives of MLMC included:

- Helping people to stay healthier
- Helping people to remain independent
- Reducing admissions to hospital or residential care
- Enabling people to design their own solutions
- Reaching excluded people

The broadest intention of these new arrangements has been to 're-design services to get better help more quickly to people who may need support and treatment' and to this end, one strand of the MLMC project considered specifically, the health and well-being of carers. Carers UK, a voluntary association providing a national 'voice' for carers, have highlighted a number of primary concerns including:

- Public health planning that explicitly addresses the prevention of ill-health amongst carers
- An active role for GPs in promoting the health of carers, eg. annual health checks
- Use of Carers' Assessments to address carers' health issues as a matter of course
- Promotion of a wider range of sources of information for carers

Following consultation across Devon with carers' networks and groups, four separate projects offering different approaches to achieving the overarching objectives of MLMC emerged as follows:

Project 1   Carers' Advice and Support Worker
Project 2   Carers' Health Checks
Project 3   Carers' Counselling Service
Project 4   Carers' Occupational Health Assessments

All GP surgeries in Devon were invited to nominate themselves for inclusion in the projects and from those self-identifying a willingness to participate, five surgeries or sites were selected to deliver the projects. Each site appointed a Carer's Advice and Support Worker, to a part-time post funded for one year. In addition, four sites also delivered, concurrently, one of the other three projects 2, 3 or 4 above, drawing on appropriate key professionals already in post or appointed on a part-time and/or secondment basis. A 'control site' was also identified for inclusion in the data collections, matched as far as possible (eg. demography; geography; size) with the site where Project 1 only was being delivered.

3.0 AIM

Reflecting earlier work in the region (Torbay Council, 2002), the evaluation project tracked the needs of carers in five GP surgeries, to identify the key elements of four pilot schemes that best support carers in their care-giving role and contribute to the maintenance of independence, health and well-being. Evaluation outcomes should also benefit the cared for person and provide key local and national stakeholders with evidence to enhance the effective targeting of treatment and support services (Bruckner & Yeandle, 2007).

For the purposes of this project, a 'carer' is defined as 'a person who looks after a family member, partner, or friend in need of help because they are ill or have a disability. The work they undertake is unpaid (Carers UK).

Summary of Study Sites

	Surgery A	**Surgery B**	**Surgery C**	**Surgery D**	**Surgery E**	**Surgery F**
Complex Care Team	North Torrington& Holsworthy	East Exmouth & Budleigh	East Exmouth & Budleigh	East Honiton & Ottery	South Teign Valley &S.Dartmoor	South Dawlish & Teignmouth
Additional Service	Health Checks	Health Checks	Advice & Support Worker only	Occupational Health	Counselling	None Control Site
Surgery Size Patient list at 01/09/08	**5223**	**3923**	**12578**	**16191**	**5300**	**12685**
Total expected carers: 10% NHS guideline	**522**	**392**	**1257**	**1619**	**530**	**1268**

4.0 STUDY DESIGN

Benchmark data, including the number of carers on the existing carers' register and the visits made to surgeries in the twelve months prior to project implementation, was sought direct from surgery staff as at 1st September 2008. The study itself was in two stages, using mixed methods including questionnaires, interviews and focus groups, to gather quantitative and qualitative data from project surgery staff and registered carers as follows:

Stage I (**T1**) Data prior to project implementation   Sept/Oct 2008
Stage II (**T2**) Data following 6-months' implementation   Feb/March 2009

5.0 DATA COLLECTIONS

Data were collected via similar surveys undertaken at the start of project implementation (**T1**) in October 2008, and repeated six months later (**T2**) in March 2009 using the following instruments:

- **Surgery staff interviews** were undertaken, face-to-face in each surgery setting, to gather information and perceptions of the projects and issues for staff in their management and implementation, using structured questionnaires.

- **Carers' questionnaire packs** were sent from each surgery by post to all registered carers with anonymous responses returned direct to the evaluation team. Questionnaires were as follows:

  General Health Questionnaire (GHQ) – 28 questions in four categories:
  ❖Physical difficulties ❖Anxiety/Insomnia ❖Social functioning ❖Mental health

  Enhanced Carer Strain Index (CSI) – 13 questions

  Monitoring form – to gather basic demographic data and details of services received from surgeries

  Carers' Satisfaction survey (CSS) – 8 questions in a locally-devised semi-structured questionnaire to gather information and perceptions about the projects and services received at the end of the evaluation study (T2 only).

- **Carer focus groups** were held for all those who responded to an open invitation to take part, although at T2, twenty one expressions of interest could not be taken up because groups had reached maximum capacity at three sites.

  A topic guide was prepared in partnership with the evaluation project's Carers' Participation Group. Focus groups aimed to gather in-depth perceptions, expectations and experiences of the implementation of each project.

Summary of data collections (T1 Start / T2 End of Project)

Category	Date	Method	Evaluation Tool	Total	Responses	Response Rate
T1						
Carers	09/08	Quantitative	Self-completed postal questionnaires	405	97	24%
Surgery Staff	10/08	Quantitative/ Qualitative	Structured face to face interviews	-	20	-
Carers	11/08	Qualitative	Focus groups	9	32	33%
T2						
Carers	02/09	Quantitative	Self-completed postal questionnaires	793	211	27%
Surgery Staff	03/09	Quantitative/ Qualitative	Structured face to face interviews	-	19	-
Carers	03/09	Qualitative	Focus groups	9	42	20%

6.0 FINDINGS

Themes extracted from the questionnaire, interview and focus group data have been gathered together under four broad headings and are reported in this 'findings' section. Their implications for surgeries, practice and further action are considered in more detail in the subsequent section headed 'discussion' which also draws on the main themes from the Interim Report for the Implementation Group in January 2009. Findings from the second data collections (T2) are reported below in the following sequence:

- Benchmark data - registrations
- The postal questionnaires
- The project staff interviews
- The focus groups

6.1   Benchmark data

Surgery staff were asked to provide monitoring data at three points from 1st September 2008 to 28th February 2009 in relation to carer registration numbers and the results for each surgery site are recorded below in Figure 1.

The chart demonstrates a substantial increase in registrations at all sites, compared with the control, with the highest level of activity occurring during the first quarter of

project implementation. A target population of carers expected in each surgery of 10% list size (Maher & Green, 2002) had been set at the beginning of the project and the 'potential' figures in the grid below relate to the percentage of achievement in each surgery against that target expectation.

Fig. 1 Number of Carer Registrations at Study Completion
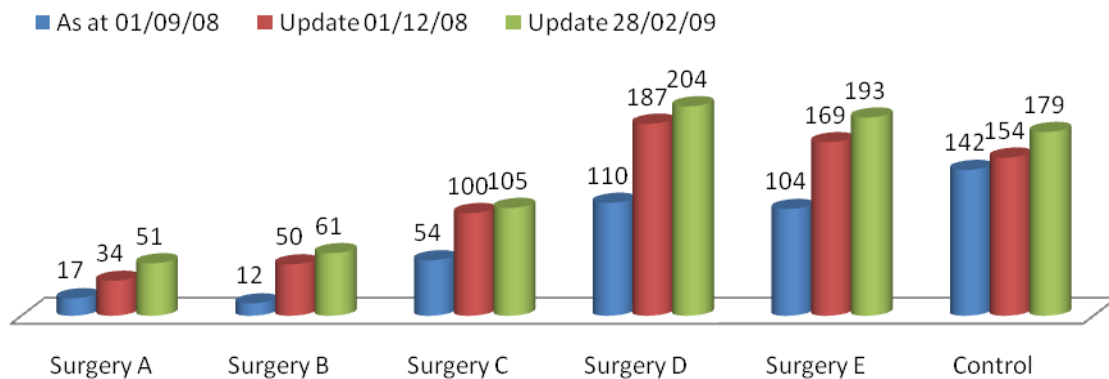
	Surgery A	Surgery B	Surgery C	Surgery D	Surgery E	Control
List size	5292	3945	12146	16145	5350	12686
Increase	300%	392%	107%	77%	74%	26%
Potential	1.3%	1.5%	0.9%	1.2%	3.4%	1.4%

6.2   The Postal Questionnaires for Carers

Packs were provided by the research team to be distributed to all registered carers as at February 2009 by each participating surgery. Surgeries generally added their own covering letter explaining their involvement and seeking carers' participation in the evaluation. Each pack contained an individual letter of invitation; an information sheet; and four questionnaires for self-completion with a freepost return envelope direct to the research team, as well as an invitation to participate in a local focus group meeting. Participants wishing to join a focus group were provided with a separate freepost envelope to return the response slip. In line with ethical approval, it is not possible to make any connection between questionnaires and focus group participants. Questionnaires were as follows:

- **Monitoring form**:   Used to gather demographic data such as age, gender, details of caring responsibilities and the sorts of services which carers considered they had been offered by participating surgeries during the six months of the project implementation.

- **General Health Questionnaire (GHQ)**:   An established and widely-used validated self-administered screening test designed to detect psychiatric disorders in primary care/community settings. It focuses on the psychological components of ill-health using four sub-scales: somatic health; anxiety and insomnia; social dysfunction and severe depression (Goldberg, 1978). It is not measuring long-standing problems but rather responding to how much someone feels that their present state is unlike their usual one.

- **Modified Carer Strain Index (CSI)**:   is a 13-item questionnaire originally developed in the early 1980s to screen for caregiver strain after hospital

discharge of an elderly family member.   The Modified CSI is a validated and reliable instrument and is a useful method for detecting strain levels among informal caregivers.   It is easily administered and scored

- **Carer Satisfaction Survey (CSS)**: is a locally devised 8-item, semi-structured questionnaire developed in consultation with the Carer Participation Group to elicit information and perceptions of services received during the course of the study. The questions comprised a mix of numerical responses together with space for individual comments in response to open questions.

6.2.1 Response rates
793 pack were distributed through participating surgeries and 211 packs were returned by final deadline (23/03/09). This represents a 27% response rate which is in line with normal expectations in a self-completed postal questionnaire survey of this type. Responses are recorded in Figure 2 below.

Fig. 2 Participant responses by surgery (T2)

| Response % | 6% | 4% | 10% | 43% | 13% | 24% | Total 100% |
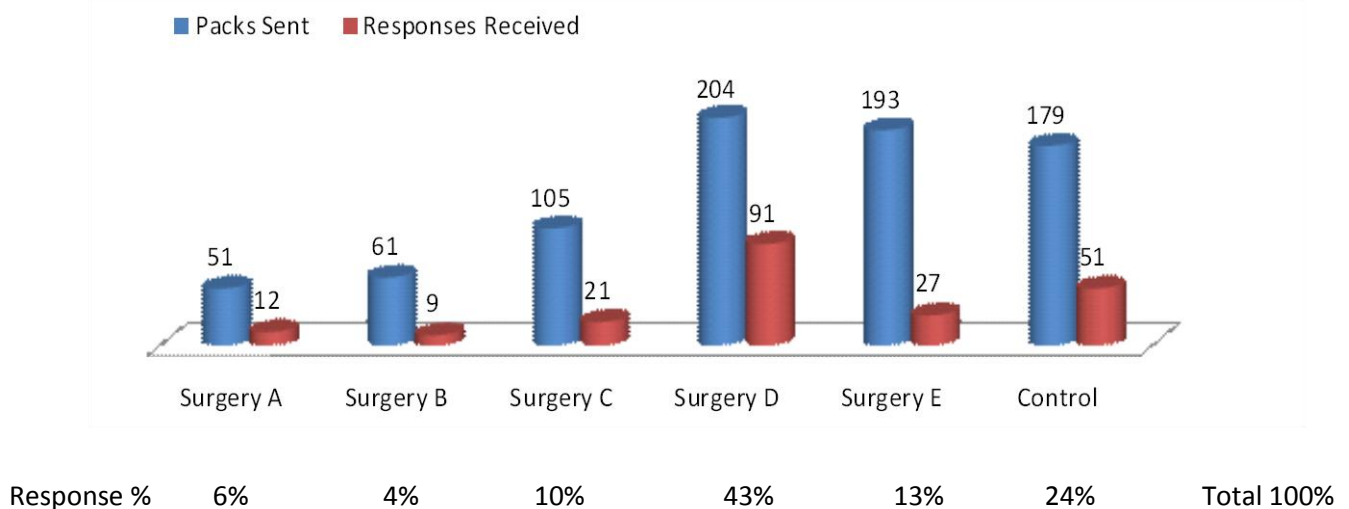
6.2.2 Demographic data – monitoring forms
Basic characteristics of the study sample gathered from the monitoring forms are recorded below. Respondents in February 2009 fall into two categories – those who were registered and responded to both surveys at T1 and T2 (Feb 09 All) and those who only responded at T2 (Feb 09 Only).   Figure 3 therefore records data for three 'types' of study respondent.

To explore the 'representative' nature of our study sample in relation to the national picture, we have drawn some basic characteristics from the General Household Survey or census undertaken by the Office of National Statistics in 2000, as reported by Maher & Green (2002), for comparison.   Our sample comprises an older population of carers, more of whom are women, who are already retired and who are caring for a partner, than in the general Census.

Fig. 3 General characteristics of the study samples

		Census 2000	All Registered Carers	Oct 08 All	Feb 09 All	Feb 09 Only
				T1	T2	T2 New
Responses		-	793	97	211	159
Gender	**Men**	39%	32%	33%	29%	29%
	Women	61%	68%	67%	71%	71%
Age	**Under 50**	74%	17%	11%	12%	14%
	60 – 64		16%	17%	22%	24%
	70+	19%	41%	36%	37%	37%
Registration Date	**Pre 2007**	-	-	66%	46%	37%
	Jan – May 2008	-	-	9%	18%	20%
	June – Dec 2008	-	-	25%	27%	30%
	Jan – Feb 2009	-	-	-	9%	13%
Relationship to cared for	**Parent**	52%	-	26%	27%	26%
	Partner/Spouse	18%	-	58%	60%	61%
	Child	8%	-	7%	8%	7%
	Other relative		-	3%	4%	4%
	Friend		-	-	1%	2%
Length of time in caring role	**1 – 5 years**	37%	-	37%	42%	43%
	5 – 20 years	52%	-	51%	38%	36%
	20+	11%	-	7%	12%	9%
Hours spent caring	**30+**	63%	-	66%	70%	68%
Employment status	**Working F/T&P/T**	30%	-	14%	24%	26%
	Retired	19%		60%	59%	56%
	Unable to work due to caring	20%	-	16%	12%	13%
Surgery visits for own health in last 6 months	**None**	-	-	23%	16%	19%
	Less than 4	-	-	60%	68%	67%
	More than 5	-	-	9%	16%	14%
Regular clinic attendance for own health		-	-	n/a	75%	72%

Better correlation with the national census data is found in terms of the lengh of time carers have been in their caring role; in the number of hours each week devoted to caring; and in the proportion combining caring with either full or part time work. None of these variations is surprising, given that the pilot projects have been designed to focus primarily on older people, defined under the European convention as those aged 55 years or over.

To enhance confidence about the representative nature of our study sample in relation to the full population of registered carers from which they are a self-identified sub-set, surgeries were also asked to provide general characteristics of the total population of registered carers (All registered carers) in terms of gender and age for comparison. As revealed in Figure 3, the study sample shows a good correlation with the population with small variations in the gender/age distribution of the study sample:

> 3% more respondents are women
> 5% less respondents under 50 years of age
> 4% less respondents over 70 years of age

Although registrations generally appeared to take place in an even pattern throughout the year, it was noticeable that January consistently produced a small 'peak' in registration activity (up to 5% increase) each year from 1998 to date.

Nearly twice as many (43%) of the second responders (T2 new) were new registrants compared with one-quarter (25%) of those who responded at the beginning of the study (T1).   Overall, 45% of the total population of registered carers have joined the register during the course of the project, which is well-correlated with the second sample of responders (T2 new).

The T1 responders were more experienced in their caring role, with 20% having spent 20 years or more as a carer, compared with only 9% of those in the T2 new sample. On the other hand, for the T2 new responders, twice as many are under 50 years of age; are more likely to be working and appear slightly fitter in that 10% less of this sample attend a regular clinic for their own health.

When considering self-reported surgery visits specifically for their own health by all respondents in the T2 sample, there is an increase in visits made. The data show a 7% fall in the number of respondents reporting not visiting the surgery at all for their own health in the last six months and a 10% increase in those making between 2 and 5 visits in the same period. Only 1 in 8 (12%) reported visiting the surgery more than six times for their own health.

6.2.3 General Health Questionnaires (GHQ)
The General Health Questionnaire (GHQ) is divided into four domains:

Section A:	**Physical difficulties**
Section B:	**Anxiety and insomnia**
Section C:	**Social and personal difficulties**
Section D:	**Depression and mental health**

Each domain comprises 7 questions and respondents may choose one from four options, which provide a total score from 0 – 7 in each domain. A high score (5 or more) in any domain is sufficient to trigger a concern in this area of functioning. Questionnaire responses were collated and scored and an initial analysis of the data was undertaken using a database (Microsoft Access) and the computer programme SPSS (Statistical Package for Social Sciences), in relation to each of the four sections of the GHQ. A primary analysis of all responses is given in Figure 4.

Fig. 4 GHQ - Responses (%) - All participants
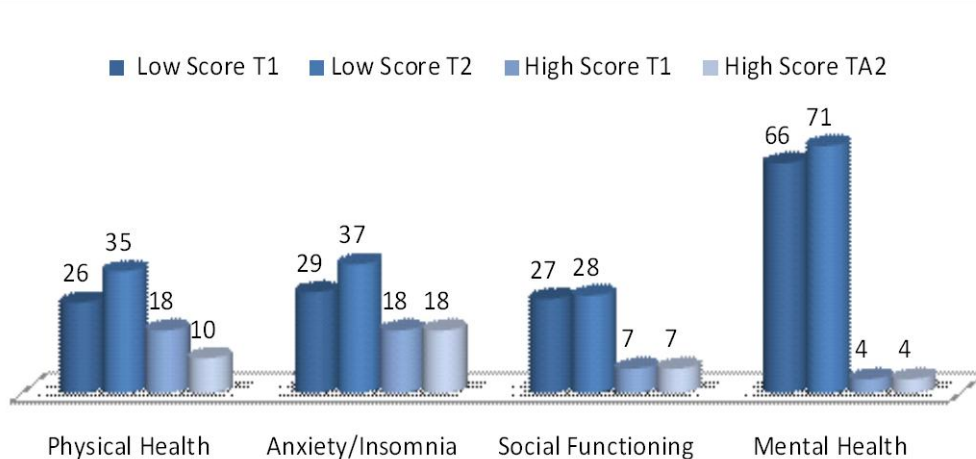
The first two columns in each set represent the percentage of respondents at T1 and T2 for whom 'LOW' scores (3 or less) have been recorded, indicating few or no problems in this particular domain. Taking the first two columns in each set together, Figure 4 demonstrates an increase in the percentage of participants scoring 'LOW' across all four domains. The data suggest that at the end of the project, noticeably more people perceived greater well-being than at the start of the study in relation to their physical health, anxiety/insomnia and depression.   The same is true but to a much lesser extent in relation to social functioning.

Turning to the second two columns in each set, these represent the percentage of respondents at T1 and T2 for whom 'HIGH' scores (6 or more) have been recorded. A decrease in the percentage of those recording 'HIGH' scores in each of the GHQ domains indicates an increase in perceptions of health and wellbeing. At this stage, a substantial downward trend is demonstrated above in relation to physical health while the situation at the 'HIGH' end of the scale in each of the other three domains has remained constant.

In a cross-tabulation which explored the relationship between high scores in each domain and carer characteristics of gender, age, relationship to cared for, hours spent caring per week and length of time in caring role for each of the three types of respondents – T1, T2 all and T2 only – high correlations were found in the following characteristics:

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Fig. 5 Characteristics of respondents scoring 'HIGH' in all domains of GHQ

GHQ Domain	T1 High Score	T2 All High Score	T2 New High Score
Physical Strain	Female 1- 5 years caring 30+ hours	Female 60 – 64 years 1- 5 years caring 30+ hours	Female 60 – 64 years 30+ hours
Anxiety/Insomnia	Female 1 – 5 years caring	Female 60 – 64 30+ hours	Female 60 – 64 years 30+ hours Spouse
Social Dysfunction	Female 60 – 64 years 1- 5 years caring 30+ hours Parent	Female 30+ hours Spouse	Female 30+ hours Spouse
Mental Health	Female Retired 30+ hours	Female 30+ hours Parent`	Female 30+ hours

Evaluating the frequency with which particular characteristics appear in the 'HIGH' scoring zone, these data suggest that carers who are experiencing most stress are likely to share the following characteristics:

Gender	**Female**
Age	**60 – 64 years**
Length of time in caring role	**1 – 5 years**
Relationship to cared for	**Spouse**
Hours per week spend caring	**30+**

The ratio of those scoring 'HIGH' - at or above the level to trigger a concern - in each domain of the GHQ at the end of the project is as follows:

- **Physical strain: 1 in 10 scoring HIGH**
  For instance, 10% of respondents had been 'feeling run down, out of sorts and in need of a good tonic' much more than usual.

- **Anxiety and insomnia: 1 in 6 scoring HIGH**
  15% of respondents 'felt constantly under strain' and 10% reported 'getting edgy and bad tempered' much more than usual.

- **Social dysfunction: 1 in 14 scoring HIGH**
  For example, 15% reported being able to 'enjoy normal day to day activities' much less than usual.

- **Mental health: 1 in 24 scoring HIGH**
  8% of respondents definitely 'thought of the possibility of making away with themselves' and a similar number reported that 'they could do nothing because their nerves were too bad'.

6.2.4 Carer Strain Index (CSI)

Analysis of responses to the thirteen questions contained in the Carer Strain Index has been used to identify those areas which give rise to most stress for carers. The highest score is represented by those selecting 'regularly' from the three response options. From those responding to the CSI at the end of the study, these 'primary stressors' are as follows in order of frequency expressed as a percentage and as a ratio of the study sample:

1. **Care giving is confining (42%)**   **2 in 5 selected 'regularly'**
2. **Changes in the person cared for (34%)**   **1 in 3 selected 'regularly'**
3. **Sleep disturbance (32%)**   **1 in 3 selected 'regularly'**
4. **Family adjustments (31%)**   **1 in 3 selected 'regularly'**
5. **Personal plans are changed (30%)**   **1 in 3 selected 'regularly'**
6. **Feeling completely overwhelmed (30%)**   **1 in 3 selected 'regularly'**

When comparing the same CSI data from the two surveys at the beginning of the study and at the end, significant reduction in reported levels of feeling 'regularly strained'- the highest option - in the following areas were noted:

- upsetting behaviour of the person cared for (- 10%)
- financial demands (- 10%)

Similarly, smaller reductions in 'regular' levels of strain were noted in five other areas considered in the CSI responses, including:

- emotional adjustments (- 7%)
- changes in the person cared for (- 6%)
- physical strain (- 4%)
- sleep disturbance (- 3%)
- feeling completely overwhelmed (- 2%)

6.2.5 Carers' Satisfaction Survey

The Carers' Satisfaction Survey was a locally produced questionnaire and was completed by a slightly smaller number of participants (176) with some incomplete or 'no response' outcomes recorded.

Of the survey respondents, 30% (53) had had direct contact with the Advice & Support Worker and 36% were satisfied or better with the service they had received. 26% reported making use of the additional project services with 5% taking up the opportunity for counselling; 6% using the occupational health assessment; and 15% having a carers' health check.

There was an increase during the study from 20% to 32% of respondents reporting referral to a carers' support group and an increase of 3% in those bring referred to a specific training course, which included St. John's Ambulance Carers' Programme, dealing with dementia; stress management; expert patient programme.

The satisfaction survey revealed a rather mixed picture in relation to referral to Carers' Link. Nearly half (49%) of respondents said that they had registered, whilst 13% were unsure whether they had or not. 36% (64 people) were satisfied or better with the service provided by Carers' Link, although 12 respondents (7%) reported some level of dissatisfaction.

When asked about other services, half of the respondents indicated that they were making use of other services, which included some or all of the following:

Social services	(51)	30%
Benefits advice	(40)	23%
Domestic/gardening	(22)	23%
Respite/sitting services	(33)	18%
Transport	(22)	12%

Interestingly, there was wide variation between project sites in the frequency with which respondents were linked to other services. For instance, Surgery A had 70% of respondents linked to other services, while surgery E had only 45%, with the control site having 34% of respondents indicating that they were using other services.

Carers were asked via open questions at the end of the satisfaction survey to identify those services which they had found most and least helpful.

The top three services considered most helpful were:

1.	**Social services for benefits advice and equipment**
2.	**Carers' health checks**
3.	**Having a sensitive and supportive GP**

The top three services considered least helpful were:

1.	**Not knowing what is available**
2.	**Lack of time for listening**
3.	**Lack of out-of-hours cover**

Asked about a 'wish list', or the sorts of things that would enhance the quality of their lives in their caring role, the top six suggestions from carers were:

1.	**Information about what is available**
2.	**Advice and support at times suitable for working carers**
3.	**Access to regular respite**
4.	**More supportive, joined-up services including home visits**
5.	**Named person for benefits and financial advice**
6.	**Condition-specific education and training**

6.3 Project Staff Interviews

All those with significant involvement in the project at each surgery – administrative and clerical staff as well as health care professionals - were invited to participate in a face-to-face structured interview. Interviews were held in a private room at each surgery site and were recorded for reference purposes. All participants had received an information sheet and completed a consent form before the interview began. The same 16-point questionnaire was used with all staff. Questions required a numerical response, using scales from 1 – 10, to generate quantitative data for ready comparison between sites, although there was also space on the schedule for the recording by the researcher of a limited amount of more qualitative material, through individual opinion and comment gathered during the course of each interview. A total of 18 staff, including 3 GPs, were interviewed. An initial analysis of numerical data is recorded in Figure 7 below.

Fig. 6 Analysis of second interviews with project staff
Key to scoring: 1 = Poor   2 = Satisfactory   3 = Good   4 = Excellent

Interview Questionnaire	Surgery A Health Checks	Surgery B Health Checks	Surgery C A&SW only	Surgery D Occ. Health	Surgery E Counselling
Surgery size – Total patient list as at 01/09/08	5223	3923	12578	16191	5300
Total number of carers registered	51	61	105	204	193
Number of staff interviewed (Total 18)	4 inc. GP	1	3 inc. GP	6 inc. GP	3
Commencement of services	Sept 08	Sept 08	Oct 08	Sept 08	Sept 08
How well do you gather and use the views of carers?	2	1	3	2	1
How satisfied are you with the information gathered about carers?	4	4	3	4	3
How would you rate the current attitude of staff to carers?	3	4	4	3	4
How well do you feel you are dealing with carers?	3	3	3	3	4
How satisfied are you with what the project offers to carers?	3	3	3	3	3
How well have you implemented the project?	2	3	4	4	3
How would you rate the sustainability of A&SW role?	3	3	3	2	2
How would you rate the sustainability of additional service?	2	1	n/a	2	1

6.3.1 Registrations

A primary aim of all projects was to increase carer registrations and all sites had achieved an increase in numbers well beyond that of the control site indicating that

an active and positive influence had been brought to bear in this area of activity, with an average increase in registrations across all five project sites of 207%.

Some disappointment with the final level of registrations compared with the target figure of 10% of list size was expressed by a number of project staff and certainly the data in Figure 1 demonstrate a slower registration rate in the third quarter of project implementation. There was a sense in which some staff felt that initial expectations had been too high with insufficient appreciation of the additional work and complexities involved in setting up the new services, (Haffenden, 1991). The part-time nature of many of the working arrangements for surgery staff, particularly the advice and support workers, had presented some problems with team working and communication particularly where larger teams were involved.

6.3.2 Advice and Support Worker Role

Generally, project staff felt that the advice and support worker role had been most valuable for raising awareness and assisting the whole team to 'grasp the importance of what carers do'. All sites acknowledged the value of a clearly identified, named person with whom carers and other members of the team could link, who would 'constantly remind them' of carers' issues and performing what one project manager described as a 'bridging role between the carer and GP'. We are 'constantly thinking carer' was a pertinent comment from one practice manager.

Advice and support workers had been flexible and resourceful in carrying out and developing their roles in a number of different ways according to local need, including developing paperwork and systems as well as information-gathering, sign-posting, awareness-raising, networking and promoting the service as well as developing and delivering direct input for training or support groups.   Project staff felt that offering a choice of flexible arrangements for contact with carers, ranging from formal clinics to drop-in sessions, surgery appointments, home visits, telephone and e-mail, were all vital elements in encouraging carers to come forward and take full advantage of what was on offer.

Given that the advice and support workers had raised awareness and widened perceptions of carers and helped as one GP put it 'to broaden the support and social focus' of what is offered from the surgery, there was a real sense in which the project staff felt that a service 'gap' had been addressed and consideration ought to be given to ways in which the advice and support worker role might be sustained, perhaps by integration into existing job descriptions and sharing of key tasks amongst a number of different types of staff. At Surgery D the project had provided for the secondment of a care manager from social services and an occupational therapist attended at the surgery for one day per week. The service developed here could include joint home visits incorporating simultaneous health checks, benefits advice and equipment assessments. The co-location of health and social care services in this way was regarded as 'the gold standard' by all those who experienced it, not only in providing a 'joined up' service for carers but also in extending knowledge and understanding of different professional roles, perspectives and values.

6.3.3 Services

The take-up of services, whether these were direct engagement with the advice and support worker or an appointment for an additional project service, had been slow at

the start but by the time of the second interviews, the project staff in all but one site felt that the level of take-up was in line with expectations or better   With only one exception, all interviewees rated their satisfaction with what the project had offered to carers as very high.

Work on the consultation and participation of carers in surgery activities still appears to be at an early stage of development.

All surgeries were beginning to explore the possibility of using existing regular clinics for chronic conditions for example dementia, asthma, diabetes, learning disability and public health promotions such as smoking cessation, flu vaccination etc., as a means both to identify carers and to extend the checks on offer to include some aspects of carers' health and/or well-being.

6.3.4 Systems

By the end of the study, all project teams had a copy of the most recent guidance for GPs in relation to supporting carers (Princess Royal Trust, 2007). All surgeries had 'read coded' carers on their electronic patient records and had 'joined them up' with the cared for person where they used the same surgery. Where these arrangements were new, they were regarded as a real improvement with practical benefit not only to clinical but also reception and administrative staff. Several staff indicated that time was allocated in practice meetings or at core group meetings specifically for the report of carers' issues, offering good professional development opportunities for a number of the advice and support workers.

6.4   The focus groups

Nine focus group sessions were undertaken both at the beginning (T1) and at the end (T2) of the study, with a self-identified sub-set of participants from each data collection. The meetings took place in a private room within the surgery building or in a meeting room at a nearby community hospital to ensure that venues were familiar and accessible to all participants. Participants were sent an individual invitation, information sheet and joining instructions one week prior to the event. Attendance, travel and sitting service expenses claim forms were distributed at each meeting. Due to the very low registration numbers at the start of the project at Surgery B, the decision was taken to combine participants from Surgeries B & C in Exmouth into one set of focus group meetings.   Participant numbers are set out in Figure 7.

Fig. 7 Summary of Focus Group Participants - Numbers

Project Site	No of groups	Participants			
		T1		T2	
		Female	Male	Female	Male
Surgery A	1	2	1	2	1
Surgery B & C	2	2	3	2	3
Surgery D	2	6	1	8	5
Surgery E	2	5	1	8	4
Surgery F	2	5	5	4	5
Sub-Totals	9	22	10	24	18
TOTALS		32		42	

6.4.1 Demographic data

The table below compares some of the important characteristics of the second focus group participants with those of the end of study sample (T2 questionnaire respondents) from which they are a self-identified sub-set. The data suggest that the focus group participants are broadly representative of the overall study sample, although they tended to be slightly older and more experienced in their caring role. The only significant difference is in the greater percentage of the focus group participants (11% more), who reported spending 30 hours per week or more in their caring role compared to the whole study sample.

Fig. 8 Characteristics of Focus Group Participants Compared to Total Sample

Characteristic		Focus Group Participants	Total Study Sample
Age (yrs)	Under 50	12%	12%
	60 – 64	24%	22%
	70+	38%	37%
Gender	Men	40%	29%
	Women	60%	71%
Relationship to cared for	Parent	29%	27%
	Spouse	55%	60%
	Child	7%	8%
Time in caring role (Yrs)	1 – 5 yrs	33%	42%
	6 – 19 yrs	45%	38%
	20+ yrs	19%	12%
Caring (Hrs per week)	30+ hours	81%	70%

Each focus group meeting was recorded and transcribed. Themes were identified from the focus group material which were then coded manually to build up categories which were sorted, compared and refined.

The main findings are reported under seven thematic headings.

6.4.2 Functional tasks & physical tending

All of the focus group participants reported the need to assist the person they cared for with a wide range of activities of daily living which were limited in some cases to functional tasks such as transport, shopping, cleaning, laundry and cooking or were extended for others to include a range of more personal activities such as eating, dressing, bathing and toileting. There was sometimes resistance to help from anyone other than the main carer from the cared for person, highlighted by the following extract:

> "He would pay for somebody a specialist to come in, but his wife won't let him. She doesn't want strangers coming in. It's not just what's available …. Sometimes it's the patient if you like saying, I don't want strangers coming in. I mean if they have to when they have a medical condition but someone to come in for company …"

By their very nature, personal care tasks need to be performed at certain times and this posed problems for carers in arranging formal help from potential outside service providers, eg. home care, as the services were sometimes not available outside 'standard' hours or providers would not commit themselves to coming at particular times:

> ".... but sometimes they come at seven o'clock to get her ready for bed. And I say this is too early, I sent one of them away, I said come back later, it's too early. Because they've got a list of people and they do them in a rota and if we're at the bottom of the list...... but it's too early."

As a result, few carers in the focus groups reported any additional help, other than from family, friends and neighbours, with the physical tasks of caring. Although these functional tasks and physical tending could be relentless and could occupy what many described as '24/7' rather than a discrete and quantifiable number of hours each week, there was a sense in which the focus group participants found value in their caring role and self-efficacy in their ability to cope with whatever was presented to them 'even when they were not feeling 100%':

> "I mean my wife and I, we've been together for well over sixty years and whatever comes, you do it. You don't think about anything else … you just do it. Well I used to be dependent on her for all the cooking but I do it all now …. I'm doing things that I never knew I'd be able to do"

> "Well, 90% of people would have given up [about getting the service] but you do get extremely good at fighting as a carer, even if you do get tired of always having to."

6.4.3 Behaviour problems and relationship changes
Beyond the general burden of care-giving in relation to the activities of daily living described above, focus group participants frequently reported the increased stress brought about by changes in the person they cared for, in terms of the relationship between them, or their behaviour or decreasing mental capacity.

> "My wife isn't too bad but she does illogical things, that's the thing, so you've got to be on the watch all the time. What she thinks is normal behaviour makes you wonder sometimes. You've got to be wary all the time and that takes a lot of energy really".

Those caring for a parent found the 'reversal of roles' in which their mother or father became 'more like the child now' difficult to manage and these feelings were compounded where the cared-for person also found the changes challenging and difficult to accept.

> " my mother doesn't want to be here. You're doing your utmost …. I know she'd be even more miserable if I put her in a home … I don't want to … but I just wish she'd appreciate you know… she's in her own home, everything around her ….. her own bed…. But she's unhappy … she'd much rather be in her coffin …. I get this every day and I don't find it funny you know."

The emotional impact of changed relationships was particularly highlighted by many of those caring for a partner:

> "Well, it's your wife's illness that triggers that anger I think. I mean I get angry because of the situation. I think of what we've lost, this is not the life we were supposed to be living".

> "Well, in my case it's my husband … there isn't any real discussion, any participation But there are pockets when he seems to be perfectly alright and I slip in and out of this role of carer and wife and the blurring of the roles sets up a confusion in me … How far is my caring separate from my wifeliness?

> "In many ways, [my wife] is exactly the same person in relation to other people but in relation to me, you know, she just completely takes for granted everything I do, she doesn't notice about three quarters of what I do or actually resents it and actually protests about it. And you know, quite often I will sort of just blow up really…"

> "…but there's something about your relationship with your partner where there is – I hate to ever use the word trapped as you mentioned , I don't feel trapped but there are times, because it's *my life*, when I've so become this person that his illness requires of me – that I'm happy to do – but it is so narrowed, I am so narrowed … you know, that's when I feel as though I'm going to explode."

> "Yes, the other general point that's come out for all of us in different ways is this thing about being aware, not just being aware of us but also being aware of us as part of a relationship and that they – that obviously if you've got someone who is very ill and getting iller, it has drastic implications for your relationship and that's not acknowledged".

6.4.4 Lifestyle changes and restrictedness

The focus group participants reported a number of changes to their lifestyles in order to undertake and continue with their caring responsibilities and restrictions impinged in a number of different ways on the quality of their lives as a result of their care-giving role. Lifestyle changes included giving up work altogether, working from home or taking part-time work with hours that permitted the caring role. No-one mentioned help from a current employer to 'wrap' their existing job around caring responsibilities.

> "I look after my eighty year old mother and I fit all this in. I took a job working very early hours – I've been up since half past four this morning - and I get home about half past ten to make sure she's OK and then I usually spend the day and obviously the nights with her."

> "I only had the job for six months. She needed me more so I gave it up and I don't officially retire for another five years but I've been full-time caring now because she needs me. The job was to give us sort of extras."

For those who were in full-time or part-time employment, access to services and support specifically aimed at carers was perceived as very limited if not impossible:

> "Well, nothing seems to come to you …and if you're working, you don't have time to chase things up all the time. You can't because at the sort of time that they might be available to give you help, you're at work".

A primary limitation on any independent activity arose from the obvious need to do things for the person they cared for or to be there in order to keep them safe but hobbies or interests often had to be abandoned:

> "It's become clear now that [my wife] can't count the right number for her medication so I've got to be there all the time. So the golf has gone pear-shaped and my own fitness levels have gone down which my GP is worried about …"

Moving in with a relative or having a relative move in with them was a common solution to providing functional care and safety for a number of the focus group participants, particularly those caring for a parent or sibling:

> "My mother has just recently moved in with us – we've moved up and she's got three rooms downstairs. She's alright around the house but I have to watch what she's up to really".

> "I'm caring for my mother-in-law. I suppose actually if you think about it I've been caring for her for several years but living in my own home. Now I'm living in her home, things have changed. It's so very, very difficult".

Forward planning and the need to make arrangements in advance for the cared-for person removed much of the freedom from the social lives of the carers that would be regarded as a normal expectation for non-carers:

> "Yes, there's no spontaneity. It's very difficult to be spontaneous about anything because everything has to be planned in advance. If you want to go out for the day, you've got to book it in advance. You can't just ring up and say can I have somebody for tomorrow".

Nearly all of the focus group participants referred to feeling a general anxiety about leaving the cared-for person which meant they felt ill at ease when away which then led them in turn to try to limit the frequency and duration of any separation. Finally, particularly strongly felt by those caring for a partner, there was a 'shared restrictedness' in which carers adopted for themselves the limitations placed on the person they looked after and could not or would not contemplate separate activities.

> "Yes, I mean just going out to associations and things like this, you don't tend to go very often or only you know, if she can come with me".

> "It's just one of them things, but you know, you just… I feel I can't go out because she wants me here".

The wide variety of needs and the difficulties of meeting them through any one particular service, in a timely way was readily recognised across the focus groups and expressed by one participant as 'asking for the impossible really'.

6.4.5 Finance and benefits
Financial issues were raised by participants in all of the focus groups and there was wide variation in the extent of individual awareness of what was available and knowledge of the systems and processes for claiming, which were experienced as complex and confusing. Financial issues appeared to present less of a problem for those caring for a partner but the importance to the carer of benefits received by the cared-for could be problematic and an area of conflict:

> "In your case, being as you care for your wife, you probably have joint accounts and things like that. But for me, it all [attendance allowance] goes to Mother and it's a big, big thing – Oh, here you are dear, here's your money and I'm thinking I don't want it and in fact I refused to take it for three weeks so we had an almighty row about it…"

Inaccurate and confusing advice from a range of professionals encountered by carers was not uncommon and participants referred to the value of the help they had received from the project's advice and support workers in relation to their potential eligibility for different forms of support.

6.4.6 Recognition, talking & support
Often, it was simply recognition of the service and support they provided for the cared for person that carers felt was needed:

> "My experience [of caring] is 13 years and no-one has ever in that time actually approached me….. I think it's just the recognition really. I mean I've just felt I don't exist or else all these people come to see [my partner] but they don't even give me the time of day".

Or something that would help them to re-gain some of what was perceived as their 'lost identity':

> "Well yes, I was my mother's daughter and my husband's wife and my daughter's mother and this is where I said I think you just lose your identity".

Most carers appeared to prefer to rely on family, particularly daughters, friends and neighbours to share some of their burden as well as for social and practical support although the importance of talking was frequently referred to:

> "I find that you need someone to talk to. This is one of the things that I miss most of all … I'm not talking about medical things."

The benefit of an opportunity to release frustration and to express sometimes angry emotions was readily acknowledged but there was general agreement about the lack of availability of 'somebody to let off steam to basically, about how things are':

"You end up feeling guilty if you do explode, I know I do … but sometimes, I'm really driven to it. I try to bottle all the explosions up but just sometimes … and it's usually something trivial. Carers need … they need somebody to talk to. But that's what you never get isn't it?"

Not surprisingly, carers needed a range of different support mechanisms on which to call at different times and according to individual characteristics and circumstances. Interestingly, there appeared to be something of a gender divide, where women felt that group meetings provided them with an opportunity for wider social support, while a number of men in the focus groups expressed a preference for activities that were strictly task-focussed:

"I would go if I thought that I would really learn something and it was going to make a very positive difference. But if I went to one of those things and it was just a boring waste of time, I would feel very resentful"

As reported in the Interim Report, day care continued to be very highly valued and those using day services appeared to have either better access to or were more willing to take up opportunities for longer-term respite particularly if this happened in the same place.

6.4.7 Information
Carers were adept at drawing in information, guidance and advice from a range of local resources and frequently turned to the internet as a first 'port of call' for more general information.

"Everything I want to care for my brother, I go through the internet because there's no actual information coming to me at all since I was recognised as a carer and that was 20 years ago".

Carers often wanted more information about the cared-for person's condition, partly in order to take action – or more often in order to understand what had happened to them, as they struggled to come to terms with changes. This need was most often met through independent sector, condition-specific societies and support groups such as those dealing with Alzheimer's disease, Parkinson's disease, multiple sclerosis etc.   Some carers felt that professional advice and guidance as well as informal support was lacking:

"What I feel I need now is a bit more sort of what to expect, what sort of changes and I do have other carers coming in to sit with mum but I haven't got the other side, the professional side and I miss that at lot because I don't really know what to expect and how to deal with the different sorts of things"

Local pharmacies were particularly prominent, especially in more rural locations, in providing more specific professional advice, not only in relation to medication but also about equipment to assist daily living and for example incontinence supplies, for which they had ready samples to hand.

"Some doctors are good and some doctors aren't. But living in a small town like this is good in a way because you've got the chemist as back up. I mean you couldn't fault the chemist here".

6.4.8 Project services & take up

Knowledge about the projects and the specific services on offer at each site was by no means universal amongst the focus group participants and surprising levels of uncertainty and confusion appeared to exist in the light of the high scores given to satisfaction with the service offered to carers, in the survey of project staff. However, it should be noted that at the time of the second focus group sessions, the project services had been running for six months only which is a very short time in which to establish confidence and overcome carer resistance:

> "Well that's it. We haven't had any meetings or personally any paperwork or anything like that. What's she supposed to do for us? I mean if we knew her role, intentions and goals, we might think about using the service".

> "I've not used the services, no, because I never thought it was for me. I thought well mine's nothing in comparison to what other people have so I had always thought that it was for them rather than for me"

The features of the services that carers in the focus groups referred to most often as helpful included:

- A named person with a specific interest in carers and issues relevant to their role and part of a central information 'hub' based at the GP surgery, even though there was a recognition that the needs were just as likely to be social as medical;

> "What you really want is one person at the surgery you can ring up and say, look I've got this problem or can I speak to you for a moment…"

> "I mean, if from the surgery they can just give you a phone number to ring up and speak to one person who will tell you all these things that are available"

- Direct access to an advice and support worker as a specific resource which they could rely on to be there in times of need, even if this did not involve immediate take up;

> "So I did think if I feel myself getting in the depths of gloom again, I will ring her up and I think she's kind of more approachable than the doctor"

- A single 'gateway' to services or a 'one stop shop' where someone with in-depth local knowledge would act as a 'pathfinder' through the maze of information and criteria for access to services and providers for things like benefits, residential homes, OT assessments;

> "One of the things I've learnt about carers from those support meetings is that people want a one approach entry into the NHS. They don't want to be told sorry you have to talk to them, or them or go there and then be directed somewhere else"

- A private room away from reception for discussions and consultation

  "I thought it was nice to have the little private room … because I did have a situation that I didn't want to talk at the desk about because it's very open and that was very useful to me at that time".

- Flexible arrangements for appointments with home visits particularly valued
  "When I ring to make an appointment for my husband I understand that a little hand flashes on the screen to say that I'm a carer so they – and I am very grateful for this – because when I say my husband is very poorly today they don't say can you bring him in. They say well get a doctor to you. Now that's been a real difference!"

Emergency planning was an issue that was raised in all of the focus groups with many carers realising that they did not have sufficiently robust arrangements currently in place. Several carers mentioned this as an area on which they had worked with the advice and support worker and with help from Carer's Link, awareness of the problem and improved plans had been developed.

There was a lingering frustration with the lack of continuity in service provision, for instance a plethora of different home care assistants or sitters, and in information sharing, which meant that carers were left with the task of briefing a new GP or sitter or respite provider.

Most of the carers felt that a regular health check, linked to their caring role, would be helpful although concern about 'overlap' with other checks that were already carried out in surgery clinics, eg. asthma, diabetes etc., were raised. Carers were almost unanimous in their view that take up of the project services would be optimised if individual invitations to specific appointments, rather than an informal 'drop in' arrangement, were set up.   They did not want to feel that they were asking for a service but rather wanted the 'flow' to originate in the surgery:

  "Yes, well if you have to ask. It feels as though you have to show that you can't cope and that to me is really going against the grain. I feel I'm failing"

  "And to be invited to come, well yes actually that would be good. If I was invited, Id' come".

DISCUSSION

Significantly, the data from the GHQ (Section 6.2.3) suggest that those carers experiencing greatest stress are likely to be women of 60 – 64 years of age, caring for a partner in excess of 30 hours each week and in the early years of their caring role. A number of earlier studies (Charlesworth et al, 1984; Gilhooly, 1984) lend support to our assertion here that women carers report higher levels of stress. It is not difficult to imagine, as mentioned in several of the focus groups, the increased stress that might result from finding a very different life at the beginning of retirement when a partner becomes dependent rather than being the active companion that was expected or hoped for. The restrictedness of the role and the close co-habitation in the same household of partners have been shown to increase the mental ill-health of those in the caring role (Singleton et al, 2002). The amount of time spent caring together with the 'worry work' of coming to terms with a new, changing and perhaps initially unstable situation would not be unreasonable contributors to increased levels of stress. Consideration could be given to using these characteristics to identify risk and target appropriate support.

Carers inhabit a 'grey area' in which health and social care services overlap. In this study, carers reported that services were set up most frequently as the result of a crisis, usually the hospitalisation or emergency respite admission of the person they cared for, which did sometimes mean they were able to tap into support for themselves as a 'side shoot' of the arrangements for the person they cared for, but outside of these occasions, carers felt that they were very much left to 'soldier on' alone (Hirst, 2004). Often, it is not a direct health difficulty with which carers need assistance but the resolution of concern in other areas, ranging from finance or benefit queries to emotional distress, which may have a positive impact on their psycho-social functioning. Although it has not been possible to establish a direct causal relationship from our data, ideas about the positive benefits of wider support for carers are strengthened by an analysis of responses to the general health questionnaires (GHQ) which were beginning to show improvement across all four domains by the end of project implementation. The area showing least improvement is that of social dysfunction, which is not an altogether surprising finding, given the comments made throughout the focus groups in relation to lifestyle changes and restrictedness so closely associated with the caring role. Although many carers took advantage of and felt grateful for the 'take a break' sitting service offered by Carers' Link, wider evidence (Vellone et al, 2007) suggests that longer time away may be needed for any measurable benefit to accrue. Indeed, focus group participants often alluded to the difficulties of having free time but not a 'free mind', because even when they attempted independent activities, this did not feel like independence because the cared for person still depended on them. Lack of resources for meaningful breaks, such as regular and frequent day care or longer-term respite, coupled with their own reported reluctance to take up opportunities for independent activities, hobbies or interests outside of caring, means that a high level of social dysfunction is almost inevitably experienced by many carers, (Kelly, 2007). It should be noted here that in the carers' satisfaction survey, access to regular respite was high on the 'wish list' of services to improve their quality of life.

In this same survey, carers also highlighted the need for specific advice about the condition of the person they cared for and a wish for particular training and education sessions. Although this sort of information is clearly important, there is evidence to

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show that the possession of information itself does not reduce the stress felt by carers (Orbell & Gillies, 1993).

At the end of the study, as highlighted in Figure 3, A&SWs were identifying carers with a range of different characteristics than those who were already registered or who signed up in the early stages of project implementation. A greater percentage of those registering later in the study were in the first few years of caring and were attempting to combine work with their caring role. The concerns of those in this position, to have more services and supports available at times that would be suitable for working carers emerged strongly from the focus groups and appeared in second place on the 'wish list' collated through the carers' satisfaction survey.

It was recognised in all project sites that considerable investment in terms of time and resources is necessary to set up new systems and processes. Those to increase identification and registration of new carers in each surgery were clearly effective, efficient and robust, having achieved an average increase in registrations of 205%. Surgery B recorded an increase of 392% in registrations. Beyond this, there is however a need to develop a 'mind set' and culture in which carers are given appropriate status which requires a 'whole team' approach. At this level, strategic or cultural change will require the active involvement and commitment of a lead GP in addition to the work of the advice and support post holder. The part-time nature of many surgery staff had led to fragmentation or discontinuity of services in places and some communication difficulties had arisen where key members of staff were absent or unavailable at particular times. To address these difficulties, all sites had begun to develop a wider team approach to carers' issues including regular space at surgery meetings for a report from the A&SW with feedback and discussion of carers issues with professional and administrative staff. Where awareness training had been taken up as widely as possible by surgery staff, there appeared to be a positive impact.

Surgery teams recognised the benefit of developing an up-to-date and active register of carers; introducing a 'carer flag' on the front page of electronic patient records, visible for both GPs and reception staff and most particularly making the link between carer and cared for. All pilot projects had achieved this objective and project staff reported that systems were working well. Indeed, members of the focus groups also reported a significant improvement in the recognition of their carer 'status' when making appointments for the person they cared for.

Through the exceptional enthusiasm and commitment evidenced by all those appointed to the A&SW roles in the pilot schemes, all the projects had been very successful in raising the profile of carers, using leaflets; the reverse of prescription form; web sites; and notices and electronic boards in the surgery. A wide variety of promotional activities had taken place, including local radio and newspaper articles, posters in the wider community in pharmacies, libraries and volunteer bureaux, and information and leaflets distributed by direct mail or even hand delivery door-to-door in one more rural setting. The value of local networking was exemplified by the 'chain' of informal referrals described by one participant in the focus groups which began with her stress being recognised in the local library and ran via the volunteer bureau, to the GP surgery and finally to the advice and support worker.

The importance of establishing and maintaining a named 'lead' for carers issues, to co-ordinate activity and keep the profile of carers high on the agenda across the

surgery, was recognised at an early stage by all project sites and was clearly identified by carers who took part in the focus groups.   All those moving into the A&SW role found high levels of job satisfaction and rewarding new challenges in their professional development through the opportunity to lead and develop a specific area of patient/surgery activity. Where particular staff exist, who have an interest in working with and supporting carers, the A&SW role could be written in to job descriptions as part of on-going performance management and appraisal processes, for personal and professional development.

With one exception, the A&SWs had been seconded to the role from existing staff in each surgery. Two A&SWs had been drawn from an administration background and three were health care assistants. By the end of the projects, there was general agreement that the role that was emerging for the A&SW was primarily an administrative one, setting up and co-ordinating systems for registration and secondly, signposting carers to local services and support rather than undertaking direct work in this area themselves.   As noted in the interim report, some early difficulties had arisen in terms of recognising boundaries, accepting limits and dealing with rejection for some of the advice and support workers as well as health and safety issues in relation to lone working in the case of home visits. Where consideration was beginning to be given to the future sustainability of a named contact for carers, the focus appeared to be moving away in many cases from a clinical towards a more administrative base. For carers themselves, the skill set of the A&SW - incorporating high level inter-personal skills, in-depth knowledge of caring and of local services, flexibility to include home visits, and ready availability – was considered much more important than qualification or background *per se.*

Co-location of professionals delivering a mix of services to address the needs of carers emerged as 'the gold standard' for the site where this arrangement had been adopted as part of the pilot project.   Staff experiencing this approach all placed a high value on the presence *in the surgery* of a care manager, albeit on just one day per week.   Staff reported improved understanding of contrasting professional roles and values as well as increased knowledge about what services are available locally and who is eligible. For the care manager herself, in her substantive post with social services, she was used to being greeted on the telephone with a certain ambivalence or disinterest in her offers of help and was shocked in some ways to find that by simply announcing herself as coming from the GP surgery, she could quite literally 'feel people standing to attention' at the other end of the telephone!

Having established a variety of good initial systems, all pilot sites were considering issues of sustainability, including:

(a)   sharing the duties of an advice and support worker between existing staff to undertake checks as an extension of existing appointments. 75-80% of registered carers reported attending regularly for other condition-specific clinics.
(b)   sharing a full-time advice and support worker post say one day per week at each of five surgeries perhaps as part of a complex cluster arrangement. One GP reported how useful being able to refer individual patients to a graduate mental health worker employed on this basis was in relieving him of 'talking therapy' time with some patients and the carers A&SW could function in much the same way.

CONCLUSIONS & RECOMMENDATIONS

This section of the report draws together the considerable changes and substantial improvements which have been achieved by the pilots in a relatively short period of project implementation. There are seven recommendations and suggestions for further development and sustainability of the advice and support worker posts.

ACHIEVEMENTS

A more holistic approach

All sites have recognised the importance of taking a more holistic approach and have sought ways to develop a broader support and social focus to the interventions offered to carers, identified and presenting to the GP surgery. A surgery-based champion for carers, the advice and support workers have continually reminded staff throughout the surgery to 'think carer'.

Systems links for carer and cared for

A major achievement of the advice and support workers in all pilot sites has been the establishment of robust 'read coded' systems for the identification and linking of carer and cared for. As already noted, the needs of carers frequently lie in a 'grey area' where health and social care overlap. Their position is further complicated by the inter-connectedness of the needs of the person they care for and their own needs. Some of the tensions inherent in this close inter-relationship are exemplified by the comments from the focus group participants who said that they 'felt invisible' and just wanted some recognition of their existence, which is facilitated by the electronic 'tags' now in use.

A face-to-face 'listener'.

GPs recognised the need for talking with carers but also acknowledged their limited appointment time for this more supportive intervention. In the focus groups, carers identified the importance of having a named person, such as the A&SW, with whom they could make direct contact, without having to 'bother' the GP. A personal contact, as opposed to a telephone call centre, was highly valued by those in the focus groups but did produce some concerns around the personal impact of the work for the A&SWs themselves and projects had begun to put arrangements in place for more support and clinical supervision.

Flexible consultations

All pilot sites had identified the need to provide a range of ways of accessing their services and the importance of offering a choice of times and location to carers, so that sensitivity to the needs of individuals and flexible ways of setting up a specific appointment or consultation was a priority for all A&SWs.

A local information 'hub'

The importance to carers of one central, easily accessible, 'hub' through which they can receive guidance, advice and information about what is available to them in their own locality cannot be over-stated. Carers felt most confidence and trust in services derived from the GP surgery and preferred this, as opposed to social services offices, as the conduit for access to sources of help. A particular strength of the A&SW role based in the GP surgery is the ability to deliver a flow of information and advice at times which are appropriate to individual needs and sufficient for the particular stage in the journey through caring.

Range of services

It was clear from even the few words that each carer used to introduce themselves at the beginning of the focus groups that carers cannot be regarded as an homogenous group. Carers need to be offered a wide range of different services which will not necessarily be taken up by all, but which might be needed by different people at different times. All project sites had established an 'information bank' about local resources for carers including those aiming to meet their needs in four specific ways:

- To relieve the pressures of care-giving, e.g. support groups
- To assist with practical tasks e.g. aids and adaptations, laundry and domestic help
- To provide relief from caring e.g. sitting services, day care or respite
- To help carers get more from the care system eg. advice and information

Generally, sign-posing involved handing on a leaflet or telephone number to carers. Given more time, there is scope to develop the advocacy role of A&SWs included as one of the initial pilot project objectives.

RECOMMENDATIONS

None of the pilot sites wished to see the demise of the achievements identified above and seven recommendations for future developments to consolidate the services and ensure sustainability are made.

Recommendation 1

Clarification of the role of the advice and support worker, identifying a clear job description, linked to on-going training and support for the role.

Recommendation 2

Identification of a GP lead for carers' issues to develop a strategic 'whole team' approach in the surgery including reception as well as administrative and clinical staff.

Recommendation 3

Continuation of work to increase registrations by drawing on existing clinics, chronic disease registers and public health promotions to identify harder to reach individuals.

Recommendation 4

Prioritisation of carer and their role at an early stage, as part of the diagnosis in a cared-for patient's plan with three primary aims:
- to increase registrations
- to facilitate take-up of advice and information
- to target support services to those identified in the study as most at risk of experiencing damaging levels of stress i.e. women, aged 60 – 65, caring for a partner for 30 hours a week or more

Recommendation 5
Development of training and support for carers, particularly condition-specific information and groups
Recommendation 6
Improving information and communication between carers and the surgery through:

- Website updating
- Development and co-ordination of specific carer participation groups and forums
- Routine inclusion of carers issues on core group and practice meeting agendas

Recommendation 7
Sustaining the A&SW posts in alternative ways:

- **Integrating the role into the workforce** by sharing the key tasks across a number of existing staff workloads and designing job descriptions to reflect opportunities for personal and professional development in leading and developing carers' issues in the team.

- **Building on the success of co-located professionals** by creating a shared, jointly-funded post, for instance within a cluster group to reflect similar arrangements already in place for graduate mental health workers.

- **Adding specific elements of the additional carer checks to existing clinics**, which are already attended by 75% of registered carers, linked to either specific chronic conditions or to particular public health promotions.

9.0 LIMITATIONS

This is a small empirical study being undertaken in a group of self-identified GP surgeries.

9.1 Assumptions
A number of assumptions have been made:
(i)   that the sites and participants comprise a representative sample of the whole population.;
(ii)   that all surgeries will achieve identification and registration of all carers equivalent to 10% of list size

9.2 Limitations
There are limitations when seeking to generalise any findings to a wider population:
(i)   Sample size is very small
(ii)   Participants have identified themselves and may be introducing bias because they possess particular characteristics as people who put themselves forward rather than reflecting the differences across the whole population, including those who do not choose to come forward.
(iii)   Low response rate means that even though 793 packs were sent out, the number of responses (211) is too small to be broken down into sub-groups and subjected to meaningful statistical analyses.

9.3   Mitigation

Having acknowledged the assumptions made and the limitations imposed by a small, self-selected study sample, we are encouraged to find congruence of our sample externally with national data (General Household Survey 2000; Health & Wellbeing of Carers Survey, 2002) and internally with the total population of registered carers at all sites, across a number of important characteristics which provides confidence that the study has not identified an aberrant group.

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