



York Carers

Carer's Scrutiny Review

Final Report

March 2011

COMMITTEE MEMBERSHIP

The Heath Overview & Scrutiny Committee established a Task Group to carry out this review on their behalf. The Task Group was made up of the following three members:

- Councillor Barbara Boyce (Chair)
- Councillor Tom Holvey
- Councillor Siân Wiseman

ACKNOWLEDGEMENTS

The Task Group would like to thank all those that took part in the review including officers at the Council, representatives from the voluntary organisations and the members of the public who attended the event at the Monk Bar Hotel.

FOR FURTHER INFORMATION

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CHAIR'S FOREWORD

As I type this foreword the spellchecker doesn't recognise the word "carer" - I get the zigzag red line to say the word isn't in its dictionary. A fitting metaphor for a role which is often unseen, unrecognised and unappreciated.

There are thousands of carers across York, often female and middle-aged, but they can be of any age or gender and any educational or occupational background. What they share is commitment, hard work and worry. For many these are accompanied by exhaustion, struggle and ill-health.

In purely economic terms these unpaid carers give incredible value, but if they are to be relied upon to continue they need a little bit of care themselves.

Some of them have never had their work acknowledged in any way by anybody, they ask for nothing and that is exactly what they receive.

Members of the Task Group found the research for this report an enlightening and humbling experience. We are now asking for a little support for our recommendations which would make such a difference to those who work tirelessly to support their spouses, parents, relatives or friends who are in need of their care.



Councillor Barbara Boyce,
Chair

OBJECTIVES

At the start of the review the Committee agreed the following overall aim and key objectives for the review:

Aim

To promote the valuable work done by carers and to improve the way City of York Council and its key partners identify carers and ensure they have access to information and the support available.

Key Objectives

- i. To raise awareness of carers
- ii. To improve access to information for carers

CORPORATE STRATEGY

This review was closely linked to the 'Healthy City' element of the Corporate Strategy 2009/2012:

'We want to be a city where residents enjoy long, healthy and independent lives. For this to happen we will make sure that people are supported to make healthier lifestyle choices and that health and social care services are quick to respond to those that need them.'

RECOMMENDATIONS

The Carer's Review Task Group have made the following recommendations which were subsequently approved by the Health Overview & Scrutiny Committee:

Recommendations arising under Key Objective (i)

- a. That health commissioners and providers ensure that there is greater consistency around how carers are identified and once identified their needs addressed. This would need to include:
 - Training in carer awareness for all health professionals and allied staff
 - That the hospital looks at extending the innovative approaches they have been piloting and embedding these into standard practices for all admissions and discharges
 - That a written report be provided to the Health Overview & Scrutiny Committee on a six monthly basis in relation to quality indicators that are being monitored in respect of carers.
- b. That the Multi-Agency Carer's Strategy Group identifies where it would be helpful to provide public information about what it means to be a carer and how to access support to enable carers to identify themselves earlier.
 - Where places are identified carer awareness training should be made available for key workers.

RECOMMENDATIONS Continued

- c. That City of York Council reviews its Equalities Framework to ensure that carers become an integral part of all equality and inclusion work and this to include:
- Inviting a carer representative to become a member of the Equalities Advisory Group

Recommendations arising under Key Objective (ii)

- d. That health commissioners ensure that all care pathways provide guidance on the information and advice carers will need regarding specific medical conditions as well as sign-posting them to support and advice. This will need to address what the impact might be on:
- The carer
 - The family as a whole
 - The cared for person
- e. That Adult Social Services develop a clear pathway, which provides an integrated approach to assessment for the whole family whilst recognising the individual needs within the family and the impact of caring on the carer
- f. To continue to promote carer awareness an annual update on the Carers Strategy for York be presented to the Health Overview & Scrutiny Committee and thereafter to the Executive Member for Health & Adult Social Services

METHODOLOGY

The review took place between November 2010 and February 2011. The Task Group held both informal and formal meetings as well as a public event to gather evidence.

Meeting one: This was an informal meeting to scope and timetable the review and included setting the remit that the Task Group worked to. The remit, scope and timetable were subsequently agreed by the Health Overview & Scrutiny Committee.

Meeting two: This was a formal meeting to look at good practice examples, carer awareness raising, information provision in other areas, current practice in York, the York Strategy for Carer's document and information relating to key partners.

Meeting three: An informal meeting to put together questionnaires to gather evidence and plan the public event.

Meeting four: A public event was held to enable the Task Group to talk in person with carers and care workers

Meetings five & six: Discussion of the evidence gathered through the public event and returned questionnaires

Meeting seven: Consideration of the evidence received during the course of the review and formulation of the recommendations arising from the review.

NATIONAL & LOCAL POLICY CONTEXT

The Government's recently refreshed Carer's Strategy 'Recognised, Valued & Supported: Next Steps for the Carer's Strategy was published on 25th November 2010. One of its key messages echoes the overall aim of this review:

'Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of the contribution and involving them from the outset both in designing local care provision and in planning individual care packages.'

The key messages contained within the refreshed national policy do not significantly change the priorities within the current York strategy for carers, however this will be refreshed over the next 12 months.



KEY FACTS

For further information and reference sources on information within the Key Facts section of this report please refer to the full final report considered by the Health Overview & Scrutiny Committee at their meeting on 2nd March 2011. This can be found at: <http://modgov.york.gov.uk/ieListDocuments.aspx?CId=671&MId=5633&Ver=4>

Profile of Caring Nationally & Locally

- * Carers are of all ages and come from all walks of life
- * Three in five people will become carers at some point in their lives
- * In 2009/10 City of York Council completed assessments or reviews for 1473 carers and York Carers centre had 1959 carers registered on its database.
- * It is estimated that 37% of the caring population start caring and a similar proportion cease caring every year in the UK, which means over 6, 000 new carers in York annually
- * In a survey undertaken by Carers UK for a report in 2006, 65% of carers did not identify themselves as a carer in the first year of caring
- * Many carers are sustained in their role through natural support from their communities

KEY FACTS continued

Profile of Caring Nationally & Locally continued

- * The 2001 census records 17, 009 carers in York and 342 young carers aged 8 to 17. Since then the population of York has risen and gives rise to an estimate in carer numbers of 18, 676 in 2010.
- * York's older population is likely to increase by 32.7% within the next 20 years. The rise in the ageing population will mean a rise in the numbers of carers and a rise in the number of older carers.
- * There are various services in York that support carers & both the City of York Council and third sector organisations provide these.
- * A multi-agency Carers Strategy Group meets on a quarterly basis and there is an agreed 'York Strategy for Carers 2009-2011' (extended to 2012) and a Carers Strategy Action Plan. The York Carers Centre is also commissioned to provide a range of support for carers in York.



KEY FACTS continued

Economic Importance of Carers

- * In 2007 Leeds University published 'Valuing Carers: Calculating the Value of Unpaid Carers' which stated that *'The true value of the care and support provided by carers cannot be quantified, as caring is also an expression of love, respect, duty and affection for another person. However it is important to recognise the true scale of carers' support provided to frail, disabled and ill people. Our estimates here seek to highlight the importance of the contribution carers make, unpaid, in relation to the amount of money spent annually on health and social services.'*
- * The report indicated that unpaid carers in York alone are saving local health and social care systems approximately £223 million per annum.

Performance & Funding

- * Funding for carers support is currently provided primarily through the Carer's Grant which has traditionally been paid to the local authority as part of the Area Based Grant, but which will, from next year, form part of the overall grant settlement.

KEY FACTS continued

Performance & Funding continued

- * The Government gave Primary Care Trusts additional funding to support more carer breaks, this funding was part of their base budget. It was understood by the Task Group that the Primary Care Trust had not been able to release funding from base budget to increase services for carers. The multi-agency Carer's Strategy Group for York were advised that there was no specific funding allocated in the Primary Care Trust's budget for 2010/11 for carer's breaks.
- * Currently City of York Council is performing against its targets; however it is struggling to keep pace with the demand for assessments and there are currently waiting lists for new carer assessments.

OTHER INFORMATION GATHERED

Identification of Carers by York Hospital

The Chair of the Task Group wrote to York Teaching Hospital NHS Foundation Trust to ask them about their procedures for identifying carers who may be supporting patients at the Hospital. The following response was received from the assistant Chief Nurse:

OTHER INFORMATION GATHERED continued

Response from York Hospital

'We are piloting a health passport in neurology and this would be a useful way to identify carers formally and ensure robust communication with them. The Learning Disability Liaison Nurse works with all patients with learning disabilities who attend the hospital and she routinely identifies and involves carers as part of her role. Her input includes asking carers for feedback on their experience. In more general terms when a patient is admitted to hospital our routine information gathering is expected to identify who is a carer. In some instances this would be to ensure that there is not a 'cared for' person at home who requires urgent input as a consequence of an emergency admission of their carer for example and the converse to ensure we know who to communicate with if the 'cared for' person is admitted to hospital. Carers needs are considered in discharge planning, more specifically for complex discharges rather than routine hospital discharge and their needs are taken into consideration or indeed carers would be invited to a discharge planning meeting.'

The Task Group were encouraged by the new ways of working to identify carers & wanted the Hospital to embed these approaches into all hospital admissions and discharges.

OTHER INFORMATION GATHERED continued

Information Received at the Public Event & Via Completed Questionnaires

The Task Group were particularly interested in hearing first hand from carers and care workers and held a public event on 7th January 2011 at the Monk Bar Hotel, York. This took the form of a drop in session and ran from 2pm until 6.30pm. Approximately 20 people (both carers and care workers) attended the event to give their views to the Task Group.

In addition to this two questionnaires were devised and these were e-mailed to carer's organisations, condition groups, voluntary sector organisations, care workers and key partners. One questionnaire was targeted at carers and another at care workers. In total 34 of these were completed and returned.

The information received at the public event and that contained within the questionnaires was subsequently collated and attached as annexes to the final report arising from this review. This can be found at :
<http://modgov.york.gov.uk/ieListDocuments.aspx?CIId=671&MIId=5633&Ver=4>
or by contacting the Scrutiny Officer at City of York Council

FINDINGS

This section sets out a brief summary of the review's findings after consideration of all the information gathered. This formed the basis of the recommendations arising from the review and the following key themes were discussed:

The Importance of Early Identification of Carers

The NHS is undergoing significant change with new legislation aiming to pass the responsibility of Public Health to local authorities and commissioning to newly formed GP Consortia. It was therefore vitally important that key professionals, especially GPs were aware of carers from an early stage and identified them as soon as possible. GPs were often the first point of contact for carers who frequently accompanied the person they cared for to GP appointments.



There had been an incident reported in one of the returned questionnaires where a GP had refused to talk to a carer and not wanted them present with the patient for the appointment. However, overall the responses given were mixed in relation to how carer aware GPs were. There were strong indications that the way GPs behaved in relation to carers was variable. Other comments suggested

FINDINGS continued

the GP would be the best person to hand out information to carers in the first instance. Care workers who attended the public event believed that GPs should keep a register of carers.

Having noted the variability of the information received the Task Group asked York Health Group and NHS North Yorkshire & York the following questions:

Question 1 What is being done by NHS North Yorkshire & York and York Health Group to raise GP's awareness of carers and the role that carers undertake?

Question 2 Are NHS North Yorkshire & York and York Health Group currently undertaking any work to close the 'gaps in service' indicated by the variable comments received?

In summary the Task Group received the following responses:

From the York Health Group

York Health Group is very aware of the needs of carers and would like to raise their profile. There is not a specific plan to do this at present but it is an aspiration to be handed on to the new GP commissioning consortium. GP practices are

FINDINGS continued

The Importance of Early Identification of Carers continued

encouraged to hold a carer list and identify patients who are carers and offer them support and contact with York Carer Centre. York Health Group is in the process of commissioning a memory advisor whose role will include provision of information, guidance and support for carers.

From NHS North Yorkshire & York (the PCT)

The PCT chairs the York Carers Health Group that has an action plan with the aim of improving the health and well being of the carers. This includes the promotion of a self-assessment tool for carers to complete and then discuss with their GPs. The PCT also commissions the Carers Centre to promote carer's issues with practices, including how to identify carers and how to provide them with the relevant support.

As part of the Quality & Outcomes Framework (QOF) GP practices are expected to have a protocol in place to identify carers and a mechanism for referral to social services for assessment. There are no further requirements as part of their contract to do any more than this. However many GP practices have carer registers and some are more proactive than others in supporting carers. QOF visits are undertaken and questions are asked in relation to the support offered to carers.

FINDINGS continued

The Task Group appreciated that there was a willingness within both York Health Group and NHS North Yorkshire & York to address issues around carer identification. However it was unclear how the quality checks detailed in the responses would lead to a clear action plan and a clearer understanding by GPs of the impact caring can have on a carer's health.

On balance and having taken all the evidence into consideration, the Task Group believed that this was an area where there was room for ongoing improvement. There was further scope for some GPs and GP practices to be more carer aware and a need to establish consistent practice across all GP surgeries, ensuring all GPs and practice staff were able to identify carers and offer appropriate support and services. GPs also needed to work more proactively to recognise a carer's own needs as well as those of the person they were caring for. Recent changes to the NHS and the introduction of GP consortia made this a prime time to encourage GPs to undertake some work in this area.

Some GPs had been highly praised for their attitude towards carers and the help and support they had given and the Task Group did not want this to be forgotten.

FINDINGS continued

Recognising you are a Carer

Responses to the questionnaires and at the public event indicated that most people did not immediately recognise themselves as a carer with many feeling that they were 'just looking after my mother/child/spouse' or 'just doing my duty'. From the comments received recognising that you were a carer was often a gradual process, however it often became very clear at a point of crisis, such as hospital admission or diagnosis of a particular condition.

In some cases it was friends or health professionals that were the first people to recognise that someone was a carer. The Task Group felt that steps needed to be taken to encourage early carer self-identification so that the right information could be provided at the right time.

The multi-agency Carer's Strategy Group could undertake work to identify the key places where information can be made available, so that people can be encouraged to identify themselves as a carer at an early stage.

FINDINGS continued

Provision of Information

From responses received it became apparent that not all carers wanted or needed the same level of support as others. Information needed to be proportionate to the needs of each individual carer.

Some carers said that they preferred written information whilst others would prefer to talk with someone face to face. It was also important who gave information to carers, as they needed to be able to have confidence and respect for the person or organisation providing it. In the first instance the Task Group identified, through the comments received as part of this review, that this was about providing the right advice on the cared for person's medical condition.

It was important that a carer was able to understand the impact a particular condition would have on both the cared for person and the carer. In the second place it was important to have clear and up to date information and advice on rights for both the cared for and the carer and the support available to them. All Health professionals needed to think about the information they were giving and the impact it might have on the carer.

FINDINGS continued

A Carer's Own Needs

Some comments received identified that often more emphasis was placed on the needs of the cared for than on the needs of the carer. This meant that the carer's health often suffered as a consequence. Carers didn't always get enough time to spend on their own needs, especially if they were caring for more than one person. One person said directly that *'the impact caring has on carer's lives is not always recognised.'* However, other people commented on this point in different ways such as identifying the need for day care, respite care and help with non-personal matters such as organising housing or utility repairs. One commenter said that employers did not always afford the same consideration to carers as they would to parents for example.

In a recent case reported in the national media a child's parents spoke about the situation that many carers faced as well as a lack of available respite care:
'Caring for my daughter is relentless. She needs someone 24 hours a day. Caring takes over your whole life. Carers across the country are struggling the same way. It's not a new thing. It's been going on for years.'

FINDINGS continued

The public event and questionnaire responses highlighted the fact that some carers did not feel they received an holistic or integrated assessment. In York a carer's needs should be identified through the carer assessment process, however it was understood that this did not always happen in tandem with the assessment of the cared for. If the carer's needs had not been appropriately identified then the care package in place should be checked to ensure that it was providing the relevant help.

The Task Group asked the Assistant Director (Assessment & Personalisation (Adults)) at the City of York Council the following:

Question 1 How are carer and 'cared for' assessments currently undertaken and are there any plans to change this. Do you think there are any ways the assessments could be undertaken in a more holistic/integrated way?

Summary of Response *Assessments for the cared for person start with the Social Care Assessment following a referral to Adult services. The Care Manager undertaking the assessment would ask the Carer if they also wanted to undertake a Carer's Assessment. When there is a need to look at longer term support for the cared for person carers are asked what level of support they are able to give so that this can be taken into consideration.*

FINDINGS continued

A Carer's Own Needs continued

Question 2 Are there any reasons why both assessments could not take place at the same time/in parallel to each other?

Summary of response *There is no reason why an assessment can not take place at the same time. The difficulty for the carer could be that they may not be able to express their needs in front of the cared for person. Older people can sometimes underestimate their needs as a cared for person thus the Care Manager will have to support the family in making positive choices that do not diminish their independence.*

Many of the challenges facing carers and their families are understood by Care Management but the Task Group were not confident that there was an agreed way forward that would address the needs of a family as a whole as well as the needs of each individual within that family.

Apart from the benefits to both carer and cared for of having an appropriate care package in place there are also economic benefits that should be acknowledged. If carers are not fully supported they will be more likely to give up their caring role and the responsibility for and cost of care would most likely need to be borne by the public sector.

FINDINGS continued

Carer Awareness Raising & The Cheshire Carers Link Model

The Task Group considered the 'Cheshire Carers Link Model' which was developed through a multi-agency strategy group identifying 'carer link workers' or champions across health and social care teams. The carer link workers take on additional responsibilities and are a pivotal point of contact to provide advice, information and support to colleagues. Workers are provided with training and a toolkit to help them in their role. The Task Group did not look into the model in any detail but did recognise that it would not be difficult or expensive to build a carers element into the already existing Equalities Champion role at the Council.

The Task Group asked the Corporate Equality & Inclusion Manager at City of York Council for her views on this and she was of the opinion that this should be championed by the Executive portfolio holder for inclusion. She also suggested that it would be timely to consider amending the membership of the Equality Advisory Group to include a carer representative.

The Task Group were keen to encourage the Corporate Equalities agenda to support the changes brought in by the Equalities Act 2010, which gives carers greater recognition.

CONCLUSION

The Task Group were of the opinion that reviewing this topic was a significant milestone in itself towards raising the profile of carers within the city. The review had highlighted many positive aspects of the services available, in particular the 'Caring & Coping' course run by the Alzheimer's Society. This had been mentioned many times by carers at the public event and in responses to the questionnaires. In addition the Task Group recognised that several professional individuals had been named during the review in relation to the outstanding care and services they had provided to carers.

The Task Group also wished to acknowledge the valuable and unpaid work undertaken by carers. Carers saved the local economy a substantial sum every annum and in the hope that they would continue to do this it was important that, whenever and wherever possible, they could receive support and assistance.

The Task Group appreciated that in the current time of financial restraint there was a need to obtain the best results for the budget we currently had. However, if any additional monies were to become available the Task Group hoped that consideration could be given to fund respite care in order that carers could take some well-earned breaks.

SCRUTINY'S ROLE



For each completed scrutiny review, the Overview & Scrutiny Committee produces a final report containing their proposed recommendations for the Executive's consideration.

In most cases, the Executive will approve all of the recommendations made and will instruct officers to proceed with the actions required in order to implement them.

The Overview & Scrutiny Committee is responsible for monitoring the progress of implementation and receives regular update reports from the Scrutiny Officer. Once they are confident that a recommendation has been fully implemented they will agree to sign it off.

In addition, each year Scrutiny Services produces an Annual Report which includes an assessment of the successful outcomes from each completed scrutiny review.

Equality In Accessing Information

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