

East Midlands Improvement and Efficiency Partnership



Practice based commissioning scheme to support carers in the East Midlands ▼



Improving help for carers in the local community.

Two initiatives set up in the East Midlands to improve support for carers ▼

Funded by the Department of Health East Midlands to support implementation of the national carers strategy, two projects have successfully taken place in the region to improve early access to information, advice and support for carers in primary care health settings.

Practice Based Commissioning (PBC) consortia were invited to submit innovative proposals costing

up to £25,000, to improve support for carers of people with long-term conditions. This recognises the pivotal role that primary care clinicians have in identifying and supporting carers, both in terms of their own health and in helping patients to maintain their support network in the community.

Newark & Sherwood PBC Consortium and Nottingham City Central PBC Cluster were both

chosen. Through different project approaches, to date, Newark & Sherwood has identified 85 new carers and Nottingham City Central made 37 onward referrals to other services.

“Being able to provide a carer with information at a time of great pressure is of enormous benefit to the patient, their carer and also the

primary medical care team. We are now in a position to identify carers at the earliest available opportunity and general practice staff are far more aware of the issues surrounding this most important area.”

Dr Mark Jefford
GP Principal
Clinical Lead for Newark & Sherwood Health

Background: The national carers strategy ▾

The national carers strategy, first published by the Department of Health in 1999, and refreshed in 2010, identified priority outcomes including carers being supported to stay mentally and physically well, to be given earlier access to services and to be treated as partners in care. Good information and advice is crucial for carers who may have just heard that their relative has a diagnosis, or be under pressure as a result of their caring role. GPs and practice nurses are often in the best position to identify carers who need

support and primary care teams can be at the forefront in helping to link up carers with services and support networks, to prevent care at home breaking down.

As well as improving quality of life for carers, successful schemes had to evidence that they would provide a primary care perspective about how best to support implementation of the national carers strategy, as well as be cost-effective, sustainable and replicable.

The Newark & Sherwood Project ▾

The Newark & Sherwood PBC Consortium includes 14 GP practices and their carers scheme initially covered two practices, Barnbygate Surgery and Fountains Medical Centre, with a combined registration population of 27,070.

A further four practices will form part of the scheme in due course. They had identified a gap in support for carers particularly for people dealing with dementia and end of life cases.

Key Performance Indicators

- To identify more carers in the target area.
- To identify carers from the harder to reach groups such as the travellers community.
- More carers will receive information about the condition for which they are caring and where they can access advice and support.
- To create an improvement in carer's health and feeling of well being.
- Carers feel better able to carry out their caring role.
- To contribute to a reduction in unplanned hospital admissions for patient and carer.
- Assessment process is accessed and needs addressed.
- Promote carer awareness in general practice.

The importance of working in partnership

A fundamental element to the success of this project was working in partnership with relevant local organisations. Three partnerships in particular stood out:

- Voluntary sector: The voluntary sector is at the heart of this project. It can signpost what is already available and therefore avoid duplication and identify gaps in carers' needs.

- NHS: In Nottinghamshire, it was found that the NHS provided a key link between the key teams dealing with dementia and end of life influencing strategy and service development.
- Patient participation groups (PPG): PPGs are a key resource for gaining understanding of the needs of carers and how best to meet these needs within individual practices. The PPGs have been joining forces to make a new joint PPG within Newark. Last October they put on a Health Awareness Day, where GPs did short talks on various issues.

Activity to support carers in Newark & Sherwood

In Newark and Sherwood, a number of different activities took place with the two GP practices to meet the project's objectives.

Carer Co-ordinator: A Carer Co-ordinator was appointed to work three days a week based within the Community Voluntary Services to work with practices and patients. This included a day in each GP practice. All identified carers were sent a letter to say this role had been created and were invited them to drop in for a chat, to book an appointment, or even a telephone discussion, whichever best met their needs. The GPs also promoted the service in the local and free newspapers to generate awareness in the local community.

Website: Both practices were encouraged to put information about the role of the carer through their websites. Through this, carers are prompted to identify themselves to reception staff.

Halo symbol: Once it has been established that someone is an unpaid carer, a special, instantly recognisable symbol of a person with a halo is added to the patient's records. This ensures that the GPs and practice nurses are aware of their role and that practice staff can be more sensitive to the individual carers needs.

Questionnaire: During the peak flu season between September and December 2010, a questionnaire was distributed among local surgeries and carer groups, targeting both registered and unregistered carers. The questionnaire asked people if they had registered with their GP practice and if so, what information they accessed and what they found useful. It also asked if they had received a carer assessment. 60 people responded to the questionnaire and as a direct result 41 new carers were identified.

Practice training sessions: Training took place with staff from both practices to ensure that all team members were engaged with the project. 12 people attended, including GPs, nurses, reception staff and PPG members,

representing 44% of the total staff. The training began with the County Carer Co-ordinator giving an overview of her role, with more detailed information then given by the local Carer Co-ordinator. She spoke about direct carer issues and the challenges of accessing services with a cared for person at home, for example, the need for more flexibility for appointments.

Alzheimer's Society training sessions: A six week training course by Alzheimer's Society was provided to help patients and carers understand the information that people need around dementia care.

Dementia cafés: Two dementia cafés are run by the Alzheimer's Society in Newark, providing an informal environment for carers of people with dementia as well as the cared for. Guest speakers are invited along to give additional information and advice, for example about carer breaks. The dementia cafés also provide a forum for carers and the cared for to undertake activities together, for example, gentle exercise, in a fun and relaxed environment. At the start of the project there was just one dementia café in Newark, with approximately 20 attendees. This has now risen to three, with approximately 60 attendees each month and still growing.

Dementia Cafés Carers Group –
Due to the success of the dementia

cafés, a more focused group has been established, aimed at new carers who may wish to seek out more detailed information and advice at the beginning of their carer journey.

Handbook for Carers – An A to Z of carer support information was developed using currently available information to avoid duplication and make it easier to access by carers. This information will be available in Libraries and also local information centres and district council information. The A-Z directory means that information is readily available at many local sites including GP practice, Libraries, The Alzheimer’s Society, Local Hospice, Local Information Centre and Community Service Volunteers.

Information Sheet – It was agreed from the onset that sustainability was an issue and to be mindful of rolling this project out to all Newark & Sherwood practices. As the patient participation groups meet quite regularly it wasn’t long before other local practices were asking for the Carer Co-ordinator to help them improve awareness for carers in their own practices. As a result of this a one page information sheet was produced entitled ‘How to improve carer awareness in your practice’, which covers the basic quick wins for practices and their carers.

Outcomes against the Key Performance Indicators

To identify more carers in the target area

A total of 85 patients and carers attended regular meetings at The Hospice and Alzheimer’s Groups, which raised awareness and encouraged more carers to come forward. Within the GP practices, the training and awareness sessions with staff meant that more carers were identified when visiting the practice. Regular Carer Co-ordinator sessions were also held in the waiting room to let patients know that the Carer Co-ordinator was available to give them advice and support on a one to one basis.

To identify carers from the harder to reach groups such as the travellers community.

As part of the local voluntary sector, the Carer Co-ordinator had access to current schemes being run for the local traveller community and worked closely with the Traveller Support Officer, a joint health and voluntary sector funded role. As a result of the joint working, information was shared and available for travellers and their families, which meant that rather than asking for help, it was instantly available.

More carers receive information about the condition for which they are caring and where they can access advice and support.

As part of the partnership working with the Local Alzheimer's Society and Hospice current relevant information became easy to access for patients and carers. This information was included in the A-Z of services developed as part of the project and both agencies will be using the directory in the future. Both the local Hospice and Alzheimer's Society agreed it was beneficial to have the local information for carers in one place and easily accessible for the various local groups.

To create an improvement in carer's health and feeling of well being.

Carers identified on questionnaires and through group events that they now know where to access unbiased advice and support. Carers commented they felt less stressed and had an increased feeling of wellbeing when concerns could be talked over and discussed immediately with the Carer Co-ordinator instead of having to worry alone. Carers also like the convenience of the Carer Co-ordinator being available at GP practices so the service could be accessed along with a regular appointment or prescription collection. In the future carers will be able to access information via a variety of sources including GP practices, websites and a local hospice information centre.

Carers feel better able to carry out their caring role.

Consensus of opinion was that the presence of the Care Co-ordinator helped to alleviate stress for the carer, enabling them to focus on carrying out their caring role. The creation of two new Dementia Cafés meant carers could attend with their cared for and share experiences, obtain support and advice and have social interaction outside of the home, making their caring role more manageable for the rest of the time.

To contribute to a reduction in unplanned hospital admissions for patient and carer.

Carers have commented that their discussions with the Carer Co-ordinator have resulted in fewer GP visits. Carers commented that at times they were using GP appointments to try and gain support and information. Now they have access to this information through either the Carer Co-ordinator or GP practice via a call to the Carer Co-ordinator or through the Directory of Services for Carers.

Assessment process is accessed and needs addressed.

Working in partnership with the practices, the Carer Co-ordinator contacted all the carers identified on practice systems and asked them to fill out a questionnaire and asked if they had received any support or if they still needed support.

Promote carer awareness in general practice.

Carer awareness in GP practice was definitely a very positive outcome for this project. Involvement in the local patient participation groups means that the project was held at the heart of the practice and very patient focused. Highlighting to GPs

what a big difference some very small changes could make helped to gain GP and whole practice engagement.

Carers Identified

The above activity led to many new carers being identified in the areas involved in the project:

	Year	No of carers identified
Barnbygate Surgery	2009	3
	2010	16
	2011	1 (early part year data only)
	Sub-total	20
Fountains Medical Centre	Year	No of carers identified
	2009	6
	2010	38
	2011	7 (early part year data only)
	Sub-total	51
	Overall total	71*

*An additional 14 carers were identified through the questionnaire from outside the two GP practices, making the grand total 85. They were advised to tell their GP that they are a carer

Questionnaire Results

Questionnaires have been distributed at a variety of events including flu clinics and carer events and also through the patient participation groups within the GP practices. 14 practice staff undertook carer awareness training. 200 questionnaires have been circulated and 91 carers contacted via GP registers. Of these 291 carers, the survey showed that:

- 60-40 not registered/registered split as to whether carers are registered or not.
- 71% of people had heard about carer assessments.
- 34% of people had received an assessment.
- 62% of carers are female, 31% are male.
- 81% of people identified themselves as a carer.

- 40% of carers have their own long term conditions.
- 71% of carers care for more than 50 hours a week.
- 90% are the main carer.
- Just over 50% say it's not easy to find the support needed.
- 50% say they would benefit from training to help in their role as a carer.
- Over 50% disagree with the statement "the help I received was given at a time it was most needed".
- 62 carers were identified in total, 14 from GP practices.

"Following the success of the initial phase of the project we are continuing the work into the future by working in partnership with the local hospice information centre, who are using our information packs and practice contacts to support carers, also ensuring that information is available within practices and local libraries. We continue to work with other local practices to ensure that project is rolled out across the whole of Newark & Sherwood."

Sue Cox
Pathway Development Manager
Newark & Sherwood Health

The Nottingham City Central PBC Cluster Project ▾

This pilot scheme was set up to provide information, emotional support and signposting through a facilitator for carers, referred by GPs or identified from the Community Neurology Service (CNS). The support for carers of patients with long term neurological conditions is a joint project between City Central PBS Cluster and the CitiHealth NHS CNS. The CNS is a multi-disciplinary team spanning health and social care, and offering the service user choice, joined up service provision and excellent rehabilitation and support within the community setting.

Key objectives

The key objectives identified for this project were as follows:

- Help carers and families feel that they have been appropriately supported.
- Enable carers and families to feel more able to cope with the physical, psychological and social effects of long term neurological conditions (LTNC).
- Improve carer access to a range of services through signposting.
- Empower carers to make beneficial lifestyle changes.

- Improve carer support awareness and competence in primary care.
- Reduce the number of carer support-related GP consultations.
- Increase the information and emotional support available to people with LTNCs, their families and carers
- To promote better physical, psychological and social coping with the effects of LTNCs and related disability
- By offering regular support, the service will ease the burden on GP services, knowing they have a trained worker whom they can discuss fears and worries, hence a reduction in support visits by carers to GPs
- Reduce emergency admissions for NLTCs related to carer not coping with their role

Project approach

The approach for this project was to identify and target a small number of GPs with a specific interest in carer issues. A specific Carer's Support Worker role was also established to scope out what information and advice was already available and how best to target the GPs.

Rebecca Thompson who took this role, said, *"I have a special interest in this area and also work for the Carers Federation. The biggest challenge is engaging GPs and we talked to Newark & Sherwood about their*

activity in order to share learnings and best practice."

Activity to target carers and GPs

Information Leaflet: An information leaflet was produced to introduce the carer support service and the Carers Support Worker role, giving contact details and availability.

Carers Information Leaflet: An information leaflet was also created for carers and distributed when any carer visits took place, as well as when the Carer Support Worker first started working with carers. This provided details of the advice and information available to them.

Support Pack: A support pack was prepared to assess carers' needs in order to develop an action plan. This included an initial questionnaire as well as an exit questionnaire, which covered general health service contact for example contact with nurses and clinicians, such as physiotherapists. The initial questionnaire established if the carer had received an assessment, their awareness of the support available, including financial support and the number of visits made to the GP. The exit questionnaire established how the carer had benefited from the role of the Carer Support Worker. An assessment was also completed to record the levels of carer strain on the Caregiver Strain Index (CSI). All carers indicated a high level of carer strain, scoring seven or over, from a possible 13.

Team training: Training was provided for the community neurology team who work closely with clinicians. The training was based around common carer themes such as guilt, fear, anger, as well as the grief of losing the person they once knew and loss of sense of self and confidence. The training reviewed two case study examples and looked at the support which was needed and the support which had been given. Approximately 20 people attended this training.

One-to-one support from Carer Support Worker: This became available for people in their own homes on a fortnightly or monthly basis. It also enabled referrals to be made organisations such as the Carer's Federation, Action for Young Carers, benefits advice, Parkinson's UK, MS Society and Dial-a-ride.

Carers Support Group: The Carers Support Group started in January 2011 and meets on a monthly basis to provide an informal environment for carers to spend time with other people in the same situation and share their experiences. 17 people attended the first meeting.

Voluntary Group Links: The Carer's Support Worker is liaising with specialist nurses and voluntary groups such as Parkinson's, Epilepsy as well as MS specialist nurses and Parkinson's UK, Epilepsy Action, MS Society and Carers Federation projects to generate

referrals and establish joint working methods.

Case Study – Monica's Story

Monica is a single parent caring for her young adult daughter, Sarah. She also has two other children living at home.

Support needs

Monica has been resistant to letting services into the home, especially those involved with her daughter's care, often feeling criticised. She can often become defensive, responding to care or medical staff in a hostile and aggressive manner. As a result of this Monica is left almost solely on her own to care for Sarah.

Monica feels isolated and anxious about engaging with the outside world and subsequently doesn't go out very often and has very little direct contact with others socially.

Due to Monica's low mood, anxiety and lack of routine within the home, there are substantial issues around her youngest child's school attendance.

Monica and her family have not settled into the house after their recent move; there are unpacked boxes and furniture everywhere. Monica states that she does not have the time or motivation to organise rooms and storage in the new home.

Although Monica did not identify this as a support need, her youngest son is not attending school.

Support given

Initially support was offered on a weekly or fortnightly basis and sessions took place both within the home and at community venues such as cafés. Monica spent a great deal of time talking over the traumatic course of Sarah's illness and her experience of caring for her with the Carer Support Worker.

As Monica began to feel lifted in mood she felt more motivated to begin to get the house in order. One support session focussed around going out to get decorating materials as Monica wanted to decorate her living room as the first step to sorting the house out.

The Carer Support Worker made double visits with a clinical staff member so that she could undertake direct work with Sarah without having to manage Monica's sometimes negative and/or aggressive attitude and behaviour.

The Carer Support Worker referred Monica to the Carer's Federation. The purpose of this was to open up access to another carer's support group and network. As Monica had identified that the family had not had a holiday for many years, it was also hoped that they could access one of the Federation's caravans, which has disabled facilities for Sarah. Although initially resistant, Monica

has now made the decision to access their counselling service.

Monica was supported to liaise with school to get youngest son back into regular attendance. The Carer Support Worker also informed Monica and her youngest son about Action for Young Carers and how they work to support children and young people in their caring role. Support was offered to the oldest son; he was unemployed and wanted information about accessing to volunteering opportunities.

As Sarah's health has improved, support sessions have become less frequent as Monica has regained more personal free time and subsequently feels better in mood and more able to pursue her own interests again.

CSI Results

Carer strain was measured using CSI and both pre and post input showed that carer stress levels had reduced for 90% of carers questioned. However, 60% of the carers whose CSI score came down, still indicated high levels of stress, as their score stayed above 7. Upon completion of their second CSI, 50% of carers' scores were below 7, indicating that stress levels are no longer 'high'.

The table overleaf shows the results of the post input satisfaction questionnaire.

Had someone to talk to.	100%
Had been listened to.	100%
Had received advice or information about other services.	90%
Had been referred to another service that helps or supports me.	60%
Had a better awareness of the welfare benefits they are entitled to.	70%
More capable of coping psychologically (e.g. feeling more positive, less stressed, tearful and angry).	80%
More capable of coping physically (e.g. better able to carry out day to day caring responsibilities).	70%
More capable of coping socially (e.g. less isolated, seeing friends and relatives more, more informed of other services that can help, contact with other carers).	80%

Comments from health professionals from within the CNS ▾

Social Services Occupational Therapist, Community Neurology Service, Nottingham City Council

Knowing that the Carer Support Worker was there to offer support to the carer meant that I was able to focus on client’s needs and remain confident that the carer’s needs were also being addressed. I was also able to gain very useful information from Carer Support Worker regarding the carers’ feelings about his caring role and this helped me with planning my intervention and methods of approach. As the Carer Support Worker was able to be very flexible about meeting the carer around his work schedule, this was invaluable as I would not have been able to offer that.

The support offered by the Carer Support Worker to another carer enabled me to have a clearer picture of the situation as a whole and to be confident that this carer was given opportunities to share her views and express any difficulties. It also gave me useful ideas for strategies to use when discussing the future with both of them as I was able to gain an understanding of her mind set from the Carer Support Worker involvement with her. Due to this we managed to work through some difficult issues and make plans for the future, something which they had both avoided previously.

I feel very lucky that we have such a valuable resource as a carer support worker on the team and I know that

as the Carer Support Worker also offers groups as well, that carers of our clients have good opportunities of different types to meet their needs. This is invaluable when they are in a caring role for someone with a degenerative condition. Without the Carer Support Worker I feel those carers would have access to far less support and this could impact on the care they are able to offer and their experience of it, therefore impacting on the client themselves.

Occupational Therapist, Community Neurology Service, Citycare Partnership

I have found it very useful to have Carer Support Worker input with clients. The Carer Support Worker has been able to focus on carer's issues, which has enabled me to focus sessions on the client.

The Carer Support Worker has brought knowledge and expertise of carer's issues and services available. For four clients it would have taken valuable clinical time trying to find out that information and offer the support required. This had direct impact on meeting needs identified by the client and families as efficiently as possible.

Carer needs are integral in ongoing long term management and support for a client. The Carer Support Worker has been able to see four clients that I have been involved

with. Without her input I would have spent at least 25% of my time dealing with their issues. Therefore I believe that the Carer Support Worker has clearly developed a person centred support for carers and our clients, which has not only freed up therapy time but allowed the carers and clients' needs to be more fully met. The Carer Support Worker is an integral part of the Community Neurology Service and highly respected member.

Assistant Practitioner, Community Neurology Service

It is great to have a Carer Support Worker in our team. I have found the carer's service really useful for our client group. In our current caseload we come across complex cases and I strongly believe that carers need a good level of support which has been excellently provided by the Carer Support Worker. Referring to the Carer Support Worker has been really easy. From my experience, carers have felt a lot more supported, which, in turn, has surely helped in achieving positive outcome for our clients, thus fulfilling our team goals.

The Carer Support Worker role is definitely a team requirement and I do hope this service is extended for the dual benefit of patients and their carers.

Nurse Specialist, Community Neurology Service

I have been impressed at the way the Carer Support Worker has quickly picked up referrals for carer support. The Carer Support Worker understands the complexities of the client group, especially people with Parkinson's and dementia. I have been able to prioritise my case load and visited my patients earlier because of the Carer Support Worker's timely referrals.

We work well together and the Carer Support Worker knows when to refer for urgent social services

assessments and emergency respite. The Carer Support Worker helps me with my clinical caseload as I am able to prioritise my visits depending on the level of carer strain. We can work on crisis avoidance, arrange respite, day care, hospice at home and prevent hospital admissions wherever possible.

The Carer Support Worker shows emotional intelligence and I trust her judgement when she brings back a complex medical situation to the team. She is a valuable member of the Neurology team.

Looking to the future ▾

A Steering Group has been established, which includes representatives from health and social care, and the voluntary sector. Part of the remit of this group is to offer guidance and expertise, and to look at options for sustainability.

"It is clear that the Carer Support Worker role has been a success and sustainability is crucial to build on this success. There are many further developments that the Carer Support Worker would like to pursue should this pilot be extended. This includes developing links with the GP practices, establishing

clear pathways through primary, secondary and voluntary sector for carers and training and development to raise the profile of carer needs. The Carer Support Worker would also like to see further development of the Carers support group and links into established support groups in the area.

We are currently exploring funding avenues through the commissioning process."

Julia Webster
Team Manager
Community Neurology Service
Nottingham Citycare Partnership

Contacts ▾

For more information about the Newark & Sherwood project, please contact:

Name: Sue Cox

Job Title:

Pathways Development Manager

Organisation:

Newark & Sherwood Health

Tel: 01636 594818

Email: Sue.cox@nottspct.nhs.uk

Web: www.nottspct.nhs.uk

For more information about the Nottingham City project, please contact:

Name: Julia Webster

Job Title: Team Manager –

Community Neurology Service

Organisation: Nottingham Citycare Partnership

Tel: 0115 883 4830

Email: Julia.Webster@

nottinghamcitycare.nhs.uk

Website: [http://www.](http://www.nottinghamcitycare.nhs.uk/)

[nottinghamcitycare.nhs.uk/](http://www.nottinghamcitycare.nhs.uk/)

[your-services/your-community-](http://www.nottinghamcitycare.nhs.uk/your-services/your-community-services/402)

[services/402](http://www.nottinghamcitycare.nhs.uk/your-services/your-community-services/402)

For general enquiries, please contact:

Name: Sue Batty

Job Title: East Midlands Joint

Improvement Partnership Manager

Organisation: Nottinghamshire

County Council

Tel: 0115 977 4417

Email: Sue.Batty@nottsc.gov.uk

Website: [http://www.](http://www.thinklocalactpersonal.org.uk/Regions/EastMidlands/)

[thinklocalactpersonal.org.uk/](http://www.thinklocalactpersonal.org.uk/Regions/EastMidlands/)

[Regions/EastMidlands/](http://www.thinklocalactpersonal.org.uk/Regions/EastMidlands/)

East Midlands Improvement and Efficiency Partnership Case Studies

The East Midlands Improvement and Efficiency Partnership (EM IEP) is committed to celebrating the successful, innovative and imaginative project work that exists in the East Midlands region.

The EM IEP Support Team publish case studies showing how East Midlands councils are improving services and delivering significant improvements and efficiencies.

The case studies are intended to inspire councils in the region, and indeed nationally, to transform services and benefit from the processes developed by those councils that have pioneered the way forward.


East Midlands


East Midlands
Improvement and
Efficiency Partnership