

Scrutiny review: Support for Carers

Joint Review of the Health Select
Commission and the Improving Lives
Select Commission

October – December 2013

Scrutiny Review Group:

Cllr Brian Steele (Chair)
Cllr Colin Barron
Cllr Christine Beaumont
Cllr Jane Hamilton
Cllr Denise Lelliott
Cllr Lyndsay Pitchley

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Executive summary

The aim of the review:

The review group was made up of the following members:

Health Select Commission

- Cllr Brian Steele (Chair)
- Cllr Colin Barron
- Cllr Christine Beaumont

Improving Lives Select Commission

- Cllr Jane Hamilton
- Cllr Denise Lelliott
- Cllr Lyndsay Pitchley

Summary of findings and recommendations

The six stated objectives of the review were to consider, as follows:

1. if carers generally identify themselves as carers
2. the degree to which carers access support or consider they need support to assist them in their caring role
3. who carers go to for initial support when they first become a carer
4. where carers usually go for ongoing support
5. the key factors necessary for ensuring carers receive good and timely information
6. any areas for improvement in current information provision

The review was therefore structured around these six objectives through engagement with carers at two events and through an on-line survey, followed by discussions with two small groups of carers to explore issues in more depth. Further evidence was provided by Council officers and partner agencies in health and the voluntary and community sectors.

Key messages that came out of the review are as follows:

Although many carers do access support there are a large number of “hidden” carers in Rotherham, who are key to the effective provision of social care. There is no doubt that should this hidden support system not exist, the cost burden to the main service providers would be huge. There is a very strong case, both morally and financially, to ensure that carers are provided with the most effective support possible.

Carers praised a number of organisations across all sectors, including some excellent work by named individuals, but also raised areas where their experiences had been less positive. The review discussed a number of good examples and noted recent work through pilot initiatives with scope for further development, but there are still some core areas requiring improvement in order to support carers.

It is the view of the members of the review group, therefore, that these carers represent a vital unpaid workforce within the Borough, and like all workforces they need investing in to get the best out of them. It is estimated that nationally, carers save the country an estimated £119billion in care costs. The review group consider that any resources invested within the carers community in Rotherham, therefore represents an invest to save opportunity, particularly with the demographic pressures created by an ageing population.

There are ten recommendations and in summary these focus on:

- increasing the number of people recognising themselves as carers and willing to seek support for this vital role they carry out;
- ensuring that support for carers adequately includes emotional support and counselling;

- providing a multi agency “carers pathway” that recognises the journey that carers are on and provides them with the correct support and information at the right time and in the right place on that journey;
- increasing the number of carers receiving a fit for purpose carers assessment, which is reviewed on an annual basis.

Recommendations:

1. That Rotherham CCG and Rotherham Council consider how this first line of support for carers to help them identify themselves, is commissioned, in partnership with GPs.
2. In looking at recommendation 1 above, the partners consider whether the positive assumption that a relative or friend is a carer unless told otherwise can be built into this process, and what information resources are required to back this up.
3. That Rotherham Council investigates further with the Advice in Rotherham partnership (AiR) and the Department of Work and Pensions, what specific information carers need to access benefits that are available to them. This may also help to identify more carers.
4. That Rotherham Clinical Commissioning Group and Rotherham Council, work with its VCS and other partners to create the carers pathway of support. This should include the effective multi agency use of carers assessments and crucially allocation of a “buddy” or “lead worker” to ensure that support is accessed consistently and according to the identified needs of the carer. This lead worker could come from the most appropriate agency identified for individual needs.
5. That Rotherham Council considers via its review of services to carers; the use of a new single contact number, a combination of Carers Corner and outreach facilities; and the replication of the carers card in schools for adult carers.
6. That the “triangle of care” presented by RDaSH be considered as part of this process as something that could be adapted and rolled out to all partners providing support to carers.
7. That Rotherham Council reviews its carers assessment tool in the light of the Care Bill to ensure it is fit for purpose. This should involve considering whether it could be less onerous and more appropriately named to reflect that it is an enabling process rather than an “assessment”, whilst complying with statutory frameworks.
8. That Rotherham Council looks to set more stretching targets for former NI 135.
9. That a full review is undertaken of the Joint Action Plan for Carers to ensure that it meets the recommendations of this review and is more accountable in terms of its delivery.
10. The review group recognises that these recommendations have resource implications but consider that the “invest to save” case for the Council and NHS is strong enough to warrant this. It therefore recommends that the £500,000 provisionally allocated to carers support in the Better Care Fund is allocated to implementing the recommendations of this review.

1. Why Members wanted to undertake this review

Following a Member seminar on dementia and ensuing discussion about the vital role and contribution of carers in Rotherham, at the request of the Leader, Cllr Roger Stone, Overview and Scrutiny Management Board agreed to initiate a review of support for carers. The purpose of the review was to establish the extent to which carers in Rotherham are able to access timely and appropriate information, which helps them to access support and services that meet any specific needs they have as carers.

There were six main aims of the review, which were to establish:

- 1 if carers generally identify themselves as carers
- 2 the degree to which carers access support or consider they need support to assist them in their caring role
- 3 who carers go to for initial support when they first become a carer
- 4 where carers usually go for ongoing support
- 5 the key factors necessary for ensuring carers receive good and timely information
- 6 any areas for improvement in current information provision

2. Method

A joint spotlight scrutiny review was carried out by a sub-group of the Health Select Commission and Improving Lives Select Commission, consisting of Cllrs Barron, Beaumont, J Hamilton, Lelliott, Pitchley and Steele (Chair).

An initial report to both commissions provided an introduction and set the local context - including the definition of a carer; a profile of carers in Rotherham based on the 2011 census; and an overview of current work to support carers through the Rotherham Carers' Charter and Joint Action Plan for Carers 2013-16.

For the purposes of this scrutiny review a carer was defined as:

“A carer is an adult or young person who provides unpaid care for a partner, relative, friend, an older person or someone who has a disability or long term illness, including people with alcohol/substance misuse and mental illness.”

Evidence for the review was gathered through the following means:

- An anonymous on-line survey on the Council website from 17 October to 15 November 2013 asking carers about their experiences of accessing information and support.
- Posters and a small number hard copies of the survey in Carers Corner and Healthwatch Rotherham.
- Direct consultation with carers at Fair's Fayre on 30 October 2013 and at the Dementia Café at Davies Court on 5 November 2013.
- Two informal discussion sessions with small groups of carers to explore issues from the survey in greater depth.
- Round table discussions with RMBC officers and partners from health and the voluntary and community sector (VCS).

Appendix 1 is a copy of the survey and Appendix 2 has a summary of the results and the equality monitoring information about the carers who took part.

Neighbourhoods and Adult Services (NAS) have also undertaken a recent review of current support services for carers, focusing on how support is currently provided to carers and how this may be improved. The intention is that the scrutiny spotlight review

complements the NAS review and adds value by looking at available support from the perspective of carers, focusing on access to information.

Members would like to thank everyone who gave evidence for the review and in particular the carers who gave up their time to participate in the discussion sessions. They would also like to thank Carers Corner and partner agencies in the voluntary and community sector, especially Alzheimer's Society, Carers for Carers, Crossroads and Healthwatch, who helped to publicise the survey and encouraged carers to take part in the review.

3. Background

In Rotherham and throughout the UK carers underpin the statutory services saving the country a vast sum in care costs annually; quite simply without their support the welfare system would fail. Estimates in 2011 by Carers UK and the University of Leeds calculated the value of care provided by friends and family members to ill, frail or disabled relatives at £119 billion every year nationally or £326 million per day. Further calculations estimated each carer saved the state on average over £18,000 a year. Here in Rotherham the role and value of carers has long been acknowledged, however forthcoming changes in the legislation will have implications for carers and the support they are entitled to receive.

Rotherham has a significant number of carers, many of whom are older people who may themselves have underlying health conditions. Having information widely available that is easy to understand and relevant is a key factor in ensuring carers are able to access services and support and maintain a good quality of life and their own health and wellbeing if they are to continue in their caring role.

The difficulty with supporting carers is that many of them are "hidden" to the various agencies that offer services to them. This has been found to be of particular concern to Members of the review group and their focus therefore has very much been about how effective information is targeted at this hidden and unpaid workforce.

3.1 Census data

The 2011 census data showed that although both women and men are carers proportionately there are more women carers than men in England and Wales - 57.7% compared with 42.3%. The share of unpaid care provision fell most heavily on women aged 50-64; but the gender inequality diminished among retired people, with men slightly more likely to be providing care than women.

Rotherham continues to have a higher rate of people with limiting long-term illness than the national average of 17.6% - 56,588 (21.9% of the population). The census also revealed that Rotherham's population is ageing faster than the national average with a 16% increase in the number of people aged over 65 (from 2001 – 2011). Those aged over 85 increased at over twice this rate (+34.6%). This population profile has implications for the number of people needing care now and potentially in the future.

In 2011, 31,001 people in Rotherham said that they provided unpaid care to family members, friends or neighbours with either long-term physical or mental ill-health/disability or problems related to old age. The number of carers has increased only slightly from 30,284 in 2001 but still equates to 12% of the population and is higher than the national average of 10%. One noticeable change is that compared to 2001 fewer people are now providing 1 to 19 hours of care a week (19,069 in 2001 down to 17,400 in 2011) but more are providing care for 20 or more hours per week. The number of people providing 20 to 49 hours care has increased (3,828 to 4,736), as has the number providing 50 or more hours (7,387 to 8,865). See graph in Appendix 3.

Carers were more likely to report their general health as 'Not Good', compared with people providing no unpaid care. 'Not Good' health was derived from those who answered 'fair', 'bad' and 'very bad' to the health question in the 2011 Census. The general health of carers deteriorated incrementally as the number of hours of care provided increased, up to the age of 65, across all economic positions. Providing 50 hours or more unpaid care per week appears to have the greatest impact on the general health of young carers under 24.

3.2 Lifestyle Survey

The Young People's Lifestyle Survey carried out annually with local schools also shows a large number of young people who identify themselves as carers. In the most recent survey 27% of pupils consider themselves to be young carers (up from 25% last year). Most are caring for their parents (57%) or siblings (60%). Around 20% were aware of the Young Carers Service (down from 24% the previous year).

4. Carers' Charter

The Council and Rotherham Clinical Commissioning Group jointly agreed a Rotherham Carers' Charter in 2013 which provides a clear commitment to all carers in Rotherham, replacing the previous Joint Carers' Strategy. Over the period 2013-2016 work is focusing on a set of four priority outcomes, based on the views and experiences of carers gathered through a range of consultation activities. These priorities are linked to the six priorities in the Health and Wellbeing Strategy.

- Priority 1 - Health and Wellbeing: all carers will be supported to make positive choices about their mental and physical health and wellbeing
- Priority 2 - Access to information: accessible information about the services and support available will be provided for all carers in Rotherham
- Priority 3 - Access to services: all carers will be offered and supported to access a range of flexible services that are appropriate to their needs
- Priority 4 - Employment and Skills: all carers will be able to take part in education, employment and training if they wish to

The charter contains various commitments linked to the four priority outcomes and each commitment is underpinned by a number of actions and measures which comprise the Joint Action Plan for Carers 2013-16. This was approved in March 2013 and in order to build on previous successes and achieve further improvements for carers, effective performance management is necessary to ensure meaningful and measurable outcomes.

5. Findings

5.1 If carers generally identify themselves as carers

A very strong issue emerging from the survey, consultation with carers themselves and with the professionals who work to support them was that for many the transition from family member/friend to carer is a gradual one. This means that they don't often see themselves as 'carers' with a common description being that it "creeps up". However for other carers the change to becoming a carer is an overnight one, for example following an accident, brain injury or stroke. Most carers see themselves in terms of their relationship to the person being cared first and foremost.

The implications of this are around how carers are identified in the first place and how support services work to support carers in these circumstances – what is provided and how. Members considered carefully how this might most effectively be addressed and

drew on experience from other areas. For example, in Swansea, professionals work on the presumption that the close family member is a carer and are encouraged to ask questions to determine if this is the case. This removes the need for the carer to self identify in order to receive support. Members felt very strongly that the onus should be on the professionals working with the person being cared for to identify the carer and to provide them with the information they need to firstly recognise their role, and secondly to access the support they need. It was considered that the point of diagnosis for the person being cared for is key, making health services paramount to this process, and thus in many circumstances is likely to be a GP. Further work with GPs on maintaining carer registers is required and this will be raised at the Practice Managers Forum as not all practices use and update them regularly as yet.

“Your details be taken at time of diagnosis and someone to contact you (shortly after) and send you more information and explain what will be available to you”
“There are plenty of posters etc in GP surgeries which ask you to register if you care for people. Not sure how registering actually benefits someone”
“Information should be available at discharge from hospital”
“More promotion needed through community corner at TRFT”
“Overall GPs are very important, doctors surgeries should have more information”

Positive work is taking place as shown by the Integrated Case Management pilot where GPs lead a multi-disciplinary team of health and social care professionals working with a group of patients with long term conditions and their carers to signpost them to early support. Linked to this is the Social Prescribing Service pilot which enables a link from GPs through a number of VCS Advisors into the VCS sector and the various alternative support options to help meet non-clinical needs of patients and to support carers.

Members also noted evidence received about the emotional impact on carers of coming to terms with this change in relationship and agreed that services need to aim to support them in this process.

“I don't think of myself as a carer but he calls me his carer.”
“I am a mother not a carer”
“Didn't realize – it was the mental health team that said ‘You are a carer’.”
“A nurse at the doctors said ‘You are a carer’.”
“Just creeps up.”
“ I think getting people to acknowledge they are carers is the first step.”
“Hard to recognise when you've reached your limit.”
“Changes the relationship with the cared for person, they can often become difficult”

5.2 Accessing support

Carers

As a result of 5.1 above, there are a large number of carers who are not accessing support. In section 3.1 it is reported that there are over 31,000 carers in Rotherham, however, the Council's Neighbourhoods and Adult Services are providing services to only a percentage of these.

The number of people receiving adult social care services was 5,229 in November 2013. So with 31,000 carers locally this suggests a significant volume of family members and/or friends providing care for people, who although not all meeting the Fair Access to Care Services (FACS) criteria, currently at substantial level, still require help and support. Thus it is important that this wider group of carers knows how to access support to help them in their caring role.

Carers praised a number of organisations across all sectors, including some excellent work by named individuals, but also noted areas where their experiences had been less positive. Of those who took part in the survey and who are accessing services or support (approximately two thirds of respondents), the majority had found this to be easy or very easy - a very positive finding for the services targeted at carers in Rotherham. There is, however, a significant number who find it difficult and anecdotal evidence from the consultation shows that at least some of those people accessing services did so because of a family member or friend having prior knowledge, or as a result of a chance comment from someone they have met. It is also clear from the survey that Council employees who are also carers do not necessarily know how to access services, despite being already “linked in” to one of the major service providers.

The two direct consultation locations were Fair’s Fayre (31 people) and Davies Court café (18) who were more likely to be people with contacts and links to information. Nevertheless ten respondents at Fair’s Fayre answered that was very difficult/difficult to find out about services or support and two at Davies Court.

Although the consultation was carefully targeted to encourage new or recent carers to respond, and those who do not self identify as carers, it should be noted that most of the consultees had accessed local agencies for support. This further emphasises the difficulties in reaching “hidden carers”.

The implications of this, considered by members of the review group, are around how to promote and make services more accessible when people have recognised themselves as carers and need/want support. This is considered in more detail in the following sections looking at initial and ongoing support needs.

“I am unaware of any support I could get to assist with the caring I provide.”
“I don’t know, I have never received help so not sure what is available.”
“I was lucky as I know about Carers through family links however if I had not been in this position I would have struggled.”

Emotional support

Discussions took place with carers around support that they may consider they need. Many carers mentioned the difficulty of the decision to send someone into full-time care and the ensuing guilt; coping with the mental aspects of seeing the decline in the person you love; and anxiety when people go for respite, worrying about how they are doing so not switching off.

“It would be good to have someone to speak to such as counsellor”
“Support later in progression of illness, own wellbeing.”
“They give you plenty of literature but our experience is that none has ever materialised.”

Framework Agreement

In terms of provision of adult social care, members of the review group heard about the Council’s Framework Agreement and how services are commissioned from a range of providers within this framework. Assessment Direct, a direct phone number, is the route via which needs are assessed and referrals made if appropriate. This all depends on whether the person being cared for meets the eligibility criteria, currently set at substantial. If they do, then a brokerage service will refer the person to the relevant service provider.

Concern was expressed, however, that Carers Support Officers who carry out the majority of carers assessments¹, are unable to refer carers through to brokerage for a respite service in their own home (particularly appropriate for people with dementia as routine is key to maintaining equilibrium). This means that carers who are assessed as requiring a break have then to be referred through to Assessment Direct for a social worker to undertake a further assessment. This is time consuming, costly and confusing. Members therefore raised the question of where carers of people who may not meet the FACS criteria (substantial level) actually receive support to prevent a breakdown in their ability to provide care. Witnesses who provided evidence felt very strongly that having a single point of contact for carers was very important and may help to overcome some of these issues. The Council used to have a dedicated Carers Officer who worked proactively to develop such relationships with partners and providers; however, this post was lost during a recent re-structure.

5.3 Who carers go to for initial support when they become a carer

The survey showed that the most frequently used sources of initial support were split fairly evenly across GPs, the Council, Carers Corner (which opened in May 2010) and "other". Hospital services and VCS were lower in numbers for initial support. In considering this information members of the review group felt that it is important that all support services are equipped to recognise carers and to have the right information to be able to link them to support and other agencies. However it was felt that GPs are critical to this early identification and referral process.

Stag Medical Centre was the first GP practice to establish a virtual carers corner (June 2013) and is pro-active in signposting people, holding drop-ins and providing information, with an area set aside in both surgeries. The practice has a good patient participation group which includes some carers and which ran with the idea of setting it up. The demographic profile of their patients has above average numbers of over 65s (23%) and 51% are over 45.

Members therefore considered the potential for further development of working in partnership with GPs on early identification of carers' needs, building on the pilot initiatives referred to above and the establishment of a clear carers pathway, including earlier referral to VCS partners. This carers pathway should include a well publicised clear entry point for all carers, commencing with a fit-for-purpose detailed assessment and including reviews at key stages. The review carried out by NAS also seeks to maximise the benefits of partnership working.

It was noted that in the evidence received from VCS partners they have to limit the promotion of their services due to capacity issues. More effective use of the VCS contributes to preventing crises and implies potential cost savings further down the line for statutory partners, such as reducing admissions to residential and hospital care. Therefore a multi-agency approach to the resourcing of the carers pathway is required.

5.4 Where carers usually go for ongoing support

With follow on support services, according to the survey, the VCS and hospital services come much higher, with VCS being the highest number. It should also be noted that although access to benefit advice is identified as an issue in both the survey and separate consultation, being described as a "minefield" and a "battle", only one respondent commented that they went directly to the Department of Work and Pensions for support and/or advice. Unfortunately the review was unable to carry out any further investigations around this agenda, in particular looking at benefits advice, however, this is something they considered to be an important issue.

¹ Carers assessments is the term used but the document is the "Carer's Needs Form and Care Plan".

Members considered this information carefully as it showed that carers use a wide range of services, being equally comfortable with seeking support from formal providers such as GPs, hospitals and the Council and informal services via the VCS. It also shows that carers needs are not met by just one or two key services. The implications of this is that they could be moving around between services and potentially be missing out on support or not receiving consistently high quality support. Some of this was supported by evidence from both the VCS and Council and NHS service providers, in that communication and referrals between the agencies don't work as effectively as they probably should. Members considered during their discussions how to ensure that a clear pathway of support exists for carers and who the key partners might be in achieving this, particularly focusing on the use of a carers assessment tool. This should also include an allocated "buddy" or "lead worker" from the most appropriate agency to ensure that support is accessed consistently and according to the identified needs of the carer.

Evidence from the sessions suggested that carers assessments were not being used consistently, with some carers saying they had never received one, and those who had reported varying experiences of how successful they had been in identifying their needs or in actually helping them on a practical level. Few of the carers who took part in the discussion groups have an updated assessment review on an annual basis.

This was considered to be very important given the fact that members of the review group had already established that carers are very often on a journey and therefore their needs change considerably over time, often requiring referral between a number of partner agencies. Members were not convinced that the carers assessment process was facilitating this adequately.

The statutory duty to carry out carers assessments will form part of the new legal framework when the Care Bill is enacted. However, of equal importance is the need to carry out regular reviews and to ensure assessments result in tangible outcomes for the carer.

"Although 'Carer's Assessments' in theory are an excellent way of identifying problems/potential 'crisis' points, help required etc., they do not seem to follow through as being a particularly helpful tool in so far as people do not seem to feel that they have been of any use."

"... led to overnight respite"

5.5 Key factors for ensuring carers receive good and timely information

Volume and timing of information

Overall the general consensus is that there is a lack of information and that difficulties exist in accessing information. Some carers mentioned overload of information at early stages, with some information only being required later on in the progression of the person they are caring for's condition, however, it was noted that this may be particularly pertinent to those caring for patients with Alzheimer's or dementia. VCS partners mentioned the need for earlier referrals from social care to help prevention of crisis.

"Carers need the right information at the right time – NOT masses of info when first diagnosed"

Accessible information

Accessibility of information was felt to be key. It needs to be accessible in equalities terms – plain English and simple easy to understand messages. Members also

considered the need for better advertising and circulation of leaflets. A well publicised single point of access was also considered, via a telephone line.

“Information in plain English for everyone, including health and wellbeing information”
“Less bureaucracy on application forms, simpler on–line screens”
“Simplified internet searches”
“Don’t use big posh words in leaflets”
“Office staff don’t explain things properly to carers”

Where to go for information

Consultation with carers highlighted the need for a range of communication methods to ensure carers are able to access information in a way that best suits their needs. Preferences for the best way to receive information varied demonstrating the need to give people options including face to face communication, telephone, leaflets and electronic communication via social media and dedicated webpages. ICT barriers were cited for some groups, especially many older carers and those without computers and internet access at home.

“Someone to speak to face to face”
“Ring the person more often to keep them up to date”
“Using local media and social media, as most carers do not have time to visit walk in centres and seek advice, you just get on with it and try to maintain your own life.”
“Ok if know where to go but need good signposting”
“I found out about Crossroads from my husband’s GP waiting room - leaflets displayed in a way that makes you want to go and read them i.e. tidy, well stocked”
“Golden phone number – staffed”
“Keep Carers Corner. Introduce and fund outreach services. Look at development and provision of Carers Corner.”
“More community based support required. Rather than all resources being Rotherham centrally based”
“1 point of call – one-stop shop”
“Include carers round the borough”
“an information hub”

As part of the review by NAS snapshot monitoring of people specifically going to Carers Corners to request help or information was carried out. During the four month period from June to September 2013 126 people went in to request help or information, an average of 1.5 enquiries per working day. 20% of these resulted in signposting to either Assessment Direct or another organisation for information and advice and the other 80% related to issues including benefits enquiries, housing advice, blue badge scheme, TV licensing and debt related advice. This monitoring does not include people who attended for other purposes, including drop-ins or services provided by other organisations.

The NAS review also identified the success of outreach workshops run to date with workers going out to meet carers in different venues across the borough such as GP surgeries and at the hospital, reflecting some of the comments above.

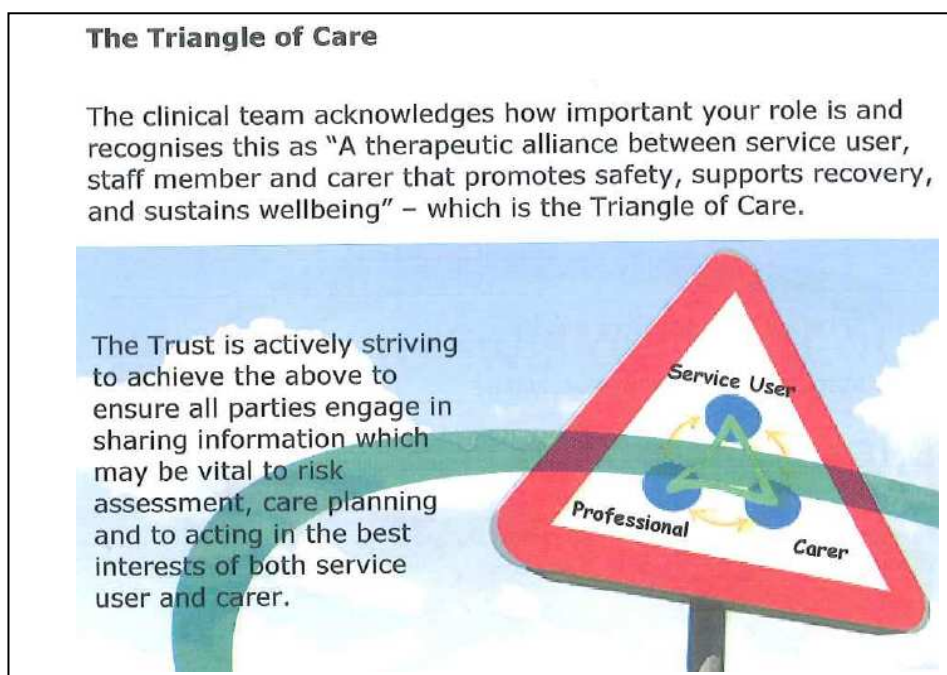
The implications for discussions around Carers Corner and the NAS review of how this service is delivered are clear. Members considered that Carers Corner emerged as very popular in the survey with some very positive feed back received. It is also clear, however, that more focused outreach would also help to address some of the issues being raised in terms of accessing “hidden” carers and getting the right information to them.

Information for young carers

The review did look at information needs for all carers, including young carers, however, it was apparent that how young carers are referred into support services works very differently than for adults. Members spoke to representatives from Barnardo's and heard how the referral process works. An initiative being developed with young carers around a carers card in schools, was received very well and members of the review group considered how this could be adapted to adult carers too. This has been considered but resource implications have precluded its implementation to date.

Triangle of Care

Rotherham, Doncaster and South Humber NHS Trust (RDaSH) brought to Members' attention their work towards the Triangle of Care, a three way partnership between the staff, the patient and the carer. Members received this information positively and considered whether it could be adapted for other partners too. This approach encompasses six standards necessary to improve partnership working in mental health services. One standard highlights the essential role of carers who should be identified at first contact and another covers training for staff to become "carer aware". More details about the standards are in Appendix 4.



Extract from RDaSH Carers Information Leaflet at Swallownest Court

5.6 Areas for improvement in current information provision

Less than half of the survey respondents (44 people) answered yes to the question: "Do you think you receive information at the right time?", showing that there are issues to address to make it easier to access help and support at the right time. In their responses to the survey and in the ensuing discussion sessions carers made some thoughtful and interesting comments and suggestions for improvements as well as highlighting examples that work well. These suggestions (summarised under 12 broad headings in Appendix 2 question 7) focused primarily on operational issues and will be fed back to the relevant agencies.

In terms of helping to plan for information provision the survey also asked about the topics that carers found most useful and the clear top five answers were:

Welfare and benefits	45
Local groups	39
Health	38
Respite	21
Council services	21

The need for information is ongoing and changing over time, also there are many new carers being identified, therefore one-off information campaigns are not sufficient. It was agreed across all witnesses that there will always be a large number of carers who are “hidden” to the support agencies. This is identified in the Joint Action Plan for Carers, but it is not clear whose responsibility this is and it is not a smart action.

It was noted that many of the actions in the Joint Action Plan for Carers would cover some of the issues that have arisen in this review, however, as with the point above Members expressed some concern that arrangements for clear targets, monitoring and accountability to key officers, were missing from many of them.

Corporate Plan outcome 17 - former NI 135 (see Appendix 3 Table 2)

Monitoring of indicator former NI 135 (one of the corporate plan outcomes) is carried out by NAS, and it measures the number of carers known to Social Services being assessed. Members were concerned to see a seeming lack of ambitious growth targets around this, both in terms of increasing the number of carers being assessed (of those known to Social Services) or to increase the overall number of carers being supported. Under current arrangements most assessments are carried out by the four Carers Support Officers whilst reviews are carried out by the Planning and Reviewing team. This review has considered ways to widen the pool of assessors.

Flexible working

Time and work pressures were raised by several carers in paid employment showing the importance of flexible working policies. Members wished to re-iterate the Council’s support in terms of flexible working and access to support for its own employees who are carers.

“I often feel that assisting my mum to attend appointments is the most difficult as I can not take time out of work.”

6. Conclusions and recommendations

Although many carers do access support there are a large number of “hidden” carers in Rotherham, who are key to the effective provision of social care. There is no doubt that should this hidden support system not exist, the cost burden to the main service providers would be huge. There is a very strong case, both morally and financially, to ensure that carers are provided with the most effective support possible.

It is the view of the members of the review group, therefore, that these carers represent a vital unpaid workforce within the Borough, and like all workforces they need investing in to get the best out of them. It is estimated that nationally, carers save the country an estimated £119billion in care costs. The review group consider that any resources invested within the carers community in Rotherham, therefore represents an invest to save opportunity, particularly with the demographic pressures created by an ageing population.

The Council and its partners should therefore seek to:

6.1 Increase the number of people recognising themselves as carers and willing to seek support for this vital role they carry out.

Recommendation 1 – That Rotherham CCG and Rotherham Council consider how this first line of support for carers to help them identify themselves, is commissioned, in partnership with GPs.

Recommendation 2 – In looking at recommendation 1 above, the partners consider whether the positive assumption that a relative or friend is a carer unless told otherwise can be built into this process, and what information resources are required to back this up.

Recommendation 3 – That Rotherham Council investigates further with the Advice in Rotherham partnership (AiR) and the Department of Work and Pensions, what specific information carers need to access benefits that are available to them. This may also help to identify more carers.

6.2 Ensure that support for carers adequately includes emotional support and counselling.

6.3 Provide a multi agency “carers pathway” that recognises the journey that carers are on and provides them with the correct support and information at the right time and in the right place on that journey.

Recommendation 4 – That Rotherham Clinical Commissioning Group and Rotherham Council, work with its VCS and other partners to create the carers pathway of support. This should include the effective multi agency use of carers assessments and crucially allocation of a “buddy” or “lead worker” to ensure that support is accessed consistently and according to the identified needs of the carer. This lead worker could come from the most appropriate agency identified for individual needs.

Recommendation 5 – That Rotherham Council considers via its review of services to carers; the use of a new single contact number, a combination of Carers Corner and outreach facilities; and the replication of the carers card in schools for adult carers.

Recommendation 6 – That the “triangle of care” presented by RDaSH be considered as part of this process as something that could be adapted and rolled out to all partners providing support to carers.

6.4 Significantly increase the number of carers receiving a fit for purpose carers assessment, which is reviewed on an annual basis. This links to the point made previously of widening the pool of assessors.

Recommendation 7 – That Rotherham Council reviews its carers assessment tool in the light of the Care Bill to ensure it is fit for purpose. This should involve considering whether it could be less onerous and more appropriately named to reflect that it is an enabling process rather than an “assessment”, whilst complying with statutory frameworks.

Recommendation 8 – That Rotherham Council looks to set more stretching targets for former NI 135.

Recommendation 9 – That a full review is undertaken of the Joint Action Plan for Carers to ensure that it meets the recommendations of this review and is more accountable in terms of its delivery.

Recommendation 10 – The review group recognises that these recommendations have resource implications but consider that the “invest to save” case for the Council and NHS is strong enough to warrant this. It therefore recommends that the £500,000 provisionally allocated to carers support in the Better Care Fund is allocated to implementing the recommendations of this review.

7. Thanks

Our thanks go to the following for their contributions to our review:

Cllr Roger Stone, Leader of the Council

Partners

Helen Cryan – Crossroads

Lesley Dabell – Age UK

Jacky Fairfax – Rotherham Foundation Trust

Lyndsey Hallatt – Barnardo's

Liz Hopkinson – Alzheimer's Society

Chris Thompson – Stag Medical Centre

Jane Whaley – Barnardo's

Helen Wyatt – Rotherham Clinical Commissioning Group

RMBC Officers

Jenny Greaves – Rotherham, Doncaster and South Humber NHS Trust/RMBC

David Stevenson

Richard Waring

8. Background papers

Report to Health Select Commission 12 September 2013

Report to Improving Lives Select Commission 18 September 2013

Notes of evidence sessions on 19 November 2013 and 29 November 2013

Results of "Are You a Carer?" Survey

Young People's Lifestyle Survey

2011 Census data

Full story: The gender gap in unpaid care provision: is there an impact on health and economic position? Office of National Statistics May 2013

The Triangle of Care Carers included: A Guide to Best Practice in Mental Health Care in England Second Edition Carers Trust 2013

Valuing Carers (2011) Carers UK and University of Leeds

Joint Action Plan for Carers 2013-16

Rotherham Carers' Charter

Terms of reference for NAS carers review

Scrutiny review reports:

- Swansea

- York

Are you a carer?

The Council is carrying out a short scrutiny review to look at information for carers. We want to hear about your recent experiences of finding out where to go, or who to ask, for information to help you in your caring role.

We are particularly interested in hearing from you if you who have become a carer in the last two years.

For the purpose of the review we are using the definition of a carer as someone who provides unpaid care for a partner, relative, neighbour or friend who is an adult who has a long term illness or condition, including people with alcohol/substance misuse and mental illness.

We would be grateful if you could assist us by completing the questionnaire, which should only take a few minutes.

Your responses will be completely confidential and the information you provide will help us to identify any areas for improvement.

1. Have you used any services or had any support specifically for carers?

- Yes
- No (if No please go to straight to Question 7)

2. How easy was it to find out about services and support available for carers?

- | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| very easy | easy | difficult | very difficult |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

3. Who did you speak to or where did you go for support when you first became a carer? (please tick ONE)

- | | |
|--|--|
| <input type="checkbox"/> GP | <input type="checkbox"/> Hospital Services |
| <input type="checkbox"/> Carers Corner | <input type="checkbox"/> Other (please let us know) |
| <input type="checkbox"/> Council Services | <input style="width: 300px; height: 20px;" type="text"/> |
| <input type="checkbox"/> Voluntary & Community Group | |

4. Where else have you been for support since becoming a carer?

(please tick all that apply)

- | | |
|---|--|
| <input type="checkbox"/> GP | <input type="checkbox"/> Voluntary & Community Group |
| <input type="checkbox"/> Carers Corner | <input type="checkbox"/> Hospital Services |
| <input type="checkbox"/> Council Services | <input type="checkbox"/> Other (please let us know) |

5. Do you think you receive information at the right time?

- Yes
- No

6. Which information do you find most useful? (please tick all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Welfare and benefits | <input type="checkbox"/> Respite |
| <input type="checkbox"/> Local Groups | <input type="checkbox"/> Leisure |
| <input type="checkbox"/> Council Services | <input type="checkbox"/> Employment and training |
| <input type="checkbox"/> Health | <input type="checkbox"/> Other (please let us know) |
| <input type="checkbox"/> Housing | |

7. How do you think information about support for carers could be improved?

Could you please tell us about you to help us with our evaluation

8. Are you male or female?

- Male
- Female

Please continue

9. Please select an age range

- | | |
|---|--|
| <input type="checkbox"/> under 20 years | <input type="checkbox"/> 50 – 59 years |
| <input type="checkbox"/> 20 – 29 years | <input type="checkbox"/> 60 – 69 years |
| <input type="checkbox"/> 30 – 39 years | <input type="checkbox"/> 70+ years |
| <input type="checkbox"/> 40 – 49 years | |

10. How do you describe your ethnic origin?

- | | |
|---|--|
| <input type="checkbox"/> White | <input type="checkbox"/> Multiple Heritage |
| <input type="checkbox"/> Black or Black British | <input type="checkbox"/> Chinese, Yemeni, Arab |
| <input type="checkbox"/> Asian or Asian British | <input type="checkbox"/> Other Ethnic Group |
| <input type="checkbox"/> Gypsy or Traveller | |

If you want to take part in the discussion please continue below

11. Would you like to take part in a small informal discussion?

- Yes
- No

12. If yes, please let us know how to contact you **(Please print clearly)**

Name:

Email:

Telephone:

If you would like more information please contact us:

Email: scrutiny.works@rotherham.gov.uk

Telephone: 01709 822776 (Sharon Crook) or 01709 254421 (Janet Spurling)

For advice and support about being a carer contact Carers Corner:

Email: carerscorner@rotherham.gov.uk

Telephone: 01709 254809

Call in – located in the town centre on the corner of Drummond Street and Effingham Square, Rotherham

Please seal your completed form in the envelope provided and leave it with a member of staff at Healthwatch or Carers Corner.

Appendix 2 – Summary of survey results

Total responses – 95 (note that not all respondents answered all questions)

1. Have you used any services or had any support specifically for carers?

Yes 61
No 28 (19 people were directed straight to question 7, see note at end)

2. How easy was it to find out about services and support available for carers?

very easy	17
easy	32
neutral	1
difficult	17
very difficult	5

3. Who did you speak to or where did you go for support when you first became a carer?

GP	13
Council Services	13
Voluntary & Community Group	7
Hospital Services	9
Carers Corner	14
Other	14

Other where more detail given or more than one chosen:

GP and Council services	
Carers Corner and Voluntary/Community group	2
Carers Corner, Council services, Voluntary/Community group	
GP, Carers Corner, Voluntary/Community group	
GP and Carers Corner	
Private Company	
Rotherham	
Macmillan	
Adult social care/Social services	2
Howarth House	
Alzheimer's Society	4

4. Where else have you been for support since becoming a carer?

GP	26
Council Services	19
Voluntary & Community Group	26
Hospital Services	19
Carers Corner	17
Other	12

Other where more detail given:

Family member who works for a charity
DWP
Macmillan cancer support hospital
Mencap
Victim Support
Red Cross
Memory Cafe/Singing for Brain groups
Memory service have provided best support
Most useful support from Alzheimer's Society
Crossroads Care x2
HealthWatch

5. Do you think you receive information at the right time?

Yes 44 Sometimes 4 No 21

6. Which information do you find most useful? (please tick all that apply)

Welfare and benefits	45	Housing	8
Local Groups	39	Employment and training	3
Health	38	Training	8
Respite	21	Employment	1
Council Services	21	Other	6
Leisure	13		

Other where more detail given:

Day care/Day care services 2

Financial

Mobility aids

How to access the right funding for residential services

Information and support when someone has been sectioned

I needed support

Alzheimer's Society

7. How do you think information about support for carers could be improved?

Responses may be summarised under 12 headings, as follows:

- 1 Identifying self as a carer
- 2 Not knowing how to access support
- 3 Wanting support
- 4 Time and work pressures
- 5 More advertising/signposting/information
- 6 Making information easier/more accessible
- 7 Specialist information
- 8 Welfare information
- 9 Single point of contact v More outreach/community
- 10 Carers' Corner
- 11 Suggestions for service providers
- 12 Suggestions for where to get more information/advertise more

Equality monitoring:

Gender:

Female 71 Male 19

Age

under 20 years	0	50 – 59 years	24
20 – 29 years	1	60 – 69 years	15
30 – 39 years	14	70+ years	13
40 – 49 years	21		

Ethnic origin:

White 80 Asian or Asian British 6 Other 1

The carers cared for people with a range of conditions – learning disability, autism, Alzheimer's, mental illness and physical disability. Some are caring for more than one person, such as two adult children or both parents.

Note:

Respondents who answered "no" to question 1 on-line were directed straight to question 7, whereas those responding "no" through other methods often did answer questions 2-6.

Appendix 3

Table 1

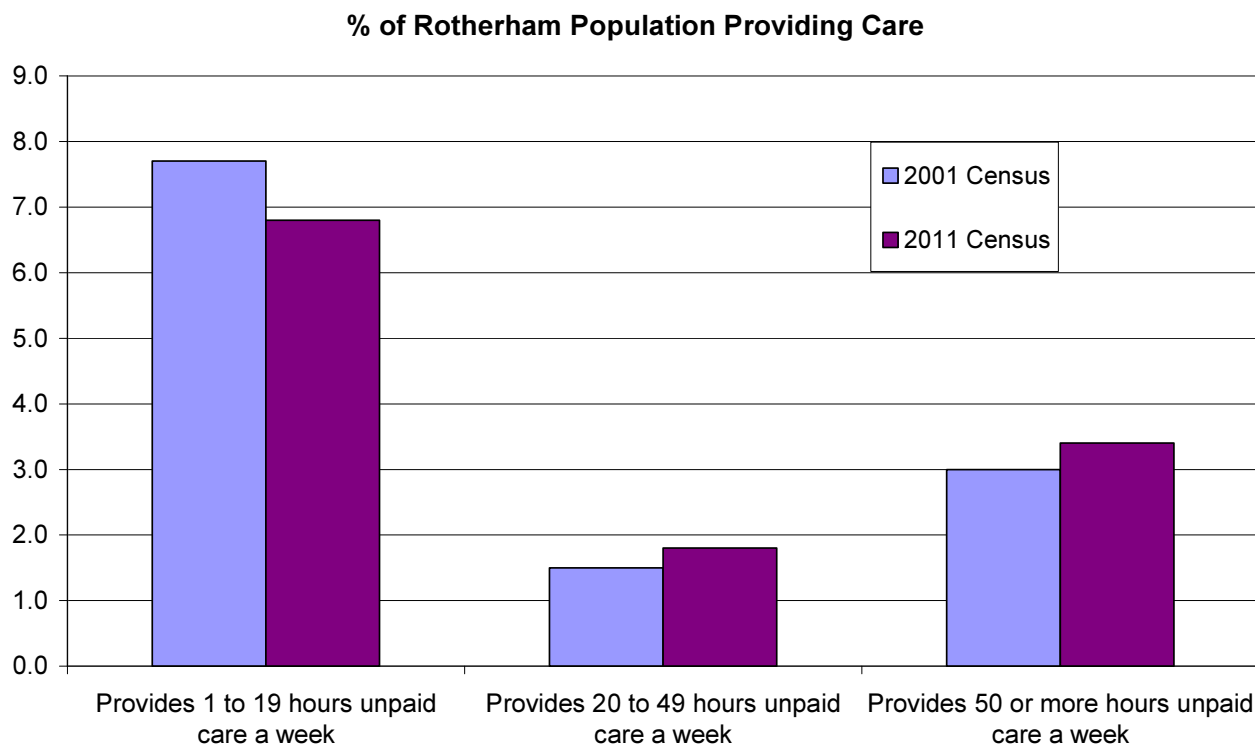


Table 2

Corporate Plan indicator 17 - Carers get the help and support they need
(former national indicator NI 135)

Indicator Title	11/12 Actual or baseline	12/13 Q1	12/13 Q2	12/13 Q3	12/13 Q4	12/13 Year end	13/14 Target	Performance as at 5/11/13
Number of carers receiving needs assessment or review and a specific carer's service, or advice and information.	41.51%	12.05%	18.77%	25.38%	42.02%	42.02% Target was 42%	43%	27%

This measure accumulates throughout year and is on track to hit the marginal continuous improvement target set at 43%. Latest figures for 2013/14 performance at 5th November 2013 was 1412/5229 = 27%. The denominator is based on the number of people receiving adult social care in the year.

Appendix 4 The key elements to achieving a Triangle of Care:

1) Carers and the essential role they play are identified at first contact or as soon as possible thereafter.

- Carers' views and knowledge are sought, shared, used and regularly updated as overall care plans and strategies to support treatment and recovery take place.

2) Staff are “carer aware” and trained in carer engagement strategies.

- Staff need to be aware of and welcome the valuable contribution carers can make and be mindful of carers' own needs.
- Staff need knowledge, training and support to become carer aware.

3) Policy and practice protocols re: confidentiality and sharing information are in place.

- To ensure proactive engagement carers need to be part of the care planning and treatment process across the care pathway, that is, for inpatient, home treatment and community, the service should have clear policies and mechanisms and ensure these are routinely used, including:
 - Guidelines on confidentiality and for sharing information – a three-way process between services users, carers and professionals.
 - Information release forms and protocols.
 - Advance statement forms and protocols.

4) Defined post(s) responsible for carers are in place, including:

- Carers lead or champion for all wards and teams irrespective of which service.
- Carers links delegated for each shift/team.

5) A carer introduction to the service and staff is available, with a relevant range of information across the care pathway, including:

- An introductory letter from the team or ward explaining the nature of the service provided and who to contact, including out of hours.
- An appointment with a named member of the team to discuss their views and involvement.
- Ward orientation/induction procedure and leaflet.
- Carer information packs
- Discharge planning and aftercare support.

6) A range of carer support services is available, including:

- Carer support
- Carer needs assessment
- Family interventions

There also needs to be regular assessing and auditing to ensure the six key standards of carer engagement exist and remain in place.

Source: The Triangle of Care Carers included: A Guide to Best Practice in Mental Health Care in England Second Edition Carers Trust 2013