

Background to the Carer Profile

A primary care liaison project for carers in the borough of Wigan was set up in June 2004 with the aim of identifying and supporting carers in primary care. The project was initiated, following the guidelines and good practice developed by the Princess Royal Trust for Carers in 2003, "Primary Carers – identifying and providing support to carers in primary care". This involved the use of a three part model to aid the development of services for carers:-

1. Identification and referral – this initial stage involved developing a way of recognising a patient/s attending the surgery as a carer and developing a system to be able if required to refer/signpost carers to relevant support.
2. Identification and practice development work – the part of the model focuses on training within the practice to help staff support carers, raising awareness of issues affecting carers and systems to help carers e.g. carer notice boards
3. Strategic work – this is the final stage and is the ongoing process of working in partnership with the PCT (Primary Care Trust) to ensure the long term development of recognition and support for carers within primary care.

The Wigan Project

1. Identification and referral

The first phase of the project, involved setting up a scheme for the identification of carers within GP practices. The aims of the project were to identify "hidden carers" in order to compile a carer's register and improve services for carers. The project worker researched similar carer registration schemes in the North West and utilised the information to develop a scheme for Wigan, which involved the "read" code computer system. This is a system used by GP's to record patient records. By using the "read" codes, via a carer registration card, carers were identified within primary care and this information was linked to the voluntary and statutory sector. This then led to a referral process connecting carers to sources of support and information on a regular basis through the carers helpline and ultimately, if the required criteria was met, a carers assessment through social services.

The carers project worker made contact with each practice manager across the borough, to arrange an introductory meeting to explain how the system would operate within their practices. The "read" code 918A (is a carer) and 918F (cared for") is entered on the patient's records from the registration card. The code appears on the computer screen, each time the record is accessed, therefore alerting the GP or locum to the fact that the patient is a carer, or being cared for and may have underlying issues to discuss. The scheme was launched in December 2004 with 98% of practices initially on board with the scheme and by January 2006 all the GP practices in Wigan Borough were participating in the scheme. Registration cards are now also available from the carers centre, carer support team, and carer support groups as well as voluntary organisations, social workers and other sources.

2. Identification and practice development work

The next step of the project included further work within the practice itself, raising awareness of carers and possible methods of identification among GP's and primary care professionals. Carer notice boards have been provided for each practice and these are dedicated to information aimed specifically at carers.

The project worker produced a training manual, "Recognition of Carers and Young Carers" to help staff recognise patients who have a caring role. The aim of the manual is to assist GP's, practice managers and practice staff and has been distributed to all practices. In conjunction with this the project worker arranged training sessions within practices to reinforce the good practice outlined in the manual following this up with handouts for staff on the subject of carer recognition.

Promotional material has been produced and distributed to all GP's as a reminder and to keep the profile of carers raised. A carer's fact sheet pack in relation to health and well being is in the process of being produced; this is information specifically for carers and will be available within the practices.

3. Strategic Work

The response from carers since the inception of the scheme has been overwhelming; with 530 previously "hidden carers" (not previously known) now registered since December 2004 up to the present day. This number continues to increase on a daily basis. In view of the high number of registration cards returned to the carer's project worker, it was decided to evaluate the work of the scheme and identify the benefit of it for carers.

A questionnaire "carer profile" was sent out to all carers who had registered through the scheme with their GP. The aim of this process was to obtain feedback from carers to identify their concerns and needs and to respond to requests for information. As completed profile forms were returned further information was forwarded to individual carers based on the information they supplied on their form e.g. carers assessments, access to the carers grant, signposting to other agencies for counselling, aromatherapy , carer outings / activities, carers groups and other available support. In some cases, services have been provided / improved for the cared for person via the appropriate social work team, thus benefiting the carer.

The initial and subsequent response rate to the questionnaire was and has continued to be, phenomenal. This report has been compiled from information gathered from 250 profiles, which were returned in the first instance and gives a breakdown of the information provided to date by carers.

The strategic work is ongoing and the feedback from the report will help in the planning and development of future services to support carers.

The Carer Profiles

The profile sent to each carer was divided into two main sections of information, quantitative, which is about numbers e.g. how many and qualitative, which is more difficult to measure as it is more about the effect or the outcome of an action/event. The profiles have helped in many ways; we have gained information from carers on how and in what way if any being registered on the scheme has helped them. The information provided by carers via the carer profile has helped the Carer Team within the Department of Adult Services to plan and develop services for carers. We have also been able to identify gaps and provide further information to carers:-

- How to access the carers grant
- How to access a carers assessment
- How to access a free benefits check
- How to obtain a free Fire Risk assessment
- How to access information if they interested in returning to work
- Signposted to other areas of support – activities/training

The overall aim of the scheme is to identify carers and provide relevant information, feedback from carers attending local events has highlighted the importance of providing “the right information at the right time” and this depends on each carer’s individual circumstances. The National Carers Strategy, Caring about Carers introduced in 1999 identified three key areas:-

- Information for carers
- Support for carers
- Care for carers

The profile was designed to enable individual carers to provide information about their caring role. This information would then be collated to provide an overall view of the information and support needed by carers in Wigan.

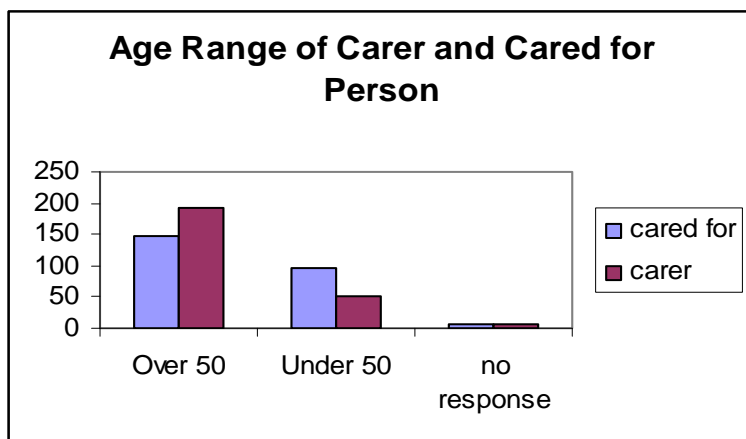
Linked to this is the development of a central register for carers which would enable carers to receive information about events e.g. carers rights day, carers day, activities during carers week and information e.g. carers news, training courses etc.

Content of the Profile

Information relating to the carer - the first part of the Carers profile picked up general background information about the carer and the person(s) they care for. i.e.

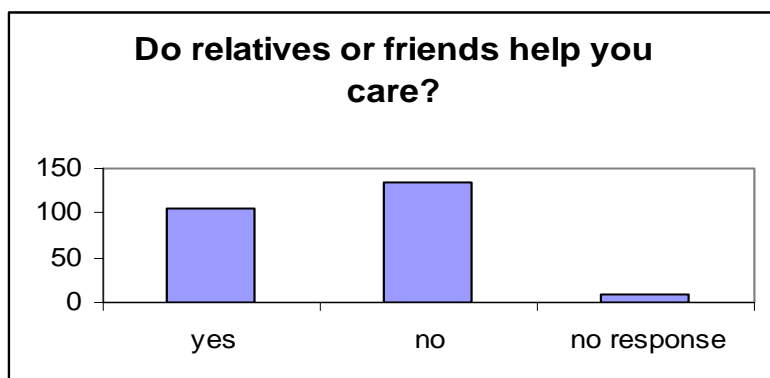
Type of information	How it helps
Name, address, postcode, telephone number	Provides a picture of carers across the borough and carers living outside the borough caring for someone within the borough
GP’s name and address	Identifies how the scheme is working in different practices
Date of birth	Identifies older and younger carers
Relationship to the cared for person	Identifies nature of the caring role
Ethnicity	Identifies possible “hard to reach” carers
Do they get any other help?	Identifies other range of support to assist
What kind of help do they provide?	Identifies type of support provided by carers
What other responsibilities do they have?	Identifies other commitments for carers
How many hours they spend caring	Identifies impact on carers on time spent caring

The graph below illustrates the age range of carers and cared for, 77% of carers who completed the profiles are over the age of 50 and just over half of the cared for are over 50.



Carers were asked specific questions about their caring role in relation to the type of help they provide and whether they get any help from friends or relatives.

As shown by the graph below the majority of carers do not receive help from friends or relatives.



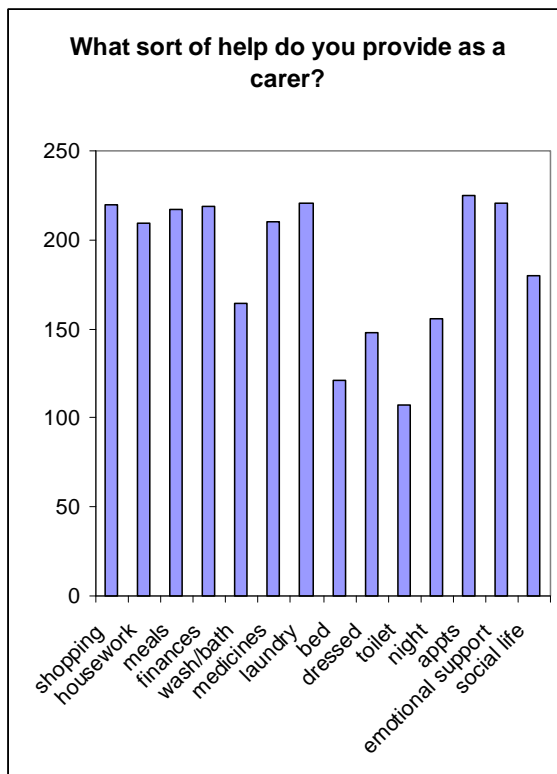
These are some of the comments made by carers about their caring role.

“I am being worn away by my role as a carer. I am a sole carer for my son and my mother and I will be 60 next year. How long will I be able to cope with this?”

“I feel very lonely, while being off colour myself and at 50 years old, I feel that no one seems to care about the carer – as I have never had a break for over 15 years of caring while poorly myself”

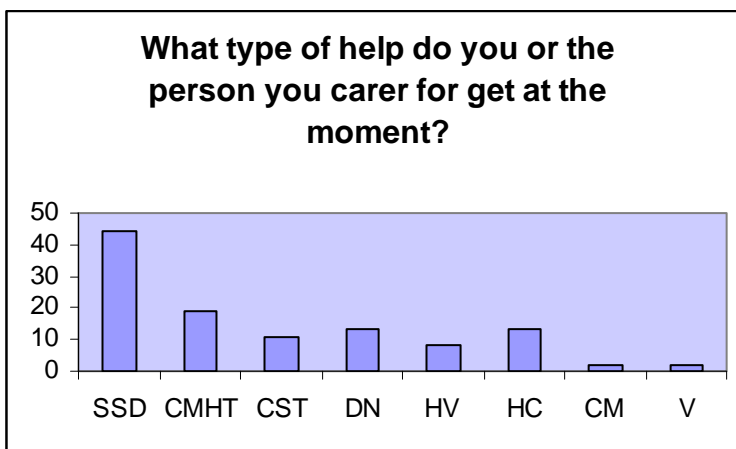
“Because my wife is 78 years and I am 79, we would just like xxxxxx to be able to look after himself.”

“He has had a lot of his problems for 57 years. He cannot read or write and I have to do everything for him. I am terrified of falling when I have to go out” (This carer is 86 years old)



As shown by the graph, carers provide a vast amount of help to the person they care for undertaking many routine daily tasks.

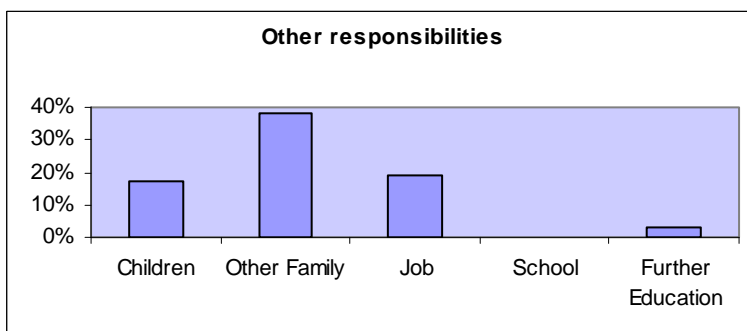
We also asked about other help that may be available to support the carer or cared for person. The majority of carers receive help from Social Services although just under 20% have support from health through the District Nurses and Health Visitors.



Sources of help

- SSD – Department of Adult Services (formerly Social Services)
- CMHT – Community Mental Health Team
- CST – Community Social Work Team
- DN – District Nurse
- HV – Health Visitor
- HC – Home Care
- CM – Community Meals
- V - Volunteers

We asked carers about their other responsibilities as well as caring and as shown by the graph the majority of carers (38%) have other family members to care for as well as children (17%) in addition to the cared for person. Just under 20% of carers are also juggling work in between their caring responsibilities.



We asked carers what types of support would improve the quality of their lives, the replies are listed below:-

- Information and advice on knowing what support is available
- Who to contact in a crisis
- More information on the illness of the cared for person
- More information on medication
- Being fully involved in the cared for persons treatment

The majority of comments received from carers were positive,

"I have found going to CIMH (Carers in Mental Health group) very good and don't feel I could have carried on without the group. It makes it easier to know you are not alone. I have made some good friends."

"We are members of a local carers group where we have access to information, speakers on a wide range of subjects and a lot of mutual support."

Carers thought that some of the benefits of joining a group was that it was helpful to meet, or just to know that there were other people in similar situations. It seemed helpful to know that other people struggled too, and carers were often able to compare notes and exchange hints and tips. Group outings and events provided opportunities for this.

"I think I am lucky in that we have a good team behind us. So far the services we have received have been excellent."

"Direct Payments has helped a lot. Social Services also help a lot but it was very hard initially to access assistance."

A number of carers felt that they had not been helped. This was mainly because they had either not asked for support, had not known it was available, or not needed it. There were a number of people who seemed generally dissatisfied with the services provided or felt it was pointless to ask for help.

"You are not given enough details about illnesses and after care, you are just thrown into things without being prepared for it"

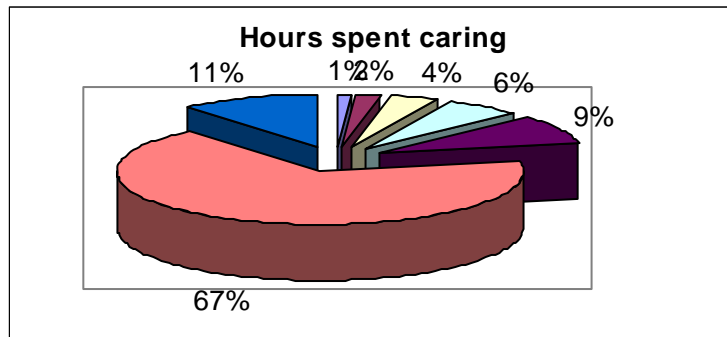
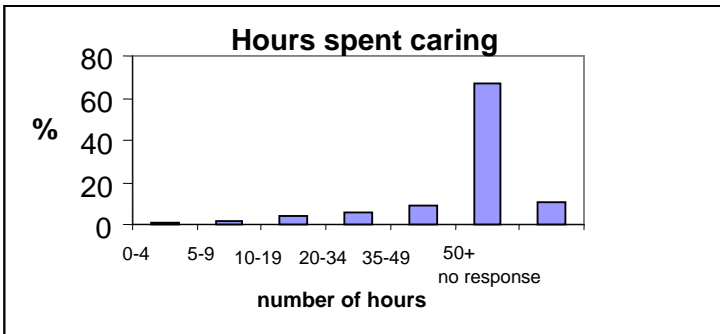
"I feel that my daughter and myself have been let down by social services. I had to fight for some months to get some funding and only the involvement of other parties made this possible"

"I have been caring for my wife for many years, it's a bit late now to be asking me what support I need"

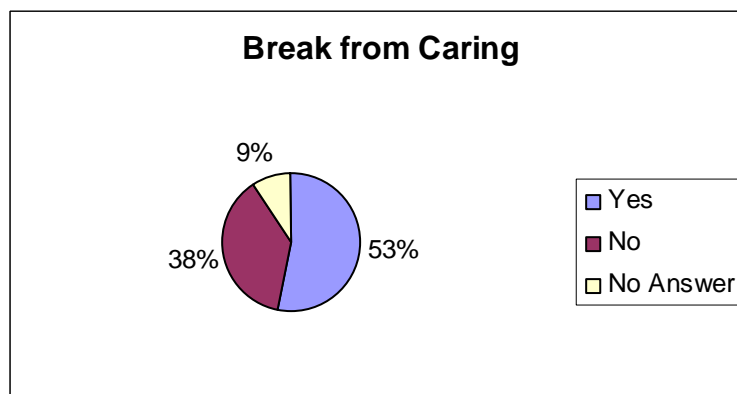
"I feel there is no point in me telling you all this, as no one ever takes any notice"

Breaks and well-being - We asked carers how many hours a week they spent in their caring role and were they able to take a break.

The majority of carers, 67% spent more than 50 hours a week in their caring role with 15% spending between 20 – 49 hours a week caring as shown in the graphs below.



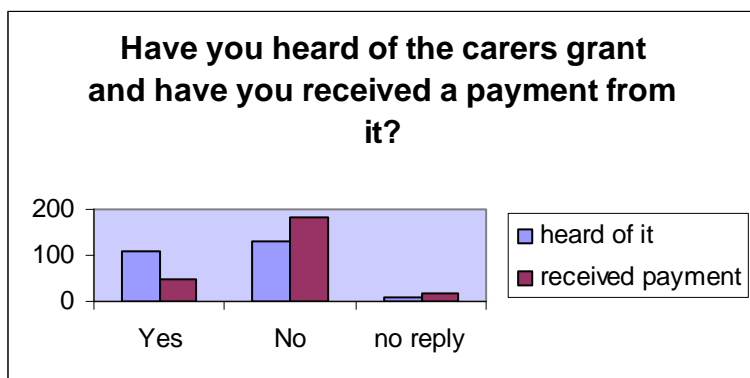
As outlined in the graph below - in relation to taking a break just over half of the carers were able to take a break from caring however a relatively high proportion (38%) were not able to do so.



Carers Grant

The Carers Special Grant was introduced by the Government as a result of the National Strategy for Carers. Every year, each Local Authority is given money to spend on helping carers take a break from their caring role. The aim of the grant is to stimulate diversity and flexibility in the provision of breaks for carers. The service/support provided is one that gives the carer a break from the direct responsibility of caring for a dependent person, by allowing them some time for themselves.

We asked carers if they had heard of the carers grant and if they had received a payment from it. The graph below illustrates the response from carers many of whom did not know about the grant. Of the carers who do know about the grant just under half have received a payment from it.



Those carers who had not heard of the carers grant and indicated that they would like information on how to apply were sent details of how to access funding from the grant.

A variety of services for carers are funded through the carer grant and a few examples of how the funding is utilised are outlined below.

- **Funding to voluntary organisations** - During the financial year of 2005/2006, approximately 900 carers in the Borough of Wigan have benefited from breaks via support groups that have received funding from the Carers Grant.
- **Individual payments** - Approximately 250 individual carers in the Borough of Wigan have accessed a one off payment from the Carers Grant.
- **Carer Centre –**
 - 23 carers regularly attended an art class at the Wigan and Leigh Carers centre.
 - Over 60 carers accessed counselling provided through Wigan & Leigh Carers centre at venues in the Borough of Wigan.
 - Approximately 75 carers benefited from aromatherapy sessions provided by the Wigan and Leigh Carers Centre.

Carers' assessments - What is a carer's assessment?

Under the "Carers' Recognition and Services Act 1995" and "Carers and Disabled Children Act 2000" carers are entitled to an assessment of their own needs. This applies even if the person cared for is eligible for services but for some reason does not want to have an assessment. The legislation provides for carers to have an assessment of their needs in their own right.

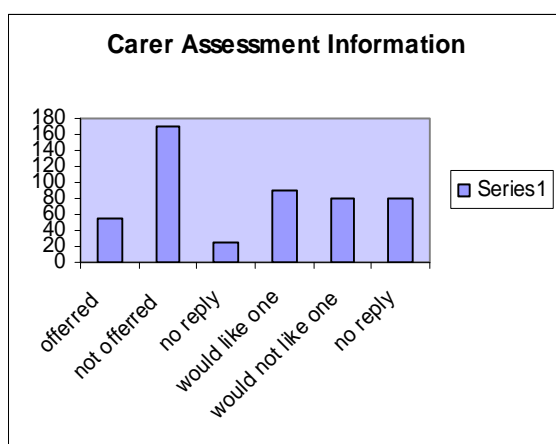
As a carer when the person you care for is having their assessment (or a review of their needs), carer you are entitled to as assessment of your own needs as well. The carer's assessment can be done at the same time as the cared for person's assessment or it can be done separately.

The recent Carers (Equal Opportunities) Act 2004 makes three main changes to previous carer legislation with the objective of providing further support for carers and helping to ensure that they are not placed at a disadvantage because of the care they provide.

1. Duty to inform – the act requires local authorities to inform carers that they may be entitled to an assessment of their needs. This links to identifying "hidden carers" those not known to the local authority and ensuring that carers are informed of their rights.
2. Carer's assessment - when undertaking a carers assessment the local authority must take into consideration whether the carer works or wishes to work and whether they participate or wish to participate in any education, training or leisure activity.
3. Cooperation between authorities – the act provides for co operation between local authorities and other bodies in relation to the planning and provision of services that are relevant to carers.

Carers were asked if they had been offered a carers assessment and if not, would they like to be offered one.

As shown by the graph the majority of carers had not been offered an assessment out of which just over half indicated that they would like to have one.

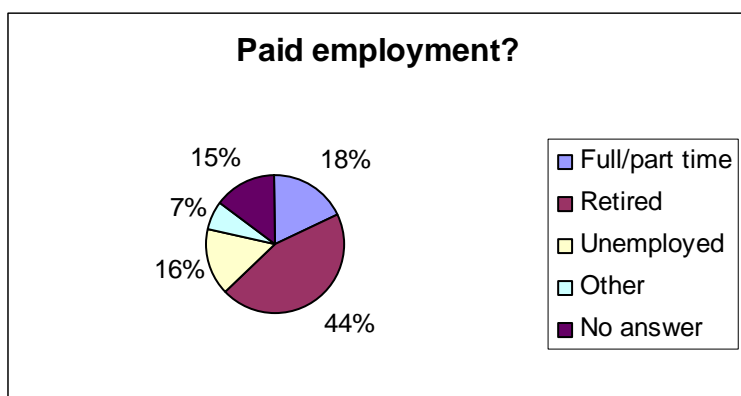


Information on how to request a carer's assessment was sent out to those carers who expressed an interest in having an assessment. As services are provided in line with guidance from the Department of Health called "Fair Access to Care Services" which says who is eligible for adult social care, carers were also sent information about other agencies who may be able to offer them support.

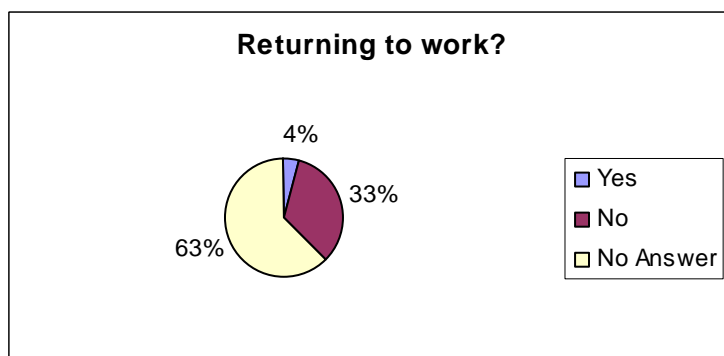
Carers can access the assessment process in the following ways:-

- Carers can Self refer through Adult Services Central Duty Team
- Carers can request an assessment from a Social Worker/care co-ordinator at the same time as the assessment for the cared for person
- Carers can indicate that they wish to have an assessment as part of the application process for the Carers Grant.
- Carers can indicate that they wish to have an assessment as part of the completion of a carers profile

Is combining work and caring possible? - As the new legislation takes into consideration whether a carer wishes to work we asked carers about their work role. As shown by the graph the majority are retired however approximately a third could be part of the workforce and of this just over half are in full/part time employment and just under half are unemployed.



We asked carers if they would they like to return to work if they could and a small proportion expressed an interest in getting back into the job market.



The carers that replied “yes” to the question were signposted to agencies that could provide support and information on the possibility of returning to work.

Training - Carers were also asked if they would benefit from training and if so, what kind?

Some of the training needs identified by carers were:-

- Mental Health Awareness
- Manual Handling
- Speech and Language
- Feeding
- Managing difficult behaviour

As a result of the responses received and the interest in training expressed by carers through the profiles a sub group has been formed from the Joint Training Partnership Group (JTPG). The JTPG has an overview of training within Adult Social Care and the sub group has been set up specifically to consider the training needs of carers

A rolling training programme aimed specifically at carers is now being developed. All carers expressing a wish for training will be given the opportunity to attend the sessions in due course. Training opportunities will be promoted to carers through contact with groups and also to all the carers on the carer register.

We also asked carers whether they would like to be involved in “Having a Say” in carers issues. Those carers who expressed an interest in being involved in the planning and decision making process on behalf of carers events, the carers grant etc., will be given the opportunity to participate in meetings and “Have a Say” as a carer.

Finally we would like to say “thank you” to all the carers who have taken the time to complete and return the profile questionnaires.

The next steps

Wigan Borough Carers Strategy 2004-9 is a five year plan which consists of 6 quality standards:-

- Information
- Providing a break
- Emotional support
- Support that helps carers to care and maintain their own health
- Having a voice
- Recognition

The strategy is updated on an annual basis through an action plan which outlines priorities for the year. Information provided from the profiles has been incorporated into the Action Plan for 06/07 e.g.

- Training – training programme for carers covering different topics will be available in the near future with a start date for the first course in September.
- Information – production of fact sheets and general information directory.

Future work for the GP project

- Hospital discharge – promotion and raising awareness about carers issues within hospital setting to ensure information is provided to carers at the right time
- Health checks – following on from the theme of carers week “maintaining health and well being” the project worker will promote annual health checks for carers within primary care and encourage GP’s to set up a system to enable carers to have an annual health check.

- Fact sheets – general information sheet for carers
- Continue to build on good practice identified through the Princess Royal Trust for Carers “Best Practice, Better Practices – A New Deal for Carers in Primary Care” 2006

Report Produced by Carers Support Worker GP
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