



# Improving the Health of Carers

## A casebook of projects

A selection of nine projects, illustrating innovative ways that Carers Trust Network Partners have supported the health of carers through the funding of People's Health Trust and the support of Carers Trust





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# Acknowledgements

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# Contents

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<b>Introduction</b>	<b>2</b>
<b>Challenges</b>	<b>5</b>
<b>Older carers</b>	<b>6</b>
Derbyshire	7
North and South Ayrshire	12
North Somerset	16
South East Wales	20
Wandsworth	24
<b>Young adult carers</b>	<b>28</b>
Blackpool	29
Central and North London	33
East Anglia	37
York	41
<b>References</b>	<b>45</b>

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# Introduction

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This casebook brings together examples of projects around the UK that have, within the space of 12 months, explored different ways of supporting the health of carers.

## The programme

In 2011, The Princess Royal Trust for Carers and Crossroads Care<sup>1</sup> were selected by People's Health Trust to coordinate the delivery of health related projects managed by carers centres, Crossroad Care schemes and young carers services within its network. As part of its Healthy Places, Healthy People funding programme, carers centres and schemes in locations pre-determined by People's Health Trust were invited to submit project proposals detailing how they would spend funding to develop effective services to improve health outcomes for either older carers (those aged 60 plus) or young adult carers (aged 16–24) from socio-economically disadvantaged communities across England, Scotland and Wales.

31 organisations were awarded funding in 30 geographical areas. 23 organisations planned to work on developing services for older carers, and eight organisations aimed to work with young adult carers. The grant available for each area was £40,000 for 12 months during 2012–13.

Carers Trust is a major new charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, **unpaid**, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with Network Partners – a unique network of 116 independent carers centres, 59 Crossroads Care schemes and 105 young carers services. Together we are united by a shared vision for carers – to make sure that information, advice and practical support are available to all carers across the UK.

People's Health Trust is an independent charity addressing health inequalities by investing in local organisations with great ideas to create fairer places to grow, live, work and age. People's Health Trust is funded through 51 society lotteries, each designed to raise money to address health inequalities in a separate part of England, Scotland and Wales. The society lotteries operate through The Health Lottery. [www.peopleshealthtrust.org.uk](http://www.peopleshealthtrust.org.uk).

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1 Carers Trust is a new charity formed by the merger in 2012 of The Princess Royal Trust for Carers and Crossroads Care. Carers centres and schemes are now known as Network Partners.

## Older carers

There are around seven million carers in the UK – that is one in ten people.<sup>2</sup> As of the 2011 Census, there were 1,277,693 carers aged 65 and over in England and Wales. People over 65 account for 38% of all carers providing more than 50 hours of care a week (UK Census, 2011).

In 2011, The Princess Royal Trust for Carers surveyed over 600 carers aged 60 plus to find out about their caring roles and the services available to them (The Princess Royal Trust for Carers, 2011).

Of the older carers surveyed:

- Two thirds reported long-term health problems or a disability themselves.
- One third reported having cancelled treatments or an operation due to their caring responsibilities.
- 70% of the respondents said caring had a negative impact on their physical health.
- 40% said their mental health had deteriorated over the last year.

More than one third do not get a break away from their caring role, and a further third only get a break once every 2–3 months. The NHS acknowledges the importance for carers of taking a break in order to manage their caring roles.

80% of the older carers surveyed have fears for the future; particularly about what will happen to the person they care for when they are no longer able to care.

## Young adult carers

Currently, there is no UK wide age breakdown available from the 2011 Census detailing the total number of young adult carers. Based on previous census data collection methods it is likely that the number of young adult carers will be underestimated. The 2001 Census indicates that there are 290,369 carers in the UK who are aged 16–24. The 2011 Census indicates that there are 314,003 carers in England and Wales who are aged 16–24. There are 254,332 young adult carers aged 18–24 in England and Wales – 4.8% of all people in that age group. 30% of all young adult carers in England and Wales aged 18–24 (75,210 people) are providing more than 20 hours of care per week. 31,905 (13% of the total) are providing care for more than 50 hours each week (UK Census, 2011).

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2 UK Census 2011. Source: Office for National Statistics licensed under the Open Government Licence v.1.0. The number we have used is our estimate of the number of carers across the UK based on the Census figures. The number of carers is fluid and can only ever be an estimate for the following reasons: People can become a carer at any time. People can become a carer for a short period of time to support someone following an accident, at the end of their life or during an illness, for example. People do not always see themselves as a carer and do not necessarily recognise their own needs. Some people shy away from having a label attached to them.

We know that young people struggle with their caring role. Many suffer from anxiety, fatigue, low self-esteem and isolation from peers, including being bullied and harassed at school.

Young adult carers surveyed as part of a study by Becker and Becker (2008) identified that caring had a significantly detrimental effect on their own health and that they experienced negative health outcomes directly related to caring. These included negative emotional wellbeing such as feeling worry, stress, anxiety, depression, anger and upset, and physical ill-health such as tiredness, exhaustion and back ache, and being prone to colds and ulcers.

One of the key challenges facing young adult carers is the lack of age-appropriate services. Legally, young people under 18 are still 'children', while those over 18 are considered adults. This leaves young adult carers in a no-man's land where they face the prospect of having to leave a young carers service as soon as they turn 18, without the benefit of transition services or suitable adult services being available (those that are available largely cater for a much older age group). Many feel trapped, unable to cope and can be left without structured support.

Added to this, young adult carers have increased anxiety and stress associated with trying to move on in their own lives, such as going to college or university or living independently, while still feeling and being responsible for the person they care for.

Young adult carers have told us that they need more awareness, understanding and advice about the crucial issues at this stage of life – careers, education, housing and budgeting – and, most importantly, they also need support from people who understand their needs and their situation.

## Meeting challenges

The funded projects have been evaluated as a programme as a whole (see separate Impact Report), and it is apparent that while the different projects are dealing with local issues, they are all facing similar challenges.

This casebook is designed to highlight the practical lessons from nine of these projects.

What is particularly important is the learning from the projects themselves about how to set up and deliver local support, and what to consider in the separate stages of work.

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# Challenges

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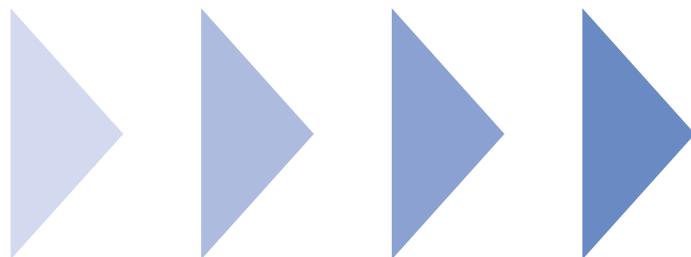
The work of 31 projects offers an enormous range of experiences and learning. This can be seen in more detail, along with the efficacy of different types of approaches, in the companion Impact Report.

What was clear from that evaluation, however, was that all the projects were using their funding to address one or all of a set of challenges; challenges for both carers organisations in particular and many local public services in general. Looking across them all, it is clear that there are five challenges that organisations need to deal with in order to put themselves in the best position to support the carers they work with.

<b>Demand challenges</b>	In many ways, the needs of carers remain similar, regardless of wider economic or social changes. But there are some changes to needs and views that it is important for services to understand – whether the societal impact of an ever aging population, or changing views of how society views the transition years of 16–24; or whether wider choices of consumption brought about by greater individual choice affect how people choose and use services.
<b>Asset challenges</b>	It is always essential for services to maximise the assets available to them, and not rely solely on grant funding, but that need is increased at time of funding scarcity. Many of the projects explored ways to use local assets, whether people, volunteers or buildings, and used the funding to lever in or gain support from other partnerships or services.
<b>Prevention challenges</b>	One of the most significant challenges at a time of reducing budgets for many services is to stop a drift towards services which only support those in crisis. Many of these 31 projects found ways to explore innovative methods to deliver preventative working and to reduce the number of individuals requiring more costly and crisis based support in future.
<b>Carer-led challenges</b>	Ensuring that carers are a key part of deciding and leading on the approach to the services that support them was an essential part of all projects. Some have tried to think creatively about how to push that leadership as far as possible, enabling carers to have more ability to control their services.
<b>Strategic challenges</b>	As the local landscape of providers is shifting with funding and other changes, it is an ongoing challenge for services to ensure that there is a local strategic fit of issues that work for carers. This could, in reality, mean building relationships with other agencies such as GPs or educational establishments, or it could mean re-assessing their organisation’s strategic priorities in light of wider changes.

This casebook focusses on how each project has tried to respond to these challenges.

# Older carers



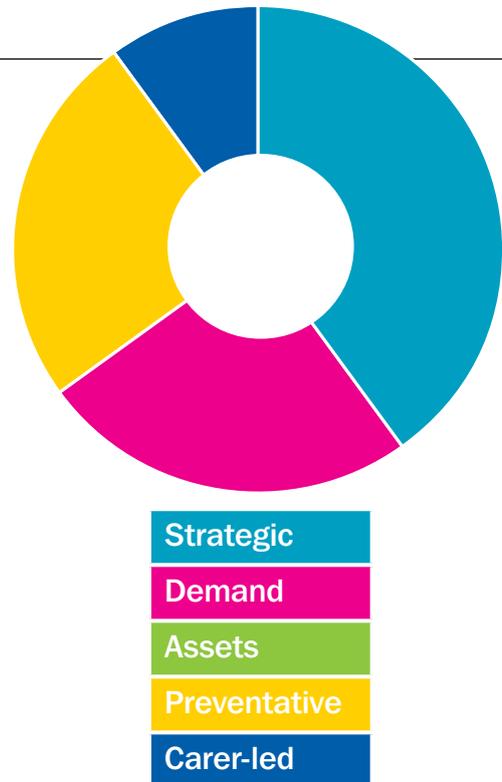
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# Trained and active carers

## Derbyshire

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Derbyshire Carers Association set up its project to support 400 older carers through a training package, a series of organised activities and a breaks fund. The training package, entitled CATCH (Carers Advice and Training for Confidence in Health), was designed to improve carers' confidence in the way they carry out caring and to improve their health. The events and breaks funds were designed to provide breaks from caring and access to activities, thereby reducing the stress associated with high intensity caring. The events also aimed to facilitate social interaction, which would in turn support carers' health and wellbeing.



### Key features

-  The project had a strong **strategic** element, building upon existing infrastructure and resources to deliver services, and providing an opportunity to specifically develop the work the organisation does with older carers.
-  The project took a **preventative** approach, providing training and breaks from caring to help prevent health deterioration. It also worked alongside its organisation's Transition Project which is designed to identify carers early on, before they reach crisis point.
-  The project was a response to a **demand** for breaks and training, identified through the organisation's work with carers. In particular the high level of demand for an existing breaks fund suggested a need to offer another fund, specifically for older carers.
-  There was also a **carer-led** element – applications for the carers fund were decided by a panel which included a carer.

## The current delivery

6,000 carers are registered with Derbyshire Carers Association. The organisation operates across the whole of Derbyshire and has offices based in Derby and Chesterfield and a head office in Ripley. The organisation has 32 members of staff and many volunteers to support the running of the projects.

The service works with carers from the age of 16 plus and approximately 75% are older carers. Services for carers include home visits for first contact, carers' assessments, information and advice, emergency planning, support groups, telephone support, and events and trips.

The organisation has received funding from the Department for Health to deliver a preventative project, working with GP surgeries and hospitals to identify carers before they reach crisis point. The funding also initially went towards training for carers. A breaks fund of £250 is available to all carers.

## The local needs

Key concerns for Derbyshire Carers Association were the stress and mental health impacts of caring, social isolation experienced by older carers, access to financial information and direct negative health impacts of caring such as through inappropriate lifting. Training to help carers manage their responsibilities, social integration and breaks from caring were therefore identified as key areas of need.

Particular to Derbyshire, the project identified geographical challenges for carers accessing services. Carers are often spread out over large distances and the carers themselves often do not like to travel far. Access to transport was thus identified as a need for the project.

The organisation already offered a breaks fund for carers, however this was unable to meet the high level of demand, and therefore the project identified a need to offer another fund for breaks, specifically for older carers.

A need to reach hidden carers<sup>3</sup> was also identified. The project found that carers tended to access the service when they had reached crisis point and were therefore keen to target carers early.

“We’d hope that our services would prevent our carers reaching crisis. We found historically they tended to have been caring for anywhere between five and ten years before they’d heard of our service and received any support from us.”

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3 A hidden carer is defined in this study as a carer that is not already known to services. It may refer to carers who do not perceive themselves as carers, those who are unaware that they can access support and/or people who are particularly marginalised in society and less likely to access services.

## The project

The project was designed to add three specific offers to the existing service:

1. **A bespoke training package:** Training to improve carers' confidence in the way they carry out their day-to-day caring. Training covered three modules – caring and me, caring and coping and coping with finance.
2. **Organised carers activities and events:** An opportunity for older carers to attend organised events and activities throughout the year. Provision of transport was included in the offer.
3. **Carers breaks:** An opportunity for carers to apply for funds for any idea that they have which they believe will offer them a break. Carers could choose the break most needed for them and could define 'break' as they wish.

## Key learning from the project

<b>Carer</b>	<ul style="list-style-type: none"> <li>● Peer support was consistently cited as being of significant value for carers. They enjoyed having the opportunity to talk to other carers, either in social or training environments.</li> <li>● Some carers did not want to take up the training offer. Those who did however, valued it highly. This suggests a need to continue to explore new ways to communicate the offer to carers.</li> </ul>
<b>Service</b>	<ul style="list-style-type: none"> <li>● The breaks fund enabled carers who could not access the events to apply for funding for a break tailored to their own specific needs. Together, the two services provided a holistic offer for a range of circumstances.</li> <li>● Provision of transport facilitated access to events for some carers, however, due to the large geographical area covered by the Network Partner, travel remained a challenge for some carers. This suggests a need to continually review how best to facilitate access when delivering services over large areas.</li> </ul>
<b>Staff</b>	<ul style="list-style-type: none"> <li>● The administration workload for the event organisation element of the service was greater than anticipated. Staff felt it would be beneficial to the service to offer fewer events and instead to signpost to external events and focus resources in other less intensive areas, amending the service accordingly.</li> <li>● The holistic offer for carers gave staff a thorough insight and therefore deeper understanding of older carers' needs.</li> </ul>
<b>Network Partner</b>	<ul style="list-style-type: none"> <li>● The project brought in a significant number of carers who were previously unknown to Derbyshire Carers Association. As well as accessing the services provided by this project they were able to access the additional services offered by the Network Partner.</li> <li>● The project increased staff hours and the services available, and staff reflected that in the current economic climate there would be a need to apply for more independent funding and to become more cost-effective if they are to continue the service and meet the needs and demands that this project has successfully identified.</li> </ul>

“Wonderful! Wonderful, wonderful. It’s so well organised. The next one is a week on Monday and I’m picked up at the end of the road, because of where I live. And it’s like sort of being able to meet other carers and you can exchange information, tips, whatever, and if they don’t have those trips how would I ever meet another carer?”

## The impact on carers

Carers highly valued the peer support they experienced through support groups and social trip/activities.

Having both a carers fund for activities and events and offering carers breaks enabled breaks to be accessible to a large number of carers. While not all carers could access respite care in order to attend the trips, all could apply to the fund and use the grant for a break tailored to their individual needs. Many carers chose to use this fund to pay for items which would make caring less intensive, such as household items, or provide them with an opportunity to take short breaks from the immediate pressures of caring.

The training did not appeal to some carers, primarily due to perceptions that it would not be beneficial when they had already been caring for years, so it took volunteers time to explain the value of it. Those who attended were very enthusiastic about the training and felt that the organisation should expand the offer.

“The [training] was wonderful. It’s all about looking after the carer, like if you don’t eat healthily and if you’re sick it’s no good hiding it away, you have to confront it. It was just very good. And coming up with stats like carers save the Government the equivalent of the NHS budget. And knowledge to me is empowerment. It’s a very nice feeling that somebody else thinks enough of you to, not exactly worry, but to be concerned and to try and lift you up. It lifts your spirits up.”

Carers also reported feeling encouraged to look after their own health needs as a result of the training.

“I needed a scan and I refused it and then I refused it again and then after that workshop, for want of a better phrase, I thought, well I’d better face up to this. So it does motivate you in certain aspects. It enforced that the carer must look after themselves and not always put themselves on the back burner.”

## The effect on the service

The project has been able to connect in with all other parts of the Derbyshire Carers Association offer, which has resulted in learning, adaptation and improvement in a number of areas. It has provided great value as a whole for the organisation and the carers it supports.

- The project increased staff understanding of the holistic needs of older carers.
- The training offer did not appeal to some carers, perhaps suggesting a need to review how it is publicised and communicated so that more carers are able to benefit from it.
- Event organisation was more time and resource intensive than anticipated. Therefore, the service successfully adapted, reducing the number of events and re-focussing resources in other areas.
- The project developed various ways to meet the challenges of covering a large geographical area, such as offering a breaks fund which can be tailored to the individual, and providing transport.

“Time is a difficult thing because if you do something at one time of day it suits some carers but not others, but for Derbyshire it’s particularly difficult with the location of anything, because we’re such a very big county and people have to travel. And that increases people’s tiredness and it increases cost. It increases the length of time that they’re away from home. So there are challenges around that and [staff] have risen to that. We’re trying to be fairly flexible about the events that we’ve run, and they’ve happened in different corners of the county and we have an open conversation with carers about transport.”

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# Counselling older carers

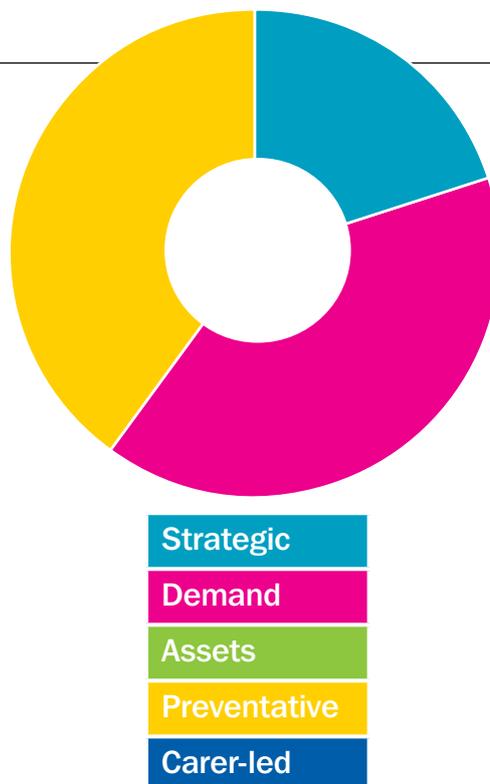
## North and South Ayrshire

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In North and South Ayrshire, Unity Enterprise set up its project to work with 92 older carers in a way that would support the mental health and wellbeing of those carers.

The main focus of the project was to use a combination of counselling, therapy and stress management sessions to provide an individual and fixed offer to carers of a set of counselling sessions, followed by a further set of fixed hours of therapies such as massage. Services were delivered in Irvine, Ayr, Largs and Girvan.

The preventative element of this project should not be underestimated – it created huge benefits for the carer and wider services in the area.



### Key features

- Preventative** The project was bid for after the success of a pilot that had been developed with a volunteer. It had a strong **preventative** approach. It worked with carers on an individual basis before, and in some cases during, the time they may have reached crisis point.
- Demand** It was the response to a growing **demand** that the Network Partner had observed, with people coming in and needing somebody to speak to. The Network Partner staff felt that to really support the health of their carers, they needed to both continue the chatty and open feel of the Network Partner, but to also bring in some professional counsellors to further the support.
- Strategic** Finally, there was a **strategic** element to the project, as it helped the Network Partner think more about how it links to other health and mental health services, and how important professional mental health and counselling support can be for all carers.

## The current delivery

The Irvine centre is based on the high street in town. There are approximately 4,500 carers on its database, and it has about 650 contacts a month with carers, which could include enquiries, drop-ins, people using its therapies or support services, or carers coming to support groups.

Older carers – those over 60 – make up about 40–45% of its contacts, but it hasn't always been able to support those carers as much as it has wanted to.

In previous years, a volunteer with counselling experience had provided a small counselling service to some carers, and this supplemented the Network Partner's wider offer – a number of support and health and wellbeing group sessions, a GP engagement project, and also the newsletter and information service.

An important offer, as is often the case for Network Partners, continues to be informal support for carers who drop in and chat to staff about their worries, experiences and the challenges of being a carer.

## The local needs

As with many Network Partners, the primary concerns around the health of older carers in Ayrshire was that they neglected themselves at the expense of the person they cared for, and they particularly struggled to look after their mental health.

More locally there was a need for services that were not designed specifically as services for older people but were applicable to the needs of older people – they didn't like the label. The experience of the volunteer counselling project highlighted that the personal identity of carers was important to consider and something that is often not a feature in carer services. This had to be considered alongside the more pressing needs of support to deal with everyday pressures – support that could be accommodated alongside the caring role, and support that was aware of carers' mental health. These needs were not unique to this Network Partner:

“I think once my husband was diagnosed I just couldn't have cared less about anything in the house that needed doing. My health ... I haven't really thought about it. Now and then I do get a problem but I'm able to cope with that even better. I've put my illness away to the side to take more control of what I'm doing with my husband at home.”

## The project

The project was designed to add two specific offers to the existing profession:

1. The development of the existing volunteer based counselling project to add a further counsellor and pay for enough time to give eight sessions each for 60 carers.
2. The extension of the sessional therapist to give a six week stress management programme for 92 carers, with carers getting the first three for free and then making a small payment for subsequent sessions.

There were two counsellors, both very experienced and both with different approaches to their profession. This gave a mix to the offer and allowed for some matching to suit needs.

## Key learning from the project

<b>Carer</b>	<ul style="list-style-type: none"> <li>● It was the carer's choice when to use the service following a recommendation from a member of staff, highlighting that counselling services must be accessed at the right time for the carer.</li> <li>● Carers were very willing to pay towards the cost of the offer, suggesting that Network Partners should re-evaluate their concerns about charges.</li> </ul>
<b>Service</b>	<ul style="list-style-type: none"> <li>● The signing of a counselling contract was essential to ensure both sides agreed to the commitment. Confidentiality was underlined, and the limitations of the service were made clear.</li> <li>● A big part of the counselling was about reducing feelings of guilt for carers. The sessions did not focus solely on the caring role however, but on the individual as a whole.</li> </ul>
<b>Staff</b>	<ul style="list-style-type: none"> <li>● The role of other staff at the Network Partner in talking to carers was also important, highlighting the role of the first person a carer sees (maybe a receptionist/ administrator) in setting the tone for support.</li> <li>● For some carers, eight weeks of counselling was not long enough. It was therefore important to manage expectations from the start. The short time frame put a burden on the counsellors who sometimes gave their time voluntarily to continue support.</li> </ul>
<b>Network Partner</b>	<ul style="list-style-type: none"> <li>● There was a need to build up publicity as it was a new service. Referrals were slow in the first instance but caught up as more carers became aware of it.</li> <li>● While the counselling was seen as a fixed course of support, it also provided the important function of a break for carers.</li> </ul>

“But what has really surprised me is the caring role is so demanding for some people that their own health is beginning to deteriorate, and it can be physical, it can be emotional or even spiritual. That surprised me: sometimes they're bringing spiritual issues and end of life issues.”

## The impact on carers

The most important impact from the perspective of carers and staff was the changing mind-set and behaviour of carers – they took more control of themselves, their feelings and their situation.

“And this has helped me because it’s given me courage to do new things. I would never have thought of that if [the counsellor] hadn’t discussed that with me and pushed me in the right direction. It’s benefitted me a lot because the talks that [the counsellor] and I have, have given me the courage and the kind of, well it just makes me feel better because everything’s off my chest.”

The project supported carers to provide better care through looking after their own health. It provided relief, a release, and an enormous amount of support for carers.

“It’s been immense. People don’t know how fabulous this place is, and of course they won’t because it takes something to happen, but some people struggle through with people who are ill and they don’t want to tell anybody and they don’t want to cope with it. There’s a lot of frustration in being a carer, on both sides, so down here you can talk all that out, vent it, or come out with it, and I will always advise people to come here, that’s how much they’ve done for me since I came.”

## The effect on the service

This project had a major impact on the wider service offer and perceptions of the staff:

- It increased staff awareness of the benefits of such an approach, and the role that talking can have in supporting carers – it is far more than just words.
- It increased awareness among staff of the depth of issues some carers are dealing with.
- The Network Partner is considering mainstreaming the service – potentially charging a fee.
- The Network Partner is looking at how to develop the service for younger carers.
- It was anticipated that the project would reduce the contact between carers and their GP, but in the first instance it increased it for many as they began to better understand their own needs. This built up the relationship between the carers and their GP, developing the strategic support for carers in the area.

“I think it’s made us sit down and think about things a lot more. I think we’re all more aware now of how stress management and how counselling can benefit people, whereas before, especially to some of the staff, it was just words. Yeah, they knew what it meant but they didn’t understand what it meant.”

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# Volunteers in GP surgeries

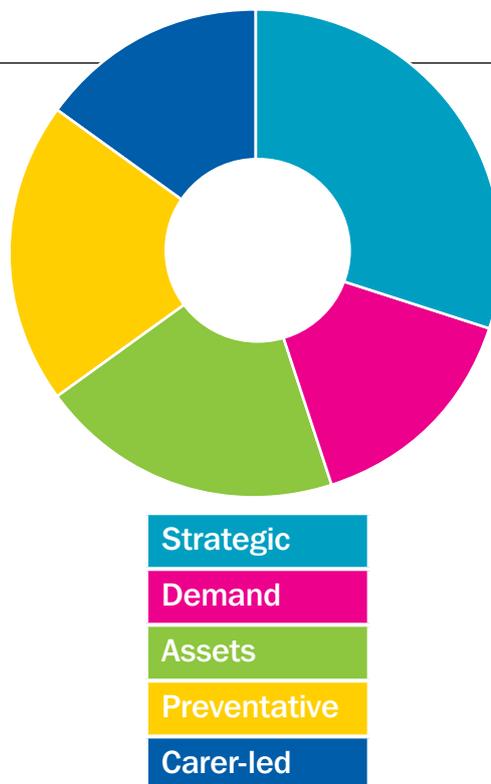
## North Somerset

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Crossroads Care North Somerset set up its project to offer a range of direct services to carers, to raise awareness of carers needs and identify hidden carers via building relationships with GP surgeries.

The GP work focussed on displaying information for carers in surgeries and working directly with GPs to encourage them to identify and meet the needs of carers. The direct work with carers was primarily an extension of existing services and included offering eight free day centre places per week giving the person being cared for social activity; providing 961 free respite care hours in carers' own homes; funding an advocacy worker to give a voice to the carer during meetings or phone calls to other agencies; and for a small items fund offering everyday life purchases.

While the direct work was an extension of existing services, the GP work was a new project and the area the project wanted to test.



### Key features

-  The project took a strong **strategic** approach, building relationships with GPs to improve the support carers receive outside the Network Partner, to increase referrals, and to ensure carers are on the agenda for GPs in the new commissioning environment. The advocacy work was also strategic, ensuring carers' voices were heard by external agencies.
-  The project had a **preventative** emphasis, working with GP surgeries to identify hidden carers before they reached crisis point.
-  It was the response to a growing **demand** for advocacy work, financial support for carers and a growing awareness of the need to identify hidden carers.
-  The project used volunteers as **assets** for the service, recruiting and managing them to maintain carers' notice boards in surgeries and to talk to carers at surgeries.
-  The project had a **carer-led** element, reflecting the over-arching carer-led approach of the organisation through a carer involvement network.

## The current delivery

Crossroads Care North Somerset has 80 members of staff (who are mostly part-time) and 75 volunteers supporting a range of services and approximately 3,200 carers.

The services include a home respite care scheme which supports approximately 240 carers, a young carers service supporting carers aged 5–18, a disabled childrens service, carers' assessments for high intensity carers, advocacy support and a personal budgets service. It also runs support groups specifically for carers with mental health issues, for carers with learning difficulties and for parent carers.

The Network Partner seeks to reach hidden carers through forum events in public locations such as shopping centres, and targets rural carers by delivering services in remote areas. The organisation is carer-led using a carer involvement network to inform services and listening to feedback from a newsletter to identify gaps in the service.

## The local needs

The project identified a range of generic physical and mental health issues affecting carers such as physical strain, and stress related illness such as high blood pressure, anxiety and depression.

“Everything we do is indirectly about health because if people don't have their health or the strength to carry on, then they can't do it. If they can't do it, it has a massive impact on the rest of the family, it has a massive impact on guilt trips, emotional wellbeing, financially on the Government or else they have to pay for a care home.”

Key needs included the importance of identifying hidden carers and enabling carers to access information and support to help remove stress and confusion.

Given the rural surroundings, it was important to ensure that services were accessible to carers living in remote areas. Deprived areas were also targeted.

## The project

The project had five key intervention areas:

1. To increase the awareness of carers support services within GP clinics through an Adopt a Board scheme where volunteers manage and monitor notice boards which provide up-to-date information for older carers. This work was managed by a volunteer coordinator who developed relationships with GPs. Carers champions were also trained to deliver support in GP practices.
2. To offer eight free day centre places per week giving the person being cared for social activity and providing a longer five hour carers break.
3. To provide an additional 961 free care hours (200 care breaks) within carers' own homes, giving the carer a more flexible approach.

4. To fund the continuation of an advocacy worker post, providing advocacy support to carers during interactions with other agencies.
5. To offer a small items fund for everyday life purchases.

## Key learning from the project

<b>Carer</b>	<ul style="list-style-type: none"> <li>● Providing information and advice in GP surgeries helped some carers to identify themselves as carers and highlighted additional benefits of GP support to them, such as free flu vaccinations and flexible appointments for carers.</li> <li>● GP surgeries that engaged became very responsive to the needs of carers, amending their systems and practice. For example, they signposted to relevant services and offered longer appointments. This illustrates that strategic work with GPs can lead to direct impacts on carers.</li> </ul>
<b>Service</b>	<ul style="list-style-type: none"> <li>● It was a challenge to engage GPs due to their busy workloads. Some GPs however, were keen to take part as providing carer support helped them to achieve points under the new Care Quality Commission scheme.</li> <li>● Forging links with GP surgeries was time consuming. The process of developing relationships however, led to understanding of how to influence the NHS, suggesting it is worthwhile spending time on relationship building.</li> </ul>
<b>Staff</b>	<ul style="list-style-type: none"> <li>● The volunteer coordinator role ensured that the volunteers were well managed and supported. Staff noted however, that it is important that the time and costs of volunteer coordination are fully appreciated.</li> <li>● The project developed staff skills in the area of NHS partnership working, which proved essential for the delivery of this type of project.</li> </ul>
<b>Network Partner</b>	<ul style="list-style-type: none"> <li>● The project enabled the Network Partner to reach hidden carers, identified through the work in GP surgeries, contributing to the Network Partner's focus on taking a preventative approach.</li> <li>● The focus on building relationships with GP surgeries enabled the Network Partner to position itself as a key contact for GPs in the future.</li> </ul>

“I think we need to, by hook or by crook, find the funding to keep [the volunteer coordinator] in post because the work with the GPs is our future. GP commissioning is the future, whether people like it or not, and if we're going to provide the best service, we're going to have to be the first stage on a GP's list, and they're going to have to recognise the carer as being the person they address before they address the cared for.”

## The impact on carers

The work with GP surgeries enabled carers to be reached at an earlier stage and led to a significant increase in the number of carers registered at GP surgeries. GPs that have engaged with the project are more responsive to the needs of carers, developing systems to accurately record information about their caring role, offering longer appointments to carers, asking them about their needs and signposting them. The project also enhanced carers' own awareness of the benefits of registering as a carer.

“It’s highlighted for me the role of the GP in the whole scenario. Maybe I’ve worded my conversations with him slightly differently so he’s picked up that I’m a carer and that’s something that the doctors know. But it’s been 15 years! He’s just picked up that I’m the carer and said, ‘if there’s anything you need you’ve just got to ask’, whereas that’s never been noticed or noted before.”

Carers also have access to a wider range of services being offered by the Network Partner. The project increased the number of places available at the day centre and carers valued the opportunity to have a rest or get tasks done.

## The effect on the service

The direct support to carers was an extension of existing services and therefore few significant impacts of these were reported. The GP engagement was a new initiative and had a significant impact on the service:

- The work with GPs evolved over the course of the project. The volunteer coordinator not only managed the volunteers who maintained the notice board but actively built relationships with GPs, supporting them to implement systems to identify and support carers and coordinating drop-in support.
- The work with GP surgeries helped identify carers from diagnosis rather than at crisis point.
- Partnership working resulted in the offer of venues and support for future events.
- The project led to a strong understanding of how to influence the NHS.
- The project worked with sympathetic GPs as they needed to meet targets for the project but there is also a need to engage GP surgeries that are less responsive.

“I think at one of the practices the number on the carers register went up from 3–53 or something like that because [the volunteer coordinator] was doing a push there. They had thousands of people on their books, but they don’t recognise the carer who might want a bit of support as well. So that’s been really big recently.”

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# Preventing crises through active respite

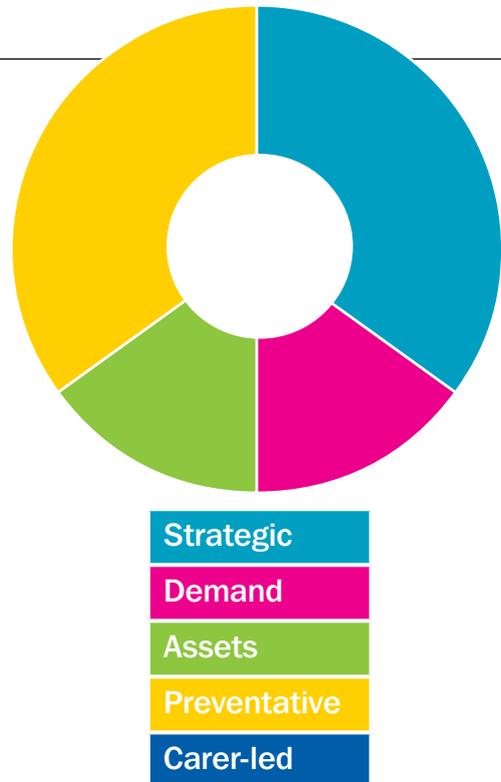
## South East Wales

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Crossroads Care South East Wales set up its project to provide an out of hours/day time respite service for a target of 100 older carers who support people with mild to moderate dementia.

The service was offered through placements at social centres where the person being cared for could take part in fun and mentally stimulating activities. This gave the carer a break from caring which helped them to manage stress and prevented the deterioration of health often associated with intense caring.

The project also offered training and financial information sessions for carers, designed to support them in their caring role and to promote carers' health.



### Key features

-  The project took a strong **preventative** approach. By providing regular respite care the carers were able to take a break which helped them to manage the accumulative stress associated with high intensity caring and prevented related mental and physical ill health.
-  The project was **strategic**, building upon the existing infrastructure to deliver respite breaks and providing an extension of these.
-  The project was a response to the high level of **demand** for respite care and a need to extend existing services in order to reach more carers.
-  The project used the **assets** of the carers themselves, charging £15 per session. Any surplus raised from this income went towards subsidising the extension of the project. The small charge for the service has helped prepare individuals for increased costs if the organisation does not secure funding for the extension of the project.

## The current delivery

Crossroads Care South East Wales works with 791 families and employs 98 staff. The organisation focusses primarily on respite provision, providing home based respite care services, sitting services and running three social centres which provide day time respite breaks. These not only provide respite for the carers but an opportunity for the person being cared for to socialise and take part in fun and mentally stimulating activities.

It also runs a service specifically targeted at young carers, as well as an emergency response service – providing a free back-up service to ensure the person being cared for is given support in the case of an emergency for up to 48 hours, and a community support service which assists carers with day-to-day activities.

## The local needs

A high level of need for respite care was identified in order to enable carers to have a break from and manage the stress of caring and to tend to their health needs. The project was also a response to the impact of caring on the relationship between the carer and the person they care for. This relationship can be supported by measures to reduce the intensity of caring.

“I think very often the stress eventually displays itself through physical illness; so again, it’s at what time you catch it. If you don’t address that I think it turns into physical problems.”

The need to extend respite services was also related to the focus of the organisation and local authorities on crisis work, suggesting a need for more respite to help prevent carers reaching crisis point.

A need to target hidden carers who do not normally access statutory services was also identified. Carers from socio-economic disadvantaged backgrounds were also targeted.

## The project

The project was an extension of the existing provision of social centre respite support – an out of hours/day time care service for older carers and the people they care for, providing approximately six hours support to at least ten carers per week. The service was specifically for carers caring for someone with mild to moderate dementia. People being cared for attended the social centres where they took part in fun and mentally stimulating activities in groups, such as singing workshops. The carers were therefore able to take a break from the role with confidence that the people they cared for were well looked after.

The project extended the existing service delivered at Blaenau Gwent, Caerphilly and Monmouthshire and created two new social centres at Newport and Torfaen. The centres were developed in partnership with the local Alzheimer’s society, the local authority and the health board.

The project also planned to deliver training to carers to help them to cope with the demands of caring and to provide health and financial advice.

## Key learning from the project

<b>Carer</b>	<ul style="list-style-type: none"> <li>● A key benefit for the carer was the peace of mind they felt knowing that the person they cared for was having a good time at the social centres, being mentally stimulated and socialising with other people.</li> <li>● Regular, good quality respite care significantly reduced stress and supported the carer's emotional wellbeing.</li> </ul>
<b>Service</b>	<ul style="list-style-type: none"> <li>● There was a significant amount of administration and red tape involved in setting up the two additional social centres which delayed progress. Similar projects should factor this into their planning.</li> <li>● Despite delays in setting up the new social centres, partnership work with local authorities and health boards was essential for sourcing suitable venues.</li> </ul>
<b>Staff</b>	<ul style="list-style-type: none"> <li>● If the service grows in future and more people attend the social centres there will be a need to increase staffing resources as everyone who attends will need support with personal care.</li> <li>● The high quality of events delivered for those being cared for was driven by highly skilled staff who ensured that those being cared for were engaged in activities and well supported.</li> </ul>
<b>Network Partner</b>	<ul style="list-style-type: none"> <li>● The project helped the Network Partner to make its case in funding bids, demonstrating that it is not totally dependent on statutory funding.</li> <li>● The Network Partner envisaged the project continuing after the lifespan of the current funding. Staff anticipate increasing the charge for the service if they are unable to obtain further funding for it.</li> </ul>

“First of all, we’ve got two, Kensington Court in Newport, which is local authority premises, and this one is health premises. But it was getting the document and paperwork signed off, it went through so much red tape to get a lease to do it. I’m not suggesting it wasn’t necessary because it gives us the protection and of course the health board, but it took us so long.”

### The impact on carers

Carers reported significant impact on their ability to manage stress, feeling more able to cope with caring due to the respite care offered by the project. It provided an opportunity for them to relax, socialise and tend to their own health needs. One carer described feeling more able to relax and ‘be herself’ as a result of having breaks from caring.

“I’ve noticed that since he’s gone to the Saturday and his day care that ... I didn’t used to talk like this you see ... I’m able to be myself more, where I think I stopped being myself. I think I was just like a little slave. Because I wasn’t able to say to people things that were happening.”

Carers were particularly supportive of the type of care provided by the project. Knowing that the people they cared for were in a supportive and sociable environment reassured them and mitigated feelings of guilt and anxiety associated with respite care.

“It’s so very useful to me. It’s usually about half ten when I get there, every other Saturday, and I fetch him about half three. And they give him his lunch, which he loves! And the people there are so. Do you know, I’d say they’re loving. They are. It’s a bit like him going to family because they’re so kind and so helpful and he feels happy there.”

“The first time she went I was a bit apprehensive and wondered if she was going to be all right for them. And when I went back they said they’d been playing a tape and one of the things was Tom Jones and apparently they all loved it! She said they all thoroughly enjoyed it and they were all singing.”

## The effect on the service

- The organisation has considered the development of the project beyond the lifespan of the funding. By charging a small amount for the service (£15 per day) it hopes to save any surplus towards future funding and will increase the amount charged in the event that it does not secure further funding. This may mean however, that the most socio-economically disadvantaged carers will be unable to attend.
- While the service received positive feedback there is a need to formally capture the impact it is having on carers’ wellbeing.
- The administrative work and red tape involved in setting up new social centres in partnership with local authorities and health boards was time consuming and delayed the project. Once in place however, the venues met the needs of those being cared for.
- Some potential clients chose not to participate as there is no transport provision to and from venues.
- Future development will focus on sustaining and developing the existing services rather than developing new ones as these are at convenient times for the carers and the people they care for.
- The service helps to meet the needs of hidden carers who do not want to engage in statutory services.

“I think for me it’s more about that it appeals to the people [...] that possibly don’t want to see themselves going through ‘formal’ routes. That I think is a bit aside, but I’d say that there are some people that would go to this project rather than a local authority day centre. Because they are different in that sense.”

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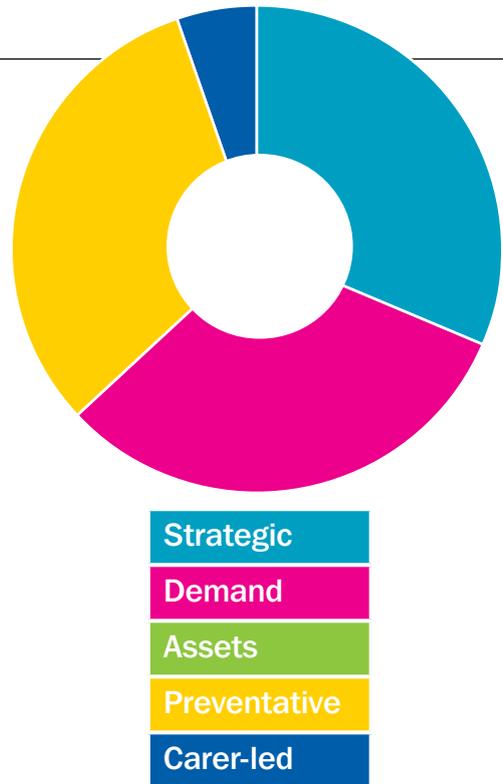
# Removing a big worry

## Wandsworth

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Wandsworth Carers Centre set up its project to provide a carers emergency support scheme to 115 older carers. Many carers are concerned about what would happen to the person they care for should something happen to them, causing stress and anxiety. The scheme therefore gave carers peace of mind and enabled them to take part in community activities which they otherwise may not have accessed due to fears of personal health risks.

The scheme built on a pilot phase and following learning from the pilot sought to target Asian carers. The scheme also targeted older carers aged 60–69, having identified them as most at risk from emotional and physical ill health.



### Key features

-  The emergency card scheme was designed to **prevent** the carer and the person being cared for reaching crisis point. It also in turn prevents the carer from feeling stressed and anxious about the future as they know that the necessary measures are in place for the person they care for.
-  The project was a continuation of a successful pilot project which illustrated a strong **demand** for the scheme. It was also a response to the identified demand for support for Asian carers and carers aged 60–69.
-  The project was **strategic**, responding to specific needs and gaps in the provision in the borough.
-  The project had a **carer-led** element, recruiting an Asian carer ambassador to promote the scheme within the community and assist with breaking down barriers and building confidence in social services.

## The current delivery

Wandsworth Carers Centre has 12 members of staff and supports approximately 2,000 carers.

The organisation offers a range of services including a mental health service, substance misuse service, breaks and holidays, social outings and support groups, alternative therapies, back support osteopathy, an Asian carers specialist service, and information and advice.

The organisation takes a strategic approach to delivery, working alongside other agencies to ensure they do not duplicate work and offers services which are not being delivered elsewhere. The mental health project and the Asian carers projects were responses to the high level of need for these services and the lack of such provision in the borough. The Network Partner does not offer a young carers service but sits on a strategy group for a young carers service in the borough.

## The local needs

Wandsworth has a large Asian population and older Asian carers were under represented in the pilot of the emergency card scheme. Issues facing Asian carers included language support needs, lack of information and awareness, lack of confidence in services provided, and exacerbated social isolation due to increased language and cultural barriers. The project therefore identified a need to specifically target this group through culturally specific support.

“One of the things we noticed when we started looking at the emergency support scheme in more detail was that quite a lot of the Asian carers weren’t registered on that.”

Older carers aged 60–69 were also identified as a key target group for the scheme, following research which suggested that this age group was particularly at risk of deteriorating mental or emotional health (The Princess Royal Trust for Carers, 2011).

## The project

The project was an extension of the pilot carers emergency card scheme. The scheme worked with carers to develop emergency plans that were specific to their needs and the needs of the person they care for. The plans were logged with social services and the carers received cards that they could carry around with them. In the event of an emergency, someone finding the card would telephone the council and the emergency card plan would be activated.

The scheme gave the carer peace of mind, reducing stress and worry about what would happen in the event of an emergency. It also enabled the carer to take part in community activities which they otherwise may not have accessed due to fears of personal health risks.

Carers registered on the scheme were also referred to other services such as benefit checks, back care treatment and stress management courses.

The project funded an additional seven hours per week for an Asian support worker, and funded 21 hours per week for the general emergency scheme worker. The Asian support worker provided one-to-one culturally sensitive support for Asian carers. An Asian carer ambassador was also recruited to promote the scheme to Asian carers and to assist with breaking down barriers and building confidence in social services.

## Key learning from the project

<b>Carer</b>	<ul style="list-style-type: none"> <li>● The scheme provided an avenue to accessing other services. The worker would signpost to services as appropriate and for some carers the scheme increased their confidence in services in general and their desire to access them.</li> <li>● The project enabled carers to consider more fully other family members/ contacts who were available in an emergency, helping to mitigate feelings of isolation.</li> </ul>
<b>Service</b>	<ul style="list-style-type: none"> <li>● There was a need to explore systems to document the effectiveness of the project on the wellbeing of the carer and the relationship between the scheme and wider access to services. Other similar projects should explore this from the outset.</li> <li>● The majority of Asian carers only required basic emergency planning as they had significant input from other family members. One carer suggested however, that the cultural expectation to support family members can inhibit a carer's ability to ask for external support.</li> </ul>
<b>Staff</b>	<ul style="list-style-type: none"> <li>● Splitting the workload between the card scheme worker and the Asian support worker was an effective way of working and ensured that the Asian carers were supported by staff equipped to meet their language and cultural needs.</li> <li>● Unforeseen time pressures on staff included the time taken to chase service agreement forms from social services, do ongoing promotional work of the project with social services and voluntary sector agencies, and explain the age criteria of the project.</li> </ul>
<b>Network Partner</b>	<ul style="list-style-type: none"> <li>● The service encouraged staff to reflect on the best way to assess the needs of carers. Key information was sometimes brought up in discussions with the card scheme worker, and also in other environments such as osteopath appointments so a need to streamline this information was identified.</li> <li>● The service lowered the barriers to accessing other services at the Network Partner as it provided a signposting facility and increased carers' confidence in the Network Partner in general.</li> </ul>

“So when I signed up for this emergency thing, the idea that there is someone who will come to our help, the fact enough is so encouraging, and so assuring. That half of your depression is gone.”

## The impact on carers

The main impact of the scheme was the reassurance or peace of mind it offered to carers knowing that in the event of an emergency the person they care for would be supported. Establishing an emergency contact also helped the carer to feel supported by knowing that there is someone else who can provide care (even if only in an emergency).

“It helps us knowing that if anything happens, it’s covered, that we’ve covered how [his] needs will be met. Because obviously our needs will be met because if anything happened to us we’d be in hospital. It did get me thinking because I’d never thought about what would happen if anything happened to us. Thinking about the plan. It is important.”

The project also enabled the carer to consider more fully other family members/ contacts who would be valuable in an emergency. It encouraged families to have conversations about their caring roles, and what might happen if something serious happened to the carer.

The worker had in-depth conversations with carers in order to draw up an emergency plan which would then lead to signposting to other internal or external services. Therefore, for some carers the scheme offered a route-in to a range of support services. The scheme also encouraged carers to prepare more generally for emergency situations and to think more fully about preventing the deterioration of their own health.

Asian carers required less support than anticipated due to the cultural emphasis on family support. This may suggest a need to explore ways to ensure that Asian carers feel that they can ask for support if needed.

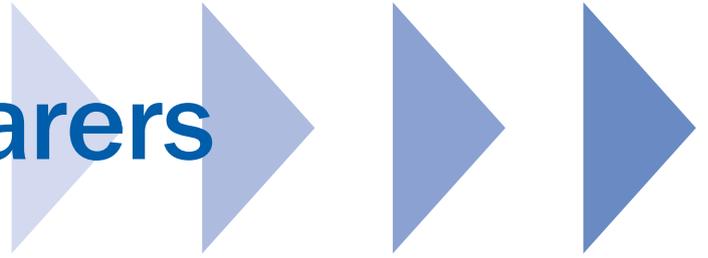
“In our society, Indian, Pakistan, South Asians, they think it’s a sin, you know, not to support your own family and asking for help from some outsider to come in and stay and help. That’s the general thing. I don’t know about others but in our society it’s just like that. So those who brought us up looked after us, and now it’s time that we should look after them.”

## The effect on the service

The project raised the following considerations for the service:

- The organisation faced challenges in communicating the effectiveness of the project to the local council.
- It was recognised that it is hard to measure the impact of the project due to its preventative and long-term focus but that it is important to explore systems to record and analyse information so that this can be communicated to decision makers.
- Having observed the benefits of the scheme on carers’ wellbeing and increased access to services, the Network Partner is keen to secure funding to be able to continue the project.

# Young adult carers



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# Understanding the whole young adult

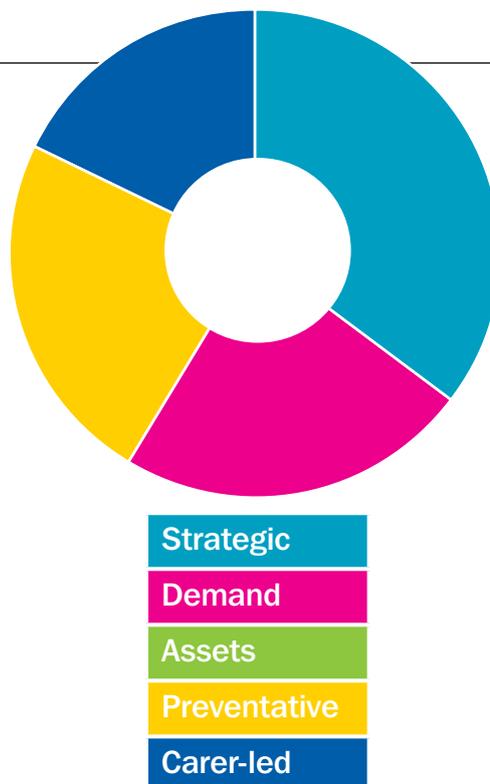
## Blackpool

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Blackpool Carers Centre set up its project to provide a holistic, tailored offer for 60 young adult carers.

The project was designed to address five needs identified in a research project by providing – a support worker to give advice, guidance and one-to-one support; one-to-one emotional support; career guidance/signposting; peer support, and breaks from caring. Multiple services were offered to the young carer, designed to meet these needs as well as the specific local needs of young adult carers in Blackpool.

By addressing the carer's needs holistically the project aimed to provide key interventions in the transition years to improve the wellbeing of young adult carers in the long term.



### Key features

Through seeking to address the needs of each carer holistically, the project took a strong strategic approach. Examples of **strategic** working included using a whole family approach to address the complex needs of young adult carers; developing a clearer link between young carer services, adult services and young adult carer services so that carer's transitional needs were met; and developing links between the project and external agencies to facilitate support outside the project and to improve referral mechanisms.

The project sought to address the individual carer's needs through a tailored, holistic approach, designed to **prevent** future health and wellbeing problems. For example, young adult carers' life chances were improved through increased access to education, volunteering and training.

The project was a response to the **demand** identified by a research project undertaken by a social work student (who also ran the project) and in response to local issues affecting young adult carers such as deprivation, high numbers of young people who are not in education, employment or training (NEET) and high levels of substance misuse and domestic violence.

The project had a **carer-led** element, recruiting a young adult carer champion to promote the service to other young adult carers, to support the project worker, to provide some additional support to young adult carers and to inform decision making affecting young adult carers.

## The current delivery

Blackpool Carers Centre provides a range of services to support and enhance the lives of carers of all ages throughout Blackpool. The Network Partner runs projects specifically targeted at young carers and young adult carers and has a strong emphasis on whole family working. The Network Partner also runs an out of hours family support service, a hospital support service, and employs a GP liaison worker to identify carers from GP surgeries. Types of support available within these programmes include one-to-one support, counselling support, trips and activities and access to training and volunteering workshops.

For 16–25 year olds, the service has been limited to sporadic residential trips or activities. The young adult carers project was designed to provide a service linking the young carers and adult carers services and to provide holistic support to meet the specific needs of carers of this age group.

## The local needs

As with many young adult carers projects, the transitional phase from childhood to adulthood was identified as a period where there is heightened caring-related stress as young adult carers gain more independence. A need to support young adult carers with long-term personal development during this phase, such as through access to education, volunteering and training and through financial advice, was identified as a key way to promote the young adult carer's wellbeing in both the immediate and long term. Peer support was another significant area of need, owing to the social isolation of young adult carers and the challenges they often face in building friendships.

“Health is the knock-on effect of what we're doing, if you will. I think a lot of it is mental health rather than physical health, in the sense that helping a family with their benefits, they're then accessing the correct benefits and they're then getting the correct money that they should, and that has a knock on effect with their health because mentally they're feeling better because they've got the right money.”

The Network Partner identified several needs relating to the demographic of young adult carers and young people in general in Blackpool. Blackpool has higher than average levels of domestic violence, teenage pregnancy, substance misuse, deprivation, and a high number of young people who are NEET.

## The project

The project was run by a full-time project worker who organised and delivered one-to-one practical and emotional support and organised group activities. The worker was supported by a young adult carers champion. Given its holistic approach, the project provided a range of training and support opportunities and peer support initiatives:

- Facilitating access to education, training and volunteering.

- One-to-one support including writing action plans with the young adult carers.
- Financial support sessions.
- Housing advice sessions.
- Workshops on specific health and social issues including mental health, substance misuse, teenage pregnancy, and domestic abuse.
- Provision of exercise and sporting opportunities.
- Provision of breaks from caring.
- Peer support groups, including training on how to use social networking for peer support, providing young adult carers with a mechanism to continue to support each other through self-sustaining social networks.

## Key learning from the project

<b>Carer</b>	<ul style="list-style-type: none"> <li>● The opportunity for carers to meet other carers in informal environments enabled them to support each other and to make friends, in turn minimising some of the social isolation associated with caring. This reiterates the importance of peer support for carers.</li> <li>● The bespoke, holistic approach enabled carers to access the services which were necessary for them. Carers reported feeling aware of the services available and able to opt into the elements they wanted to access.</li> </ul>
<b>Service</b>	<ul style="list-style-type: none"> <li>● The project worker spent more time delivering whole family support than anticipated, reflecting the need to work with other family members in order to adequately address the needs of young adult carers.</li> <li>● The project received fewer referrals from young adult carers aged 19–25 than young adult carers aged 16–18. This reflected the strong referral routes developed with colleges but suggested a need to develop additional referral routes to target the older age group.</li> </ul>
<b>Staff</b>	<ul style="list-style-type: none"> <li>● Staff reported having large workloads and identified a need to expand the workforce in order to meet the need. In particular, the demand for one-to-one support for young adult carers was greater than anticipated.</li> <li>● The project benefitted from support from the young adult carers champion, reflecting the pressures and demand on the project worker.</li> </ul>
<b>Network Partner</b>	<ul style="list-style-type: none"> <li>● Improved joined up working between the young adult carers project and the young carers and adult carers projects was beneficial for signposting young adult carers to internal services, delivering services in partnership and for internal communications regarding individual carers.</li> <li>● New gaps in provision emerged such as the need to improve the referral process for young adult carers aged 19–25. Partnership work between the young adult carer worker and GP liaison worker to encourage referrals from GPs was identified as a route to resolving this.</li> </ul>

“Initially, I directly deal with a young carer but if they highlight an issue within the family, which let’s face it, that’s what we’re dealing with at the end of the day, the family situation, the caring situation, I will end up meeting everyone, mum, dad, whoever.”

## The impact on carers

The project delivered a more joined up service for young adult carers. The young carers project and the young adult carers project worked together to ensure that carers were able to access elements of both these services if they wished. They were also able to inform the carers of the full range of services available to them so that they could make choices as to which parts to access.

The tailored approach, through provision of one-to-one support and a wide range of activities, trips and training opportunities, ensured that the young adult carers’ holistic needs were met. In particular, young adult carers valued having the opportunity to meet other young adult carers through the project and the support and friendship this provided. Whole family support provided another route to addressing the holistic needs of the young adult carer.

Colleges were more understanding and supportive of young adult carers’ needs. This was reflected in interviews with young adult carers.

“I’ve got people that help at school too and give support.”

The use of social media not only provided a peer support mechanism for young adult carers, but enabled the staff to keep in touch with the young adult carers, keep them engaged, and to monitor if there were any particular areas of need for the individual young adult carers. This enabled them to deliver a tailored service for the young adult carers.

## The effect on the service

The project had several impacts on the service and raised some further considerations.

- Close links with colleges reached 16–18 year olds, but new links need to be established to reach older young adult carers.
- The young adult carer project worker and GP liaison worker are considering working together to raise awareness of the specific needs of young adult carers and to develop the referral pathway from GPs.
- Improved joint working between young carer, young adult carer and adult support services resulted in smoother transitions between services for the young adult carers and enabled them to access the different services simultaneously.
- Whole family support was a key element for the young adult carer project.
- The project identified additional areas of need and additional staffing resources which would benefit young adult carers such as providing more one-to-one emotional support.

“I’ve found that I’m working a lot more closely with not only the young carers team, but the adult team as well.”

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# Colleges and the education of young adults

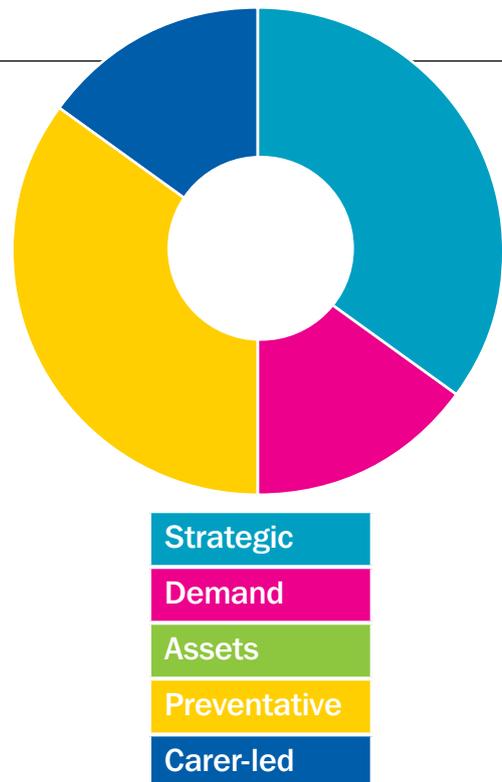
## Central and North London

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Crossroads Care Central & North London set up its project to provide direct support to young adult carers and whole family support with a view to reducing the strain on the carer; and to influence local policy and practice on meeting the needs of young adult carers.

The project sought to benefit 30 young adult carers via case management support, confidence building workshops and therapy. A key focus was on supporting young adult carers in developing their future goals and aspirations. Family members were supported through mentoring work with parents and through facilitating family support meetings.

The project had a strong focus on partnership work, working towards a joined up approach and to developing relationships with schools and education providers, social services and voluntary sector agencies to increase awareness and encourage referrals from these agencies.



### Key features

-  There was a strong **strategic** component to the project with a significant focus on developing partnerships in order to raise awareness among external agencies about the needs of young adult carers.
-  The whole family approach was **preventative**, seeking to support family members and to encourage the person being cared for to access alternative interventions. The work with other agencies also had a preventative element as it was designed to ensure that young adult carers' needs were recognised and met in other institutions, such as schools.
-  The project had a **carer-led** element, involving young adult carers in the planning of activities and development/design of the service and promoting opportunities for young adult carers to be involved in wider consultations and decision making processes such as the local youth council.
-  The project was a response to the **demand** for a transition service, as it became apparent that young adult carers' needs were not being met under the current provision.

## The current delivery

Crossroads Care Central & North London delivers live-in care support, respite breaks, a disabled childrens service, an early intervention service for older carers and a hidden carers project, focussing on identifying carers that are not engaged in services. Work with young carers is split into age categories – 5–10, 10–13, 14–16 and then 16–25 for young adult carers.

Prior to the new project there was a small young adult carers project, supporting approximately eight young adult carers, facilitating age-related activities, and enabling them to work, socialise and support one another. This service focused on providing whole family support, creative arts initiatives and counselling.

## The local needs

The mental health of young adult carers was a key area of concern for the organisation. Poor wellbeing was related to absence from school and young adult carers being unable to fulfil their goals and aspirations. A need to support young adult carers to access education, employment and training was therefore identified as a key area of need. The gap in services for young adult carers also highlighted the need for a transition service.

Due to the often complex relationship between a young adult carer and the person they care for, a need was identified to use a whole family approach to address multiple challenges affecting families, such as poor housing, domestic violence, crime, substance misuse and family breakdown. A need to focus on black, Asian and minority ethnic (BAME) groups was also identified.

“We find a lot of them ‘drifting’ if you like, where they have to be the parent at such a young age. There are some that get caught up in substance misuse that can lead to offending behaviour.”

## The project

The project was designed to extend and develop the existing offer to 30 young adult carers over the course of a year.

- The project provided direct support to young adult carers via case management and one-to-one support, confidence building workshops, therapeutic counselling, workshops for example, drama therapy or providing culturally specific support to BAME families.
- Whole family support was a key element of the project. This was delivered by extending mentoring to include families, facilitating family support meetings, and enabling families of young adult carers to take back parental responsibility by encouraging parents/adults being cared for to accept alternative interventions.
- The project also sought to influence the practice of external agencies regarding young adult carers, encouraging pro-active inter-agency work that promotes whole family assessments and joined up working between adult/children’s services, such as through multi-agency forums.
- The project also sought to support and enable young adult carers to be involved in decision making.

## Key learning from the project

<b>Carer</b>	<ul style="list-style-type: none"> <li>● Partnership work was essential for whole family working – by getting together with other agencies the support worker was able to understand the needs of the person in receipt of care and to signpost them to services which in turn eased the strain on the carer.</li> <li>● Carers were sometimes reluctant to take up support offered directly through schools as they were unsure if services were confidential. Services working in schools therefore must consider how to reassure young people regarding confidentiality.</li> </ul>
<b>Service</b>	<ul style="list-style-type: none"> <li>● Working with external agencies was challenging and time consuming as some agencies/institutions did not understand the relevance of young adult carers to them. The project was therefore slow to progress initially, however the benefits of strong partnerships were later realised.</li> <li>● The capacity for the project was 15–20 at a time. There is a need to explore ways to reach a greater number of carers for this type of project.</li> </ul>
<b>Staff</b>	<ul style="list-style-type: none"> <li>● The project helped develop staff skills in building relationships with partner organisations, which proved essential for the project.</li> <li>● The support worker role adapted to respond to needs identified through partnership working. For example, through working with partners to understand the needs of the whole family, the worker was able to encourage the person being cared for to access alternative services which eased the caring role for the young person.</li> </ul>
<b>Network Partner</b>	<ul style="list-style-type: none"> <li>● Having further developed the whole family approach, the Network Partner is keen to continue to deliver this work. However, there is a lack of generic services for the person being cared for, which poses problems in enabling them to access alternatives to support from the carer.</li> <li>● The project brought about strong partnerships which can be built into other areas of service provision.</li> </ul>

“Meeting up with these other agencies yesterday was interesting because they’ve also met her and pretty much got the same views, but we’re hitting this loggerhead. But it’s also just about raising awareness, so one of the outcomes of that meeting yesterday was because of the role that I have with the mother and the barrier that social services are facing, they’ve asked if I can get back in contact with her to just get her to accept an assessment and so on.”

## The impact on carers

A key impact on the young adult carers was the help they received to identify and develop their future aspirations and to access volunteering, training and employment opportunities. For young adult carers in education, the support worker helped them to see how further training is a development of what they are already doing. For young adult carers who are NEET and have a heavy caring role there were greater challenges in encouraging them to think about the future.

One carer was reluctant to take support offered through school for young adult carers as they were concerned that anything they said to a helper at school would not be confidential.

“A few of the helpers at school have talked to me but I’m not the kind of person to get talking to them. It’s the fact that it’s school and I don’t know whether stuff will circulate or not.”

The project helped some young adult carers to recognise themselves as carers and realise that they were entitled to support. It also reduced the stress of caring and gave young adult carers peace of mind just knowing that support was available if they needed it.

“[The support worker] told me about how I can ask for financial help, someone to speak to, help with employment, and it eased a little stress knowing they were there and there was an easy way of getting help.”

Young adult carers were also supported through whole family work. The support worker encouraged parents to engage in social services and other external support services.

The project supported a high ratio of BAME young adult carers, suggesting these groups were effectively targeted.

Despite originally planning a carer-led approach, the project adopted a needs-led approach rather than supporting young adult carers to drive change.

## The effect on the service

- It was harder to engage young adult carers who were referred via the job centre rather than those referred through educational establishments.
- The project took a while to get going due to the time taken to build effective partnerships with education providers and youth offending teams. Once relationships had been built however, referrals from these avenues were strong.
- The project had hoped to engage GPs, however there were challenges in doing so due to the many competing interests on their time.
- There is a lack of generic services for people being cared for which poses risk to the whole family approach as there are few services available to take the pressure off the carer.
- Working with partners to identify and respond to the needs of the whole family was effective.

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# Tight common bonds

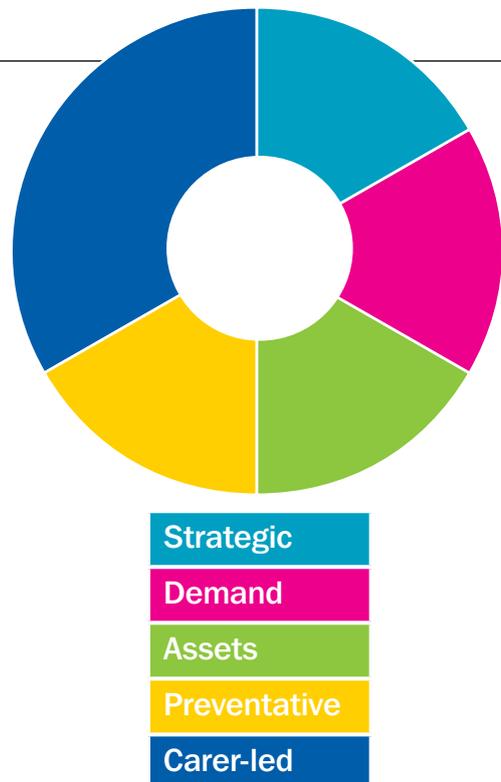
## East Anglia

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Crossroads Care East Anglia developed a project to build on a previous small project. It ran a consultation process with young adult carers to understand the impact of caring on this age group, and the sorts of things they felt they needed.

The resulting project offered a highly flexible level of part-time support for 50 young adult carers during the course of the year. 30 of those were carers that hadn't been engaged by the project before. It offered support and mentoring, facilitated groups and raised awareness among other services.

The project officer developed strong relationships with the young adult carers and supported them to build bonds of understanding and support on their own terms and with each other.



### Key features

This project had a strong mix of features, and was not too heavily weighted in any one way.

-  Like many young adult carer projects, it had a strong **carer-led** element. This was particularly apparent in the process of consultation with the young adult carers before setting up the project.
-  The project was characterised by being **preventative**, as it gave young adult carers time out from caring and the opportunity to talk about their problems with other young adult carers and the project lead. This provided valuable relief from the strain of caring.
-  It was a response to the **demand** identified through consultation with the young adult carers which highlighted a need for one-to-one and peer support.
-  Through the group activities and social media, the project used the **assets** of young adult carers themselves to support each other in peer led environments.
-  Finally, there was also a **strategic** element to the project. Along with partners it delivered training and shared information, to raise awareness of the needs of young adult carers among local services.

## The current delivery

Crossroads Care East Anglia provides one-to-one support to carers, and respite care for the people being cared for, across a large region, including Norfolk, Suffolk and Uttlesford in Essex.

This includes support for adult carers; activities and companionship for young carers; care for adults being cared for, whether they live with others or alone; care and activities for children and young people who have additional needs; and the Norfolk Carers Helpline. There is an active young carers forum that works across Norfolk. This has been a key mechanism for bringing carers together and one of the main routes to engage young adult carers for the project.

## The local needs

The rural nature of East Anglia was a key factor when considering how services are delivered. The young adult carers known to the project at the start were consulted about the impact caring had on their health, relationships, and stress and anxiety levels. Key issues identified for young adult carers included problems staying in education, low self-esteem and confidence, concerns that they don't have a future, isolation, and the consequences of these issues on their mental health.

It was also clear that many young adult carers had heavy caring responsibilities:

“I am 17 and in college. I look after my mum, my sister and my brother. My mum is bi-polar, my brother has ADHD and my sister is autistic. My dad suffers from depression too. I've been a carer since I was four.”

## The project

The key feature of this project was the flexible support provided to young adult carers through the part-time project officer. That individual has been supported through wider line management, and has worked very hard to deliver what the young people themselves wanted.

“As part of the consultation, the young people said they wanted one-to-one support. Both to have support as part of a social setting, but also to have someone they can talk to privately. And someone who can signpost them to the right support. But generally they discussed the way in which a lot of the support they need is just about having someone to go and get a coffee with, someone to listen to them. It's not always about having actions or answers – but just talking to someone.”

The work, therefore, involved a great deal of one-to-one support, delivered through a variety of mechanisms, and it also brought the young people together through group work and social activities.

The project worker actively approached, trained and shared information with partners that work with young people so that they can understand and be responsive to young adult carers.

Mechanisms such as Facebook were used to build a tight and supportive group of young adult carers that share, discuss and understand the needs of each other.

## Key learning from the project

<p><b>Carer</b></p>	<ul style="list-style-type: none"> <li>● The project highlighted the isolation of many of the young adults in a rural setting, with difficulties of getting to services and the strain this puts on them. The focus on a group dynamic, connected through a range of mechanisms including Facebook, was essential.</li> <li>● The value of having an individual that they trusted, and who was responsive to their needs, created benefits for young adult carers in terms of their sense of wellbeing and their ability to communicate with others and grow in confidence.</li> </ul>
<p><b>Service</b></p>	<ul style="list-style-type: none"> <li>● Flexibility in communication methods was essential, meaning that the service had to find appropriate ways to use Facebook, text and Twitter for providing one-to-one support. This approach became highly valued by the young adult carers.</li> <li>● The value of the group sessions should not be underestimated. While not all could access them, and the use of Facebook proved invaluable here, they provided essential peer support for those able to attend.</li> </ul>
<p><b>Staff</b></p>	<ul style="list-style-type: none"> <li>● The mixed needs of the group – some in work, some in education, some with specialist or particular needs – resulted in the project officer having to work very flexible hours, sometimes very late at night. It is important to consider this as projects attempt to personalise services around young adult carers’ needs.</li> <li>● The young adult carers invested trust in the project lead which put pressure on this worker. It was important that the worker had the appropriate support and training to deal with the range of issues that arose.</li> </ul>
<p><b>Network Partner</b></p>	<ul style="list-style-type: none"> <li>● In a large rural area a key challenge was raising awareness of the project across other parts of the service. This required the project coordinator to spend a lot of time communicating its impact to the young carers groups and other partner agencies. It is important for projects based in rural areas to consider how to ensure they do not become isolated.</li> </ul>

## The impact on carers

The most obvious impact of the project was on the young adult carers' emotional and mental wellbeing. The young adult carers talked about how building relationships between themselves had improved their confidence, self-belief, ability to cope with the pressures and realities of caring and also expanded their small social network.

It was clear that the real success of the project was the support that the young adult carers gained – it was relevant to their needs and lives, and increased their resilience to the challenges of caring.

“I wanted to quit [college] a few days ago. I'm struggling. But [the project officer] always gives me a reason not to. She talks to me about it and I see that perspective and she helps me carry on. I talk to her about anything; things I don't talk to my mum about. I offload and feel better. I used to get bullied a lot and I really feel able to talk to her about it.”

The strong peer group, facilitated by the project worker and enabled through a range of connections and communication mechanisms, was highly valued by the young adults.

“It's so important to meet other people. To know they're there. To have a bit of time away.”

Some practical work that added to this support included working directly with colleges to raise awareness of young adult carers within those settings in a general way, but also working on specific cases to ensure that individuals were supported with their particular educational needs. This could involve going into college to make sure that the particular circumstances were understood. There was a strong advocacy role to this kind of support.

A further example of this has been the work of the coordinator in negotiating slightly cheaper driving lessons with two firms for young adult carers. Key was looking for ways to not necessarily do things for them, but to remove some of the pressures, whether emotional, practical or in this instance financial, that can make life and caring for young adult carers that little bit harder.

## The effect on the service

There were two obvious wider impacts of this project, and these are perhaps best seen as slow influences due to the very internal nature of the other strong successes:

1. It raised awareness of the particular needs of young adult carers in a number of services that it has worked with.
2. It focussed understanding locally on the importance of transitioning from young carer services to young adult carer services, and the impact that this must have on how services are delivered.

These effects will be seen in the future of provision within the area, and are a key part of the success of the project.

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# Young adult leaders

## York

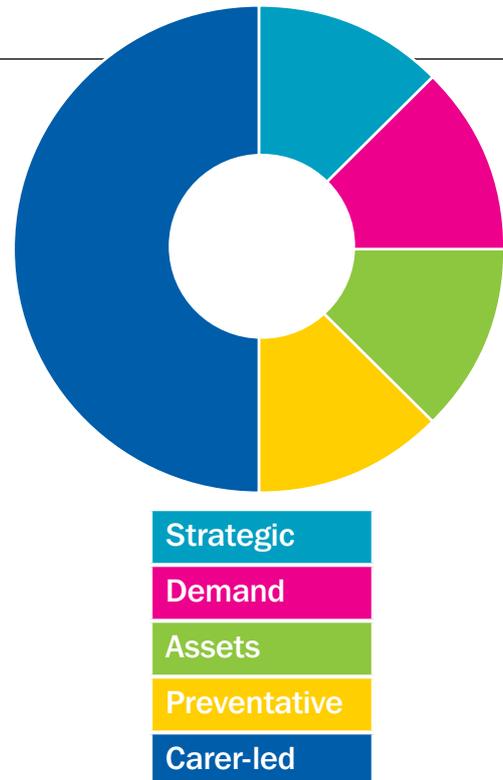
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York Carers Centre recruited a dedicated 16–24 project coordinator to work in depth with 45 young adults, building on a role which had previously been delivered for 12 hours a week, but had stopped completely a few months ago.

The key feature of this project was the focus on the young adult carers taking the lead on the kind of service that they wanted. This meant that the project coordinator was able to provide two functions that were supplemented by other activities such as training:

1. A dedicated amount of one-to-one support.
2. A facilitating and coordinating role to support the drive and ambition of the young adult carers to lead the project.

The balance of these two roles gave the young adult carers the support they needed during their transitional years, but also respected their age and desire to take charge of their situation. The feedback from young adult carers suggests that the balance was struck very well.



### Key features

- Carer-led** The most striking feature of the project was the extent to which it was **carer-led**, both in terms of decision making and direction of the project. It empowered young adult carers to be leaders, as well as individuals taking ownership of their own circumstances.
- Preventative** The project took a **preventative** approach. Through the mix of one-to-one support and being enabled to lead the project, young adult carers were able to build their confidence and resilience.
- Demand** It was a response to the **demand** of a group that wanted their own focus, but saw themselves as neither young carers nor adult carers. The project was able to use the assets of the young adults carers by enabling them to lead the project and used the strengths of all participants.
- Strategic** Finally there was also a **strategic** element to the project, as it worked with the young adult carers to create a voice for them in other young peoples services across the area. This approach built links, and raised the profile of young adult carers across York by using the young adult carers themselves as advocates.

## The current delivery

York Carers Centre works with carers of all ages and offers a broad range of services including newsletters; benefits and other advice; a carers emergency card and a carers discount card; education, employment and training support; training for professionals; specific support for young carers and carers affected by substance misuse; and (prior to this funding) a very small young adult carers offer.

The office is in part of the building which houses York Council for Voluntary Services, and so is near to a large number of other voluntary organisations within the city.

The young adult carer offer had, in the past, been a 12 hour per week post. This meant that young adult carers were able to access an infrequent offer of support on a one-to-one basis but there was no budget to organise transport or activities. Support was available for 16–24-year-old young adult carers therefore, but only a small number could be reached and there was no opportunity to resource anything further than one-to-one support.

“I think that there’s always been a gap. We previously had a 12.5 hours post but then no money for activities or transport or any of that, so the young people got to 17 or 18 and they were a bit panicky because a lot of them had been with us for a long time.”

## The local needs

As with other young adult carer services, a big drive for the project was the need to provide something specific for that age group that met the needs of young people during the transition years.

“Although we had a really small young adult service, the provision that we had wasn’t nearly coping with the needs of the young people and their anxieties.”

More particularly, the service wanted to focus on mental ill health, social isolation and hidden young adult carers in York. This resulted in targeting the areas with the highest levels of deprivation – Westfield, Clifton and Heworth. This focus also highlighted financial exclusion as an issue. Other particularly important issues to address for young adult carers included bullying, stigma and worries about the future.

## The project

The project employed a full-time project coordinator who supported the young adult carers to identify, support and develop activities reflecting their own needs and aspirations. This was, therefore, an expansion of the existing role in terms of time available, and an increase of functions of that role. This approach was developed in direct partnership with the young adult carers themselves and included:

- One-to-one support, advice and guidance.

- A budget and staff time to facilitate a range of activities for the young adult carers.
- Work with service providers to train and raise their awareness of young adult carers and their needs, with the young adult carers leading the forum.
- A healthy eating course.

The demand for this service was huge, with over 80 young adult carers signing up. This highlighted the hidden need for a service that is a balance between being supporting and enabling.

## Key learning from the project

<b>Carer</b>	<ul style="list-style-type: none"> <li>● The combination of carer-led support and facilitation of group work was highly valued by young adult carers and saw a much higher than anticipated demand.</li> <li>● Young adult carers were empowered to take the lead, including the running and management of events. Carers valued the trust and respect they received through this approach.</li> </ul>
<b>Service</b>	<ul style="list-style-type: none"> <li>● While the focus on the young adult carers was clearly the most important part of the project, resourcing the talks and training with other professionals, and the fund to facilitate activities for the young adult carers, were also essential to the project.</li> <li>● The link with young carers services allowed for a more seamless transition but it was important to offer young adult carers a different service so that they felt as if they were getting more than an 'older version' of what they had before.</li> </ul>
<b>Staff</b>	<ul style="list-style-type: none"> <li>● An increased demand risked overburdening the project coordinator. The strength of the project was the balance between support/facilitation and building the network of influence. It was important to not let the latter slip when demand for support increased.</li> <li>● The positive attitude of staff was of primary importance for the young adult carers. The worker needed to be organised, supportive, creative and empowering. This is a mix of skills that may be different to those required from a young carers worker. Other similar services should consider this in recruitment.</li> </ul>
<b>Network Partner</b>	<ul style="list-style-type: none"> <li>● The young adult carers proved to be very effective at articulating the needs of carers (of all ages) to other service providers. This is a key message for other organisations to learn from.</li> <li>● As York is a university town this meant that the young adult carers included those who were struggling with their caring role in York, but also those who were coming to York to study and were caring remotely or travelling frequently. Other Network Partners in university towns could learn from the balance.</li> </ul>

“They’re making massive decisions about, you know, ‘I wanna move out of my mum’s house but I don’t know if I can because of my caring role’, or ‘I want to move in with my partner’, or ‘can I start my own family or go to uni?’, or ‘should I get a job?’ They’re massive decisions to make and it’s so much more amplified because of their caring role, there’s just so much going on for them.”

## The impact on carers

The young adult carers who used this service talked about the impact on their lives in four, very clear ways. It was a demonstrably successful project from their perspective.

1. It increased the confidence and ambition of young adult carers, and as a result improved the mental health of and reduced stress levels for many young adult carers.

“Some people are like different people. I can think of two girls ... when I first met them, they’d been part of the service for a while but they never came to anything and didn’t have any confidence ... and now they’ve built up a massive brilliant network of people and they’ve both had the confidence to get jobs.”

2. It built the skills and experience of young adult carers to support themselves and the people they cared for.
3. It gave many of the young adult carers a sense of importance through their role in raising awareness of caring to other services.
4. Perhaps most importantly, it facilitated the development of a friendship group for the young adult carers which they drew strength, support, enjoyment and pleasure from, and which many believed would last beyond the life of the project. This was not pushed, but evolved naturally in partnership between the service and the young adult carers.

“As I got into the older group we started going to a pub quiz every few weeks and it became like a designated time to meet and talk ... that felt a bit better.”

## The effect on the service

One of the most significant effects on the service as a whole was the joint working between the young carer and the young adult carer services, and the increased knowledge of how young carers have different requirements as they get older. While all projects that have looked at supporting young adult carers have noticed this trend, the York service paid particular attention to the changing needs, and how to be as enabling as possible for the young adult carers.

The second key service-wide impact, was the use of young adult carers in the networking forum to raise awareness in other services about the needs of young adult carers, and to advocate for young adult carers more widely across the city.

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UK Census 2011. Office for National Statistics licensed under the Open Government Licence v.1.0.







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