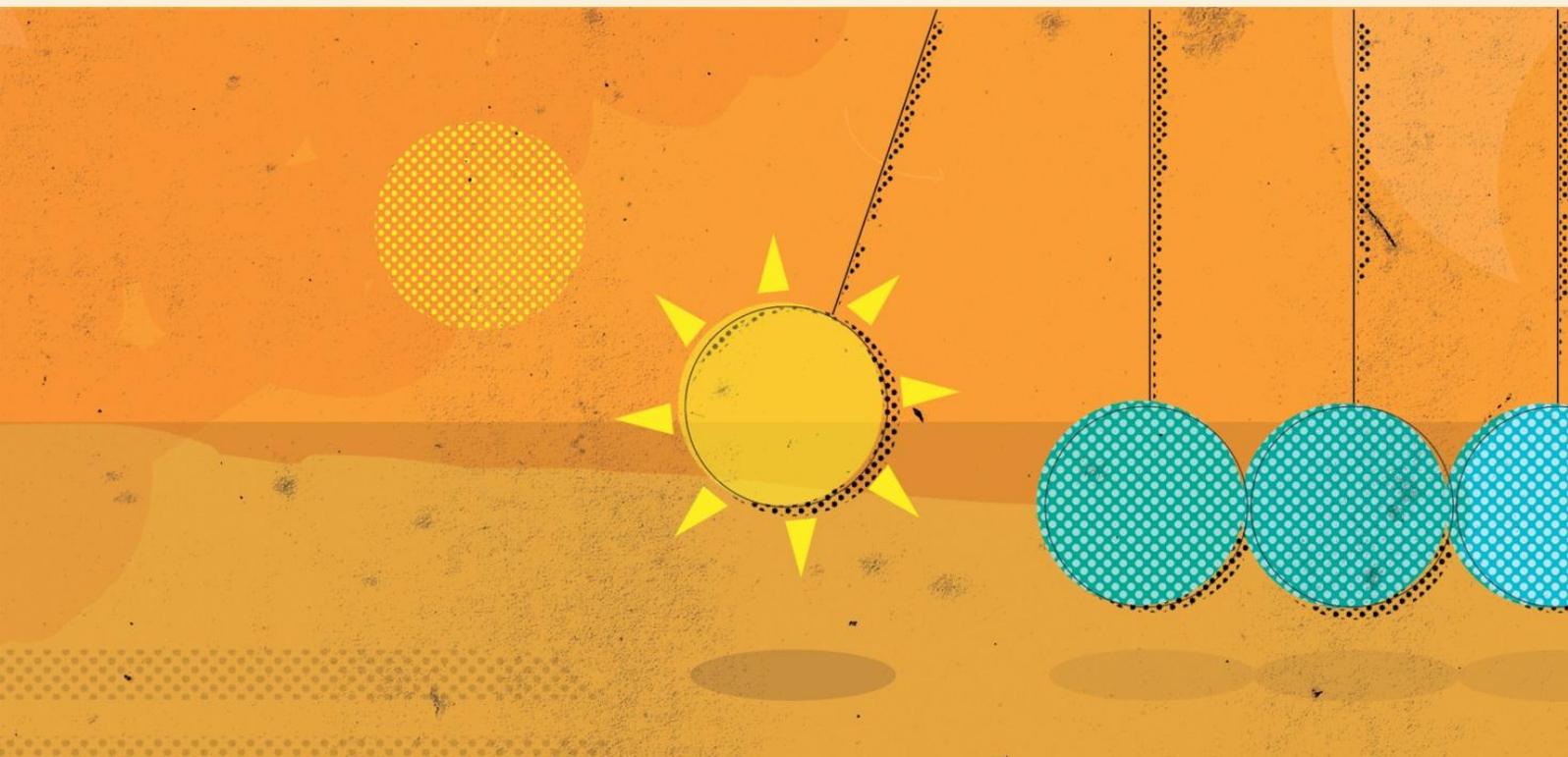


Evaluation of the Rotherham Carers Resilience Service: *Final Report*

August 2016



Rotherham Clinical Commissioning Group



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Final Report

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Introduction

This report provides the findings of an independent evaluation of the Rotherham Carers Resilience Service undertaken by the Centre for Regional Economic and Social Research (CRESR) at Sheffield Hallam University. The Service commenced in February 2015 and is being delivered in partnership by Rotherham Crossroads, Rotherham and Doncaster Alzheimer's Society and Age UK Rotherham on behalf of NHS Rotherham Clinical Commissioning Group (CCG). It is intended to support carers of people living with dementia by providing information, advice and practical support that builds resilience, enabling carers to continue caring for the person with dementia at home for as long as possible.

1.1. Evaluation Aims

The Evaluation was commissioned with the following aims:

- to understand the impact of the Service on carer health and well-being
- to understand the effect on patient and carer use of NHS care and resources
- to capture stakeholder perspectives on the effectiveness of the Service and identify key learning to inform future delivery and commissioning.

1.2. Methodology

This report draws on a variety of data sources to reflect on achievements and learning from the activities of the pilot to date:

- Seven interviews with key stakeholders during the early phases of the Service, including five service staff, one GP, and one representative of the CCG. The interviews explored the aims of the service, and the key successes and challenges of the early stages of the pilot. They included three follow-up interviews to explore how the service has progressed, revisiting successes and challenges and noting how the service had evolved.
- Nine interviews with beneficiaries of the Service, focussing on their experiences of the service, including the kind of support being received, and the difference this support was making to them both practically and emotionally.
- Three in depth client case studies collected by the service
- Questionnaires completed by 26 service users (carers) from the initial 10 GP pilot sites at two points in time: upon first engaging with the Service (baseline) and upon exit from the Service (follow-up). The questionnaires covered carer's well-being, health and their experience of their caring role.

- Data from NHS Rotherham CCG on emergency hospital admissions to all providers, for Rotherham CCG patients, where a dementia diagnosis code appears in the primary or first ten secondary diagnoses fields (April 2012-March 2016).

1.3. Report Structure

The remainder of this report is structured as follows:

- Chapter 2 provides an overview of the Rotherham Carers Service
- Chapter 3 presents evidence about the outcomes and impact of the Service, based on analysis of qualitative and quantitative data
- Chapter 4 is the conclusion and provides a summary of the main findings

An overview of the Rotherham Carers Resilience Service

This chapter provides an overview of the Rotherham Carers Resilience Service. It provides a summary of the Service, including what it aimed to achieve and how it works in practice; highlights some of the key outputs and achievements of the service to date; and provides different stakeholders' perspectives on the service's success and the challenges it has faced.

2.1. About the Carers Resilience Service

The Carers Resilience Service was commissioned by NHS Rotherham CCG in February 2015 and began receiving referrals from April 2015. It was intended to support carers of people living with dementia by providing information, advice and practical support that could build carers' resilience, enabling them to continue caring for the person with dementia at home for as long as possible and preventing care breakdown and unnecessary hospital admissions. An initial pilot focussed on 10 General Practices in Rotherham, with a phased roll-out to all GPs from June 2015

The service is led by Crossroads Care Rotherham and delivered in partnership with Rotherham and Doncaster Alzheimer's Society and Age UK Rotherham. Each organisation plays a distinct role in the delivery of the service, drawing on their existing expertise of supporting patients and carers with a variety of health, welfare and care needs. All staff working on the project have received specialist training to enable carers to become more resilient and equip them with the resources they need to continue in their caring role. This training includes the skills and competencies necessary to identify a carer that may be at risk of 'crisis'.

- **Crossroads Care Rotherham** employs two GP Link Workers who engage with practices and assist practice staff to identify carers who might benefit from the services through a referral from their GP. Carers are initially referred to a Link Worker who will make an initial assessment of carer's needs, liaise with practice staff, and then pass the referral on to a Dementia advisor. Where there is evidence of carer breakdown or crisis Crossroads are able to provide practical home based support on a short-term basis. This intervention aims to reduce the likelihood of hospital or residential care admission and ensure the on-going safety of the carer and the person with dementia.

GP Link Workers also have an important role developing relationships with practice staff and raising awareness of the project, and carers' needs, rights and entitlements. A further element of the role is working with practices to promote good practice, including the development and implementation of carers policies and carers registers, and to encourage practices to nominate a carers 'champion' or lead.

Rotherham and Doncaster Alzheimer's Society delivers a Dementia Adviser service for the carers (family and friends) of people who have received a diagnosis of dementia or are in the process of undergoing a diagnosis. New carers or carers not deemed to be in 'crisis' are referred to a Dementia Adviser who undertakes a needs assessment and provides support to understand the implications of a diagnosis of dementia for the carer, the service user, and their family. This includes up to date and relevant information about living with dementia and help to navigate and access appropriate services, often referring on to other services available from the public and voluntary sectors. Dementia Advisers have up to date knowledge and resources to enable carers to access support services which will help maintain or improve their health and well-being.

Age UK Rotherham receive referrals from Dementia Advisors where they identified a potential gap in their receipt of benefit entitlements or where there are mobility issues, and access to a 'blue badge' would improve an individual's independence or make caring easier. Upon receipt of a referral Age UK undertake a triage interview by telephone to assess their needs and offer a visit to discuss their needs further, including a benefit check and support to complete relevant claim forms. If necessary, a follow-up visit is carried out and Age UK offer to remain a point of contact if circumstance change in the future.

2.2. Outputs and achievements of the service

The project was funded from February 2015 and began receiving referrals in April 2015. The first two months were setting up and raising awareness of the project. Key activities during this period included engaging and developing relationships with key staff in GP practices and development of project processes and pathways.

In the first 12 months of receiving referrals (April 2015-March 2016) the following outputs were achieved:

- 334 carers were offered carer resilience assessments, of whom 183 were referred by the 10 pilot GP practices
- 301 carer resilience assessments were completed: a conversion rate from referrals of more than 90 percent
- 49 people with a dementia diagnosis attended a dementia café and a further 97 were signposted to cafes or 'singing for the brain'
- 35 of the 36 Rotherham GP practices referred patients in to the service
- 34 carers from the pilot practices received short term home based care support: this consisted of 230 hours of home base support, eight overnight stays and 28 hours of personal care
- 23 carers accessed the Carers Information and Support Programme
- 293 support packages were put in place

- 48 referrals were made to Age UK for information advice, enabling clients to claim an additional £81,631 in benefits.

The service has also made substantive efforts to engage carers from black and minority ethnic (BME) communities. This includes actively working with key local BME organisations such as REMA and the Older People's Group at the Unity Centre, for example attending BME Memory Cafés to engage with carers, and producing a translated information sheet on the service that these organisations can distribute within communities.

2.3. Stakeholder perspectives on the service

As part of the evaluation process, seven stakeholders were interviewed in the early stages of the pilot, three of whom also participated in a follow-up interview between 4-5 months later. The stakeholders included representatives from the Clinical Commissioning Group, GP practices, and management and delivery staff from the commissioned services. These interviews provided an opportunity to discuss the following issues:

- Aims and objectives of the Carers Resilience Pilot
- Specific roles and activities
- Progress of the pilot
- Key successes to date
- Challenges and how these were being overcome.

Through these interviews a number of themes emerged around the successes and challenges of the first year of the Carers Resilience Service. These are highlighted in the following sections.

Successes

Stakeholders were keen to highlight a number of important successes during the first year of the project.

Raising awareness of the needs of Carers

A key success reported by stakeholders was the way in which this service was often working with carers who hadn't accessed any support services previously. Although this has meant that some cases have been particularly challenging, due to the crisis point that had been reached, it has been a clear indicator that the service is responding to a previously unmet need of 'hidden carers':

"You tend to find that carers that are known get everything, whereas there are so many hidden carers. And we know that." (Stakeholder, Carers Resilience)

And:

"And obviously with a lot of people [carers] coming through that are not known to services, so we're not touching the same people, they're new people, so that's really good" (Stakeholder, Carers Resilience)

In one instance, with the support of GP Link Workers, a practice has proactively established a 'carers corner' where further information and guidance can be found. In this way, the service has led to additional support for all carers, not just those being referred within this pilot.

Successful model

Stakeholders were asked to reflect on how they felt the Carers Resilience model was working. All agreed that the model was proving to be very successful, with each role working well. The stakeholder interviews confirmed how important the key roles within the service were, and how important individuals involved were proving to be:

"Whenever a project likes this starts, however well it's designed and developed, it works or fails on personalities. So the lady that comes, she's very nice, she's very caring, she's very positive, and very engaging" (Stakeholder, Carers Resilience)

The project is adapting in response to demand, in particular in response to the high levels of people waiting for a diagnosis. Cases which are not considered too complex will in future be diagnosed by the GP which will speed up referrals into the Carers Resilience programme, thus enabling earlier diagnosis and treatment in line with local strategic priorities.

The project has also developed a number of carers information sessions within GP practices, which will provide an opportunity for carers to come to speak to Link Workers about the support available through the project. To date information sessions have been held in 17 practices and attended by 251 carers.

Positive relationships between agencies

The success of the pilot was the result of close working relationships between key organisations and individuals. Although the early phase stakeholder interviews did reveal some initial challenges in establishing how these new working relationships would work in practice, it was acknowledged by all that this process was an important aspect of any pilot. Interviews in both phases did point to very positive relationships between the central delivery organisations, and the follow-up interviews confirmed that these relationships have settled into a successful model for delivery.

Although there were some early issues in terms of clarity of roles and responsibilities, these were resolved quickly through open communication and a flexible approach to delivery. Meetings between the project partners are held every two months to ensure feedback can be incorporated in a process of continuous improvement. Close working relationships are vital to the project, and have become very positive, as explained by one stakeholder:

"I think settling-in time, and roles and responsibilities and partnership working has now gelled. People know what their roles are now and we've worked through that really well. [We've] had some frank discussions about where our speciality is from where [theirs] is, and I think that's now working a lot better...everybody's talking, communicating and we're working very much together as a team" (Stakeholder, Carers Resilience)

Improving services

A further success of the pilot has been the additional work which has commenced to make services, such as GP surgeries, more dementia-friendly. For example, practice staff have been supported to develop action plans to assist their application to become members of the Rotherham Dementia Action Alliance and improve their approach, to communication, signage and building-adaptations for dementia service users. One stakeholder described this work as bringing added value to the pilot, complementing the core work taking place.

Challenges

Stakeholders also identified a range of challenges associated with delivering the project along with examples of how these had been overcome.

High demand

Particularly in the early stages of the pilot, stakeholders reported high demand for the service, with some carers further along their caring journey than initially expected. As a number of carers being referred hadn't received support before, work was sometimes intensive and time consuming. However, the number of referrals requiring intense support was anticipated to drop as the pilot progressed, and more carers were referred earlier in their caring journey rather than at crisis point. As more practices became engaged additional staff were recruited to the project and the partners were able to meet and manage demand effectively through close partnership working.

Uptake within G.P. surgeries

Although the majority of G.P surgeries taking part in the pilot were fully engaged, the stakeholder interviews revealed that a small number of practices had not engaged as fully. Interviewees suggested that this could be down to a number of factors, such as staff holidays and the size of some practices. However, work was being done to encourage greater participation. As the relationship with frontline practice staff was reported to be vital to the success of the scheme, interviewees talked about how they have to work creatively to forge these links:

"The key to encouraging the uptake of a new service is to have a flexible approach, not one size fits all. We have found that each GP practice works in slightly different ways so we have to adapt to meet their needs while ensuring that the same information is provided to all." (Stakeholder, Carers Resilience)

Although a small number of surgeries still present a challenge, it was suggested that in most cases, the relationships were established and working well.

Perceptions about the service: focusing on intervention

A challenge that was raised by a number of stakeholders was the need to keep the Carers Resilience Service on-track, mainly due to the amount of crisis management that was needed in the early stages of the pilot, as highlighted by the following participant:

"What it shouldn't become, and what I can see it morphing into at this point in time, is purely a crisis intervention. I think we're just going to have to monitor demand closely as the project is very much about preventing carers falling into crisis by building their abilities, skills and knowledge" (Stakeholder, Carers Resilience)

Although it must be acknowledged that the high level of crisis intervention could be due to the fact that the project is in the early stages, it is a challenge to be considered moving forwards.

Outcomes of the Carers Resilience Service

This chapter explores the outcomes associated with the Carers Resilience Service. It draws on data from three sources: questionnaires measuring well-being and quality of life for beneficiaries of the service; hospital admissions data for Rotherham CCG patients, where a dementia diagnosis code appears in the primary or first 10 secondary diagnoses fields (April 2012-March 2016); and qualitative interviews with beneficiaries of the service.

3.1. Questionnaire Data

Beneficiaries of the Carers Resilience Service (only those Carers supported through the initial 10 GP pilot sites) were invited to complete a questionnaire at two points in time: when they first engaged with service, to establish a baseline; and once their period of support was complete (after approximately three months), to measure distance travelled. The survey was designed to measure a number of outcomes:

- **General well-being:** life satisfaction, feeling life is worthwhile, happiness and anxiety, drawing on measures from the Office for National Statistics 'Measuring National Well-being Programme'.
- **Self-reported health,** using the 2011 Census measure.
- **Carer quality of life,** using measures developed for the Adult Social Care Outcomes Toolkit (ASCOT).

26 beneficiaries completed a baseline and follow-up questionnaire. Analysis of their responses is provided in the following sections. It should be noted that whilst it was initially intended to involve all carers benefitting from the service (referred by 10 pilot GP sites) in the questionnaire it quickly became apparent that many carers did not feel comfortable completing the questionnaire, resulting in low rates of completion.

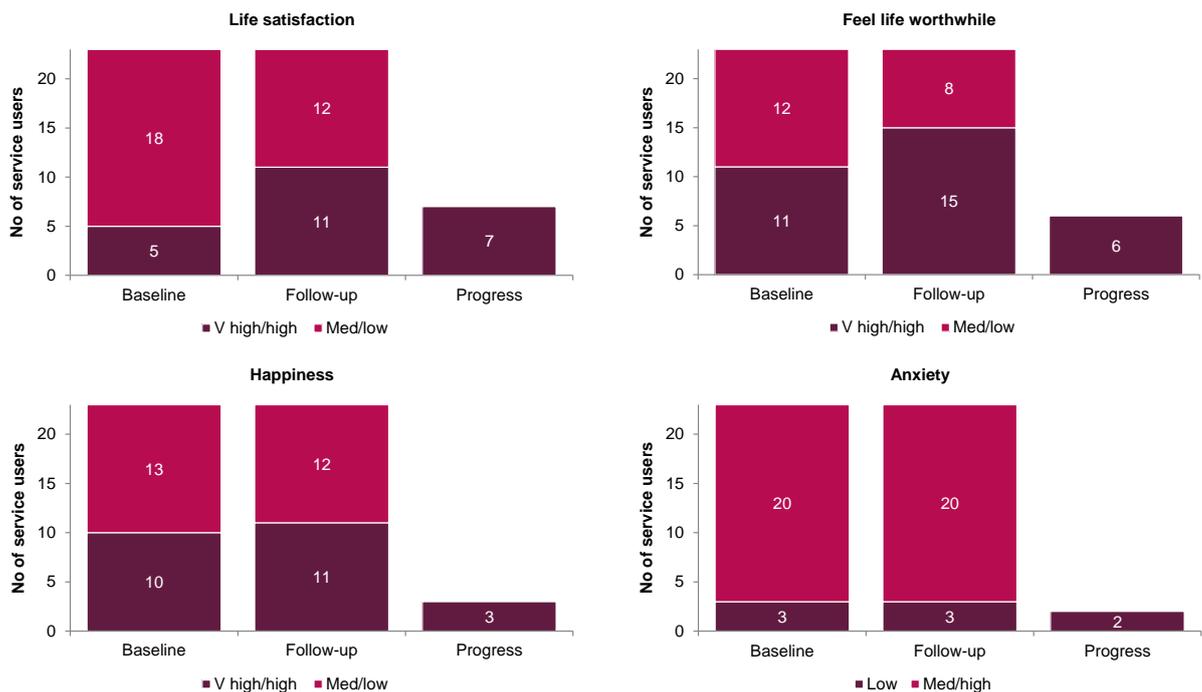
Well-being

Figure 1 provides an overview of the baseline and follow-up responses for the four measures of general well-being. It shows:

- **Life satisfaction:** more beneficiaries reported high or very high life satisfaction at follow-up (11) compared to the baseline (5). Overall seven respondents reported improved life satisfaction after accessing the service.

- **Feel life is worthwhile:** more beneficiaries provided a high or very high score for feeling their life was worthwhile at follow-up (15) compared to the baseline (11). Overall six respondents reported an improvement in how worthwhile their life was after accessing the service.
- **Happiness:** one more beneficiary reported high or very high levels of happiness at follow-up (11) compared to the baseline (10). Overall three respondents reported that they were happier after accessing the service.
- **Anxiety:** the same number of beneficiaries reported low levels of anxiety at baseline and follow-up (3). Overall two respondents reported feeling less anxious after accessing the service.

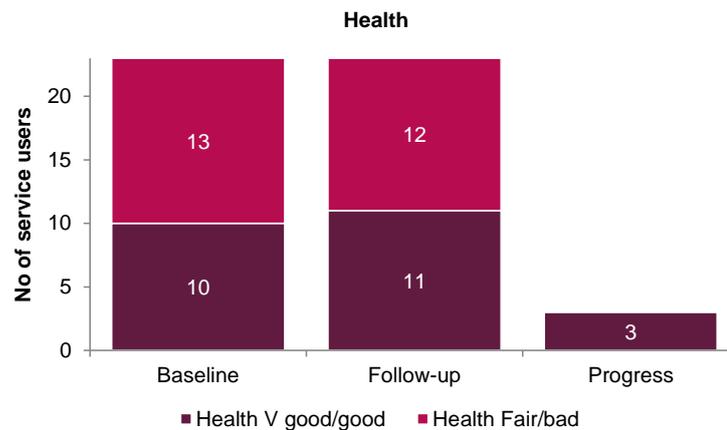
Figure 1: General well-being of Carers Resilience Service beneficiaries (baseline and follow-up responses)



Health

Figure 2 provides an overview of the baseline and follow-up responses for **self-reported health**. It shows that one more beneficiary reported high or very high levels of happiness at follow-up (11) compared to the baseline (10). Overall three respondents reported that they were healthier after accessing the service.

Figure 2: Self-reported health of Carers Resilience Service beneficiaries (baseline and follow-up responses)

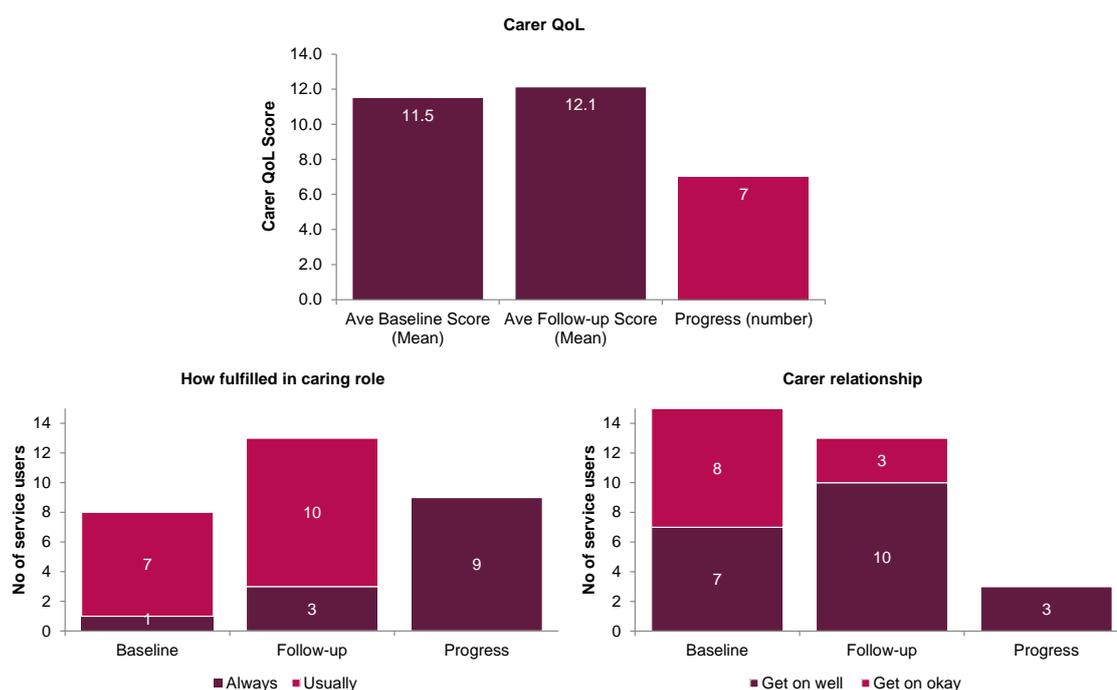


The caring role

Figure 3 provides an overview of the baseline and follow-up responses for the measures of carer quality of life. It shows:

- There was a small increase in the average (mean) **carer quality of life score** between baseline (11.5) and follow-up (12.1).
- Overall seven beneficiaries provided a higher **carer quality of life score** after accessing the service.
- More beneficiaries reported that they were always or usually **fulfilled in their caring role** at follow-up (13) compared to baseline (8). Overall nine respondents reported that they were more fulfilled as a carer after accessing the service.
- More beneficiaries reported that they **got on well with** the person they cared for at follow-up (10) than baseline (7). Overall three respondents reported that they got on better with the person they cared for after accessing the service.

Figure 3: Carer quality of life of Carers Resilience Service beneficiaries (baseline and follow-up responses)



Summary

Overall, the survey data shows that beneficiaries exhibited positive progress against each of the outcome measures in the questionnaire. Small numbers of beneficiaries reported better general well-being, better health and improvements in their carer quality of life after accessing the Carers Resilience Service. These findings are particularly positive when placed in the context of beneficiaries' lives when they accessed the service: many had recently received a dementia diagnosis for the person they cared for and/or were experiencing challenges, even crises, in their caring role. In addition, the follow-up data was collected when the initial engagement with service had been completed (after about three months) and many of the outcomes may take longer to develop.

3.2. Understanding the impact on demand for emergency care

One of the key aims of the Carers Resilience Service was to reduce demand for emergency secondary care for people with dementia. Although it has not been possible to monitor the use of emergency care by beneficiaries of the service it is possible to observe trends in emergency in-patient episodes where dementia is a primary or secondary diagnosis. NHS Rotherham CCG provided data for four years between 2012-13 and 2015-16, analysis of which is provided in table 1.

This data shows that the overall number of emergency admissions with a dementia diagnosis increased between 2012-2013 and 2015-16. This included year-on-year increases between 2013-14 and 2015-16 which amounted to an overall increase of 33 per cent over this period. However, closer inspection of the data reveals a more complicated picture:

- The number of admissions with dementia as the primary diagnosis was relatively low, although it did increase between 2012-13 and 2015-16.

- The number of admissions with secondary dementia diagnosis reduced between 2012-13 and 2015-16, although 2012-13 was a high point and there were small year-on-year increases between 2013-14 and 2015-16.
- There was a large increase (43 per cent) in the number of admissions with dementia as another diagnosis code between 2012-13 and 2015-16.

The final point above suggests that at least some of the increase in dementia related admissions may be related to improved recording of non-primary diagnosis codes rather than simply a rise in demand for emergency care amongst dementia patients.

Table 1: Emergency in-patient episodes with a dementia diagnosis (2012-13 - 2015-16)

	Number of emergency admissions			
	2012-13	2013-14	2014-15	2015-16
Any dementia diagnosis code	1374	1359	1640	1801
Dementia diagnosis code as the primary diagnosis*	50	37	62	95
Dementia diagnosis code as the secondary diagnosis**	328	248	277	291
Dementia diagnosis code as the primary or secondary diagnosis	378	285	339	386
Dementia diagnosis code as another diagnosis***	1011	1088	1314	1444

Source: NHS Rotherham CCG, emergency admissions to all providers, for Rotherham CCG patients, where a dementia diagnosis code appears in the primary or first 10 secondary diagnoses fields (April 2012-March 2016)

- * Primary diagnosis contains a dementia diagnosis code
- ** First secondary diagnosis contains a dementia diagnosis code
- *** Dementia diagnosis code appears in any diagnosis field except the primary and first secondary

The data can be analysed in more detail by exploring how patients came to be admitted as an emergency: whether it was via Accident and Emergency or through referral by their GP. Table 2 provides a breakdown of both admission routes for the period 2012-13 - 2015-16.

This shows some significant differences in the patterns of admissions from GP referrals compared to Accident and Emergency. Admissions from GP referrals increased year-on-year between 2012-13 and 2014-15 and then reduced between 2014-15 and 2015-16. By contrast admissions from Accident and Emergency increase each year between 2013-14 and 2015-16 so that by 2015-16 they were 38 per cent higher than in 2012-13. Overall, this suggests that it is admissions from Accident and Emergency rather than GP referrals that are driving-up dementia admissions in Rotherham.

Table 2: Emergency in-patient episodes with a dementia diagnosis according to referral route (2012-13 - 2015-16)

	Number of emergency admissions			
	2012-13	2013-14	2014-15	2015-16
<i>Admissions from GP referrals:</i>				
Any dementia diagnosis code	337	366	410	364
Dementia diagnosis code as the primary diagnosis*	15	11	25	23
Dementia diagnosis code as the secondary diagnosis**	85	93	70	63
Dementia diagnosis code as the primary or secondary diagnosis	100	104	95	86
Dementia diagnosis code as another diagnosis***	241	268	319	286
<i>Admissions from Accident and Emergency:</i>				
Any dementia diagnosis code	993	958	1193	1369
Dementia diagnosis code as the primary diagnosis*	27	26	33	54
Dementia diagnosis code as the secondary diagnosis**	230	151	202	218
Dementia diagnosis code as the primary or secondary diagnosis	257	177	235	272
Dementia diagnosis code as another diagnosis***	742	790	966	1118

Source: NHS Rotherham CCG, emergency admissions to all providers, for Rotherham CCG patients, where a dementia diagnosis code appears in the primary or first 10 secondary diagnoses fields (April 2012-March 2016)

* Primary diagnosis contains a dementia diagnosis code

** First secondary diagnosis contains a dementia diagnosis code

*** Dementia diagnosis code appears in any diagnosis field except the primary and first secondary

It is difficult to draw any firm conclusions from this analysis about the impact of the Carers Resilience Service on emergency admissions to hospital. As the service was only established in February 2015 its effects would only be evident in the 2015-16 data and may take longer to emerge. The reduction in admissions from GP referrals in 2015-16, following a steady increase between 2012-13 and 2014-15, may indicate that GPs' are becoming better able to support families to manage crises associated with dementia. Wider data suggests that GPs are becoming more effective at diagnosing people with dementia: of the estimated 3,010 people in Rotherham with dementia 66.9 per cent had been diagnosed in March 2014, but this rose to 71.5 per cent in March and 75.3 per cent in March 2016.

However, the extent to which this reduction can be attributed to the work of the Carers Resilience Service and/or the CCG's wider dementia strategy is unknown, and this analysis will need to be undertaken in future years to understand if the reduction is a one-off or part of a longer term trend.

3.3. Qualitative outcome evidence

Qualitative interviews with nine beneficiaries of the service focussed on their experiences of the service, including the kind of support being received, and the difference this support was making to them both practically and emotionally. From these interviews a number of key themes about outcomes for services emerged. These are summarised, along with two service user case studies, in the following section.

A valued and much needed service

Within interviews, some beneficiaries of the Carers Resilience Service reflected on how they had been feeling prior to receiving support. Often people suggested that they felt unsure and extremely anxious about the person they were caring for. For example, one interviewee talked about his worry about leaving his wife for any amount of time:

"I couldn't stay out for long. She was on my mind all the time. I was worried she was going to have a fall" (beneficiary)

All beneficiaries interviewed reported that they had been contacted very quickly following on from the referral, which they had found useful.

Reassurance and support

One of the strongest themes emerging from interviews with beneficiaries of the Carers Resilience service was that they felt that the service provided them with a great deal of reassurance, both in practical terms but also emotional:

"It's hard to explain, but it's so important knowing someone is at the end of the phone for advice or help" (beneficiary)

"To know that there's people out there that you can speak to about dementia and Alzheimer's. And what other people might think were stupid questions to ask, they know exactly where I'm coming from" (beneficiary)

A common theme was the relief people felt moving forwards. Understanding that the situation will change in the future, beneficiaries of the service described how their knowledge of the service helped them to feel more positive about the future:

"There might come a time when you've got to ask for help, when you're really desperate and looking for something. It's knowing the offer's there" (beneficiary)

Mr A

Mr A lives over an hour away from his parents but is an only child. His mother is in the early stages of dementia and his father is having some problems with his memory, although he is resisting seeking a diagnosis. Mr A is concerned about his parents, particularly because of the distance between them, and work prevents him visiting as regularly as he would like. He was called by a representative of the service and they had a conversation about his parents and their needs. They asked whether they could visit his parents, and following this visit, staff contacted him back and recommended a series of interventions. These included practical support within the home, a fully trained care support worker who stayed with his father when Mr A had to take his mother to hospital appointments.

Although Mr A had already sought some information and guidance prior to the referral (relating to dementia, as well as benefits advice for his parents) he suggested that the referral has provided a great deal of reassurance for him. He was very impressed by the staff that visited his parents. He stressed the importance of this service for him, as he lives a distance from his parents:

"I can't praise [the service] enough for how I feel about them - I feel that they're there for me"

The reassurance has changed how Mr A feels about the situation he and his parents are faced with:

"It's that confidence that I've got now that my parents are being looked after in the way that should be in their old age"

Looking ahead Mr A stated:

"At this moment in time I feel quite confident. I mean, if you'd asked me that...when all this started kicking off, I would have said, 'God knows, I don't know where this is going to go"

Another consistent theme was that people now felt 'in the system', and feel reassured knowing where they could go for support should anything occur in the future.

"And the other thing about it is I know that if I have got an issue, I can ring them and say 'look I've got this problem, is there anything you can do about it?' Again, they've got the network to be able to say, 'yeah, we'll put you in touch with so-and-so'. You know, it's that" (beneficiary)

A number of people wanted to comment specifically on the staff involved in the Carers Resilience Service. Beneficiaries reported that the knowledge and experience of the staff was key:

"[the member of staff] has seen it from other angles, and dealt with it before. It's new to [my mother in law] and I haven't dealt with it as such. It's new to us both" (beneficiary)

And:

"The ladies that visited from (the service) were marvellous, sympathetic and helpful"

Information and guidance

A number of beneficiaries discussed the information and guidance they had received through the Carers Resilience service. Knowledge about dementia and Alzheimer's varied, but in all cases, people had found that they had benefited from the information provided, whether because they had learnt something new, or indeed just the reassurance that what they were experiencing was not an isolated case, and was in fact common across many people. For example:

"It's been invaluable. The things I'm experiencing with [my wife] were actually in their booklet. It's amazing how you can relate to it" (beneficiary)

Interviewees also reflected on the support and information sessions for carers, stating that they were looking forward to learning more about the condition(s) and what is needed.

A number of beneficiaries had received information about memory cafes, and the 'singing for the brain' groups. Where attendance had started, feedback was very positive. A small number of beneficiaries were keen to take-up these opportunities but had been unable to do so due to ill health.

Practical advice and assistance

Beneficiaries referred to a wide range of examples of practical assistance that they had received through the Carers Resilience Service. Examples of help ranged from assessments of homes, recommending alarms and safety devices, through to benefits advice and information about community transport and the provision of a home based support service, whereby a care support worker can come to sit with someone for support and reassurance whilst their carer/partner is away.

"They've been there as well for [the dementia patient], they sent somebody in to sit with my dad, have a chat to him."

When reflecting on the services they had received through the Carers Resilience Service, a number of beneficiaries contrasted these positive experiences with more negative experiences within hospitals, with concerns being expressed over the lack of awareness displayed in certain hospital settings of the needs of patients with dementia or Alzheimer's.

Although interviewees didn't know whether the service was having an impact on the number of visits they made to their G.P. a number did reflect that the service may prevent the G.P. being the first port-of-call in certain instances.

Mrs E

Mrs E is caring for her parents, and her mother has been diagnosed with dementia. Following her referral, she was contacted very quickly. As well as providing her with a great deal of information about dementia, a visit was conducted to her parents' home, and safety features were installed, including an emergency alarm key for her father.

Mrs E described the reassurance she feels now that she and her parents are linked in with the Carers Resilience Service. She talked about the knowledge of the staff, and the sensitive way in which they work with both herself as a carer, and with her parents:

"They know exactly what we're talking about without having to go into depth about things" (Mrs E, Carers Resilience beneficiary)

As well as a great deal of reassurance, Mrs E described how the practical support of providing key contact information to her and her parents had helped already avert a possible emergency situation, following a fall that her father suffered:

"Like my Dad did, he phoned [the service], instead of phoning an ambulance, or his doctors, he got this emergency number on a key at the side of his phone, and they were the first people he phoned. It was them, and they phoned an ambulance straight away, and kept my Dad talking, you know, phoned him back, told them what was happening then phoned me at work" (Mrs E, Carers Resilience beneficiary)

The response to this emergency demonstrated the effectiveness of partnership working. In addition to the emotional and telephone support provided a care support worker was immediately arranged to provide home based support to Mrs E's mother until a family member was available.

Reflecting on this particular incident, Mrs E discussed how she thinks the service could make a real difference to local primary care:

"I think if the doctors, you know, get [the service] people to phone the families that are suffering, they would take a lot of pressure off doctors, definitely. They came out and saw my Dad and my Dad got on with them brilliantly" (Mrs E, Carers Resilience beneficiary)

Mrs E had also received information and guidance about the legal process of power of attorney. Following the information she received through the Carers Resilience Service, she was able to make these arrangements very easily without incurring additional legal fees.

Conclusion

This report has provided the main findings of an evaluation of the Rotherham Carers Resilience Service that is being delivered by Crossroads Care Rotherham, Rotherham and Doncaster Alzheimer's Society and Age UK Rotherham on behalf of NHS Rotherham CCG. The evaluation focussed on the first year of the service (February 2015-March 2016). The main findings are as follows.

1. The service has reached more than 330 carers of patients with a dementia diagnosis

These beneficiaries of the service have received specialist and tailored advice, information and guidance about implications of dementia diagnosis for the patient, their carer and wider family members and been helped to access a broader range of external support. In addition, a smaller number of beneficiaries have been supported through acute crises in their caring role through the provision of home based support. This support has provided carers with time and space to address their own health and well-being needs and put plans and resources in place to meet their caring commitments and personal needs

2. The service has achieved a number of notable successes in its first year of delivery

Key stakeholders reflected that the service had successfully raised awareness of the needs of carers for people with diagnosis, particularly where these might be hidden. They were also positive about the model of service delivery that had been developed and the way the Crossroads Care Rotherham, Rotherham and Doncaster Alzheimer's Society and Age UK Rotherham had been able foster positive partnership working between key stakeholders at the same time as helping to improve services.

Although the interventions by Carers Resilience Service are time limited a key aim of the pilot project was to ensure the carers had access to ongoing support which would enable them to continue caring for as long as they are able or choose to do so. In support of this carers have been linked in to other statutory, voluntary and community services with the option to return to the Carers Resilience Service should further support and advice be required. By supporting carers to access additional benefit entitlements the service has provided many carers with additional financial resources to purchase future support as required.

3. The service faced and overcome a number of challenges in the past 12 months

Demand for and uptake of the service varied considerably between GPs. In some practices demand was high and the needs of beneficiaries were quite high and time consuming due to the lack of support that had been available prior to the inception of the service. At the same time a small number of practices did not fully engage with the service meaning uptake was much lower than for other GPs. The service's flexible approach to engaging with practices was seen as a crucial factor in raising awareness of the benefits of the service.

Stakeholders were keen that the service should not become solely a crisis intervention and wanted to ensure that the majority of its resources were focussed on early help and preventative interventions before carer crisis and/or breakdown became an issue. However, this will be an ongoing challenge for the service, particularly in the context of public sector funding cuts and the pressure on the wider health and social care system.

The three project partners have worked closely with the CCG and other local statutory bodies to provide information and insight into the issues currently experienced by carers, in particular the diagnosis process. In response the recently developed Local Engagement Strategy seeks to implement a clear pathway for the swift diagnosis of non-complex dementias within the GP surgery. The Carers Resilience Service continues to work closely with local GPs to provide support at the earliest opportunity to carers during and following diagnosis.

4. There is some evidence that beneficiaries receive an immediate boost to key outcome measures upon accessing the service

Overall, beneficiaries showed progress against each of the outcome measures in the evaluation survey. Small numbers reported better general well-being, better health and improvements in their carer quality of life after accessing the Service. These findings are particularly positive in the context of the issues many beneficiaries were facing when they first accessed the service.

5. The service is highly valued by beneficiaries for the support, advice and guidance they receive

Beneficiaries who participated in the qualitative research were effusive in their praise for the service and the individual workers involved in its delivery. The service was valued for the reassurance and support it provided at an emotional and stressful time in people's lives. Participants appreciated the way the service was able to provide emotional support in combination with practical information, advice and guidance about how to cope with a dementia diagnosis, with added benefit of knowing that practical home based support was available in the event of a crisis.

6. It is too early to say whether the service is having a positive impact on the demand for emergency care

In Rotherham there has been a significant increase in the number of emergency hospital admissions with a dementia diagnosis code since 2012-13. The extent to which this is due to a real increase in demand or improvements in the way dementia is identified and recorded by clinicians is unknown. Much of the increase since 2012-13 appears to be due to patients being admitted via Accident and Emergency rather than referrals from GPs. In fact, the number of

patients with a dementia diagnosis referred as an emergency by the GP reduced between 2014-15 and 2015-16. This could mean that GPs are becoming better able to support families to pre-empt crises associated with dementia but the extent to which this reduction can be attributed to the work of the Carers Resilience Service is unknown. Further analysis will need to be undertaken in future years to understand if the reduction is a one-off or part of a longer term trend. However, as illustrated by the beneficiary case studies, there are examples of where the support provided through the Carers Resilience Service have directly prevented or delayed admission to secondary or residential care.

Appendix - Service User Case Studies

Case study 1: Mr X (male, aged 87) and his family

Reason for referral

The GP referral stated that Mr X was displaying physical symptoms of carer stress (September 2015). The GP re-referral said Mr X's health was deteriorating and that he had been referred to the memory service (February 2016).

Profile

Mr X lives with his wife in their own bungalow. His wife has a diagnosis of Alzheimer's disease. Mr X was struggling to support his wife and manage her needs. He was frequently exhausted and becoming increasingly confused, he struggled to drive but continued to do so to take his wife out several times a week. He stopped doing the hobbies he enjoyed such as snooker and painting. The couple frequently became frustrated with one another, and Mr X became anxious over his wife refusing to take her medication.

The couple received support from their daughter J, who lives in Worksop. J visited her parents several times each week and this increased to most days. J was becoming highly stressed, anxious and emotional. She was trying to meet both parents varying needs and this was having an effect on her own health and wellbeing

In April 2016 Mr X also received a diagnosis of Alzheimer's disease. Although J had been expecting a diagnosis of dementia she was still extremely distressed and worried about the future and how best to support parents both diagnosed with the disease.

Assessment of need

During the home visit it was clear that Mr X and his wife both had very different needs and their daughter J was struggling to cope. Many options of support that were discussed were declined by Mr X's wife, although Mr X seemed more open to support, it was difficult for them all to agree. The service staff provided regular telephone support to J, J was very often emotional during these conversations. Staff also discussed their concerns over her father's health and memory issues and encouraged further GP visits. They suggested J consider some professional counselling to look at coping mechanisms and help her deal with the overwhelming feelings she was experiencing. Staff also regularly talked through strategies for support and looked at how to best support two parents both with a diagnosis of dementia.

CRS actions taken

- Home visit to discuss needs
- Education about Dementia, in particular Alzheimer's Disease
- Referral to Age UK for Attendance Allowance for Mr X's wife

- Referral to Assessment Direct for Assistive Technology
- Signposted to Door 2 Door
- Provided details of cleaning services
- Signposted to Maltby memory café for peer support (J & Mr X have attended)
- Carers Assessment for J
- Rothercare & environmental package referral
- Carers Resilience emergency referral for respite in February 2016
- Signposted J for professional counselling
- J put on waiting list for Carer's Education Course and has since attended this
- Referral to Assessment Direct for Social Care Assessment for the both M X and his wife
- Conversations with social worker on package of support for the couple
- Referral to Age UK for Attendance Allowance for Mr X

Outcomes

- A social care assessment identified that social support was needed for both Mr X and his wife, however both had differing needs. In order to retain some independence from each other and initially to allow Mr X some respite separate plans were put in place.
- Mr X felt under a great deal of pressure to continue driving despite feeling that he was no longer safe or able to drive well, he felt he needed to continue his wife's social activities so that she did not become totally isolated due to her condition. With support from CRS he was linked to Door2Door which his wife now uses on a regular basis, her friend also uses it to visit her. He no longer drives.
- Mr X has had companionship support to continue his long held routine of visiting his butcher which he has done for many years and to do some shopping. He is also supported on a separate day of the week to go to the local snooker club. Initially this gave him some respite from his wife and his caring role and latterly it helps him to stay connected with his local network as his condition progresses.
- Mr X and his wife, although living independently, are now cared for by their daughter (J) who since her father's diagnosis has become increasingly worried about their ability to stay safe in their home. The couple have subsequently had Rothercare fitted in their home which has given their daughter peace of mind about them living alone.
- Due to the involvement of CRS at the early stages of Mr X's diagnosis and the subsequent referral into the service for their daughter they were given the support and information they needed to have power of attorney put in place. This has given Mr X and his wife confidence that as their condition progress their wishes will be carried out by their daughter, it has also given their daughter the capacity to make sure that she can meet their needs at any point without having to navigate any associated red tape.
- Mr X and his wife both now receive Attendance Allowance which enables them to pay for their transport and other activities/support helping them to live well with their dementia.
- The companionship for Mr X enables his daughter to take his wife out and focus on quality social time together without worrying about his care.
- J attended the CrISP programme and enjoyed the peer to peer support from others in the group. She felt better able to cope with her guilt and frustration as she realised that others also felt the same and shared their coping strategies. She felt she learned more about the physical and emotional impact of Alzheimer's and the changes she could make or support her parents to make which would allow them to live independently for longer.

- J continues to put things in place which support her in her caring role and will help her to support her parents to live independently for longer. J is now signed up to the emergency carers' scheme and has undertaken some counselling to enable her to develop her emotional resources and resilience to cope with her new role.
- Due to the package of support which has been put in place J has been able to continue to retain a degree of normality in her life with her family. She has recently been on holiday and felt confident that her parents would be able to cope well in her absence or that in the event that something did happen this would be picked up by the network around them.
- At this time J feels that she has all the information she requires, that her parents have in place appropriate support and that in the future as things progress she knows where she can get additional support and is confident enough to ask. She has increased awareness of the importance of maintaining her own emotional health and the need to have a sense of wellbeing with her own family.

Ongoing care/links to other services

The Dementia Advice and In Home Support received through the Carers Resilience Service allowed the family to experience external support and realise the benefits of this. The experience enabled them to accept a referral to Assessment Direct for support on a long term basis.

Mr X now has regular companionship and support through an external provider which enables him to continue doing the things he enjoys. His wife remains uneasy about services being involved but she has gradually accepted the workers providing support for her husband. J is hoping that in time her mother will accept help/support for herself.

J is fully aware that she can come back to us for support in the future. She is aware that the situation can easily change. She revisits her tools and coping strategies developed through her counselling sessions and has said she would access this therapy again if needed.

Case study 2: Mrs Y (female, aged 49)

Reason for referral

The carer became aware of the Carers Resilience service following contact with staff at a carers' clinic held at her local surgery. The referral form stated that the carer was distressed about her caring role and needed reassurance and support as soon as possible.

Profile

Mrs Y lives with her mother, father, and brother. Her mother has a diagnosis of vascular dementia and the whole family was struggling to come to terms with this. Her father has COPD and she stated that he was the main focus of the family's attention until her mother received her diagnosis, and then the attention was shifted to her mother. This has caused frictions within the family. Mrs Y's mother has been asking about her diagnosis and wants to know more about it but Mrs Y has felt that it was inappropriate to tell her anything.

Mrs Y works three shifts per week at a local petrol station but due to her high stress levels there had been incidents at work of her losing her temper. She was also in the middle of a part time course at a local college. Mrs Y said that even though she had time out of the house she worried about her mother constantly.

When the service first spoke with Mrs Y, she was very emotional and said that she was not getting any help from family and felt that she was not coping.

Assessment of need

As Mrs Y sounded so distressed during the early first phone conversations with service staff they felt that she needed emotional support, and someone to sit with her mother so that she could have some time to herself without worrying that her mother was safe. Service staff felt it would be beneficial in time for Mrs Y to meet with other carers in a similar situation for peer support so that she did not feel so alone. They also felt that it would be useful to meet with Mrs Y and her family to discuss the dementia in more detail so they had a better understanding of how this was affecting their mother, and coping strategies for dealing with this day to day.

CRS actions taken

- Referral to the In Home Support of the Carers Resilience Service for some urgent sitting hours
- Home visit with Mrs Y and the family, to discuss coping strategies
- Provided information on dementia for Mrs Y, her mother and the family
- Put Mrs Y on waiting list to attend Carers Education
- Provided information on social groups for Mrs Y's parents to attend.
- Provided information on LPA and financial matters

Outcomes

- Mrs Y decided not to accept the sitting service from CRS but following their support felt that she was able to cope with situations at home more effectively and this had improved her relationships with work colleagues. Due to this she feels confident and happy that she will be able to continue working.
- Mrs Y feels she is better able to recognise her own mental health needs and the need to prioritize her own wellbeing i.e. by staying in work and making that time away from home happier than it had been.
- Mrs Y has completed her college course and enrolled on the next course, displaying her increased confidence in her own abilities now that she received information and support for her caring role.
- Following the support from CRS, Mrs Y said she 'felt worlds better' as she is better able to cope within the family and is dealing with issues in a non-confrontational manner which has been beneficial to everyone.
- Mrs Y said that the Dementia Advisors visit and being able to discuss coping strategies in a non-judgmental safe environment had given her an understanding about what she could do, making marginal changes that would have a big difference for everyone.
- Mrs Y's attendance at the CrISP course enabled her to meet other people in the same situation and she valued the opportunity to get that peer to peer support. It has reduced her feelings of isolation and the guilt she has been feeling because of her frustration and anger about the situation. The group has allowed her to share her experiences and get feedback about additional strategies that would enable her to cope. She has a better understanding of dementia both medically and emotionally which will inform the way she supports both her parents with their long term conditions.
- Due to the support from the CRS Mrs Y has a better understanding of the benefit system as it relates to both her and her parents, this has reduced her stress as she is now confident that they have all the benefits they are entitled to. She is also aware that as their conditions progress she may need to revisit the situation however she feels

confident that she knows where she can get the right information and support to make any applications.

Ongoing care/links to other services

Mrs Y is attending the carers' education course with Alzheimer's Society which started on 18/07/2016. She is aware that she can come back to CRS for support in the future at any time. Her mother and father are attending regular support groups through the memory clinic. They have been referred to the SPS service and are being supported to attend these groups by the Community Dementia Support Worker giving Mrs Y the peace of mind that they are being supported and releasing time for herself.

Case study 3: Mr Z (male, aged 71)

Reason for referral

The initial referral (2015) for Mr Z came from his GP who was concerned for his wellbeing as he had recently had a fall and sustained an injury to his arm. In 2016 the 2nd referral form stated that Mr Z had surgery on his arm and he was not well. His wife who he cared for had suffered a fall and Mr Z needed support.

Profile

Mr Z lives with his wife in their own bungalow. His wife has a diagnosis of Mixed Dementia and although he has managed in the past he is now struggling to manage his wife's needs due to deterioration in his own health. Mr Z and his wife have two daughters who support with shopping and who take it in turns to visit on Sundays to sit with their mum to ensure that Mr Z has a break and some time to spend with his brother.

Initial assessment of need in 2015 (1st referral)

Mr Z was assisting his wife with all care needs, meals, shopping etc. At this time his wife was able to stand independently but needed a little support with her walking to ensure she did not fall. Mr Z told the service that he had recently had a fall and injured his arm which would need to have surgery.

Support in the care of his wife was offered but declined as Mr Z still felt he could manage on his own with the support of his daughters. Mr Z did agree that a referral could be made to Crossroads sitting service. When he became eligible for Crossroads Sitting Service a member of the Carers resilience Team was asked to complete the home visit and care plan due to previous involvement with the family. Mr Z was still reluctant to accept support but after a long discussion it was agreed that he would try the sitting service to see if it could help meet both his needs and those of his wife.

At the end of the home visit Mr Z had also agreed to referrals for:

- A carer's assessment
- A social needs assessment
- Podiatry
- Incontinence team

Both Mr Z and his wife accepted the sitting service and when he had surgery on his arm he was again referred into the Carers Resilience service for additional support during his recovery period.

2016 (2nd referral)

On first contact Mr Z informed the service that he was aware of the referral, he had tried to manage but was now aware that he could not do everything on his own. He informed service staff that his wife's mobility has deteriorated and he struggled to get her out of the chair or in/out of the bath and help her with her personal care. Service staff discussed with Mr Z accessing Carers Resilience Service in the short term until a full social care assessment had been completed by Adult Services. Mr Z informed the service that he did receive two 2 hour sits per week from Crossroads to enable him to carry out shopping and financial responsibilities.

CRS actions taken

- Referral to CRS at Crossroads to provide urgent support – this was to support MR Z to manage personal care tasks
- Home visit with Mr Z to discuss future services and coping strategies
- Contact with Assessment Direct to complete Social Care Assessment and Carers Assessment ASAP
- Referral to Age UK to complete forms for blue badge
- Referral to District Nursing Service to look at incontinence wear
- Referral to Mental Health Occupational Therapist to complete assessment for ramp to access the property
- Contacted BT regarding information for having a land line connected – a land line is now in place
- Referral to Rothercare for pendant alarm system and assistive technology
- Informed Mr Z of carers education course

Outcomes

- On referral Mr Z felt that he could not cope with the care for his wife both physically and emotionally, CRS facilitated the establishment of a formal care package which consisted of three visits per day and covered transfers and personal care tasks. This significantly reduced his anxiety about being able to maintain a decent standard of care for his wife and allowed him to continue other tasks which retained a sense of normality.
- Mr Z had been very worried about maintaining the care for his wife in the long term because of the financial implications which had an impact on his emotional health. With support he was able to undergo a financial assessment which identified that his wife is exempt from charges. This enabled Mr Z to see that with support he would be able to provide care for as long as it was appropriate.
- Mr Z and his wife had become very isolated due to her mobility problems and his capacity to make sure that she was well dressed and hygienic. An application for Blue Badge meant that he could take his wife out which had previously been limited due to her mobility, this gave them the opportunity to see their friends and access local services.
- The service identified an issue with pressure sores which were impacting on the quality of life for Mr Z's wife, he was physically unable to move his wife to relieve any pressure or ensure that the areas were kept appropriately clean. The implementation of the care plan and the involvement of the District Nursing Service where able to ensure that this condition could be managed.

- A referral to Occupational Therapy services has provided a hoist, walk about commode and bed sensor to decrease the physical load on Mr Z as well as give peace of mind during the night.
- In addition a separate referral to Adult Services to look at adaptations to the property has resulted in a wet room being installed and a ramp which has improved access in and out of the property. This in itself has enabled the couple to feel safe getting in and out of the property and provided appropriate bathing facilities so that care staff can continue to provide personal care to his wife.
- Mr Z reported that he had been trying to manage for so long on his own and it was now much better with support in place.

Ongoing care/links to other services:

Mr Z is aware that he can come back to the Service at any time for support and knows to contact Assessment Direct for any changes to the care. Even though he was aware his case had been closed Mr Z contacted the service in July to say that things have deteriorated and he would like some respite care. The service contacted Adult Services to try and assist getting this put in place.