Supporting carers
Guidance and case studies
Foreword

Unpaid carers are the backbone of the care system, many of whom feel they are unable to take a break, putting their own health on the line. Without these often unsung heroes the health and social care system would collapse.

Caring for a loved one can be a positive and rewarding experience, but carers need support to continue their vital role. Devoting significant time to unpaid care can not only lead to a downturn in carers’ health, it can also make it hard for them to maintain social relationships, keep working or learning, which could affect their financial security.

More people are caring for a loved one than ever before and councils remain committed to helping carers, but significantly reduced funding is making this difficult.

Councils in England receive 1.8 million new requests for adult social care a year – the equivalent of nearly 5,000 a day – and despite some helpful extra funding there is still a £3.5 billion funding gap facing adult social care by 2025 just to maintain existing standards of care.

Despite these tremendous pressures this publication demonstrates current examples of how councils support adult and young carers locally in a range of different ways from respite breaks to discount cards to tailored information and advice.

Councils are committed to support the wellbeing of unpaid carers to help them continue the essential work they do.

Cllr Ian Hudspeth
Chairman of the LGA’s Community Wellbeing Board.
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Introduction

Becoming a carer can mean many different things. Some people find themselves providing a few hours of help a week to a family or friend by picking up shopping or taking them to medical appointments. For others, it can mean providing round-the-clock care for everything from washing and dressing to making meals.

But what is certain is that the majority of us will find ourselves with these responsibilities at some point in our lives — estimates suggest three in five people will become a carer.

Many are willing and happy to undertake this role for loved-ones and in doing so help keep the cared-for person independent and out of hospital. But being a carer can take its toll — and some will need help and support to allow them to continue.

Young carers face particular disadvantages. Caring often takes its toll on their education, physical health and wellbeing.

The pressures of being a carer can place a burden on physical and mental health. Carers are more likely to suffer depression, anxiety and stress and nearly two-thirds of carers have a long-standing health condition. The impact is often exacerbated by carers being unable to find the time for medical check-ups or treatment. Personal relationships can also suffer and carers are more likely to be socially excluded.

Councils have a duty to make sure this doesn't happen to such an extent that it impacts on their wellbeing in a significant way. That means we need to provide assessments and put plans in place for those who need help.

That help can just involve information and advice or it may require attempts to lessen the caring responsibility by providing respite care. Other forms of support, from help with employment to linking carers up with community services such as gyms and art classes, may also be appropriate.

But just identifying carers can be a challenge. Most are unknown to councils. Many do not ask for help or may not even recognise they are carers. So it requires councils to work with their partners to reach out to carers.
Key statistics

- 1 in 10 people are carers
- 40 per cent increase in carers predicted over next 20 years
- £132 billion worth of care provided by carers
- 1 in 5 carers are aged over 65
- 1.4 million carers provide over 50 hours of care a week
- 7 in 10 have suffered mental ill health and 6 in 10 physical ill health from caring
- 166,363 young carers in England – a fifth higher than a decade previously
- 1 in 12 young carers is caring for more than 15 hours a week
- 1 in 20 misses school because of their caring responsibilities
- young carers are 1.5 times more likely to have a long-term illness, special educational needs or a disability
- there are 670,000 unpaid carers of people with dementia in the UK
- two thirds of people with dementia live at home and most are supported by unpaid carers.

Source:

Carers UK two reports/briefings and Carers trust one report.

State of Caring 2018: [link]

Facts About Carers: [link]

Carers Trust – Key facts about carers [link]

Hidden from view: The experiences of young carers in England. The Children’s Society 2013. [link]
The importance of carers

Carers play a vital role in society – through both their sheer numbers and the amount of care they provide. According to the 2011 Census, 6.5 million people in the UK are classed as carers. That equates to one in 10 of the population. And it is a figure that looks set to rise. Carers UK estimates there will be a 40 per cent rise in the number of carers over the next 20 years.

The amount of care provided differs greatly. Nearly a quarter of carers provide over 50 hours of unpaid care a week. The care that is provided is worth an estimated £132 billion, about the same amount that is spent on the NHS in England.

The type of care that is provided varies greatly too. According to the Survey of Carers in Households, 82 per cent provide practical help such as preparing meals, doing laundry or shopping. Another 68 per cent keep people company, 49 per cent help people with financial matters and 38 per cent help with aspects of personal care such as washing, dressing and eating.

So who are these carers? The first thing to note is that they are changing all the time. Every year over 2 million adults become carers and almost as many people find that their caring responsibility comes to an end.

There are nearly 50 per cent more female carers than male. And carers are more likely to be older too. There are more than 2 million carers are aged between 50 and 64, while another 1.3 million are over the age of 65. The oldest age group is the fastest growing population of carers.

But, of course, people can find themselves providing care at any age. There are approximately 166,000 under 18s with caring responsibilities in England currently. Overall, more than one in five carers live in poverty.

Most carers, about 40 per cent, care for their parents or parents-in-law, while over a quarter look after their spouse or partner. Caring for disabled children, both adult and under 18, accounts for one in seven cases.
The policy picture

When it comes to caring, the 2014 Care Act is without doubt the most significant piece of legislation of recent times. It introduced new rights for carers - it gives them a legal right to an assessment and support for their needs when eligible.

Policy has been further developed by the publication of the government’s Carers Action Plan in the summer of 2018.

The plan sets out a detailed timetable for 2018/19 and 2019/20, covering a wide-range of individual actions including:

- the publication of Care Quality Commission standards setting out what carer-friendly GPs should aspire to
- identifying exemplar bereavement care pathways
- reviewing the progress made by councils in meeting the requirements of the 2014 Care Act and introducing a support programme to help those that are struggling
- piloting an integrated, single-assessment process for carers and the people they care for
- developing a carer-friendly employer benchmarking scheme
- reviewing how best to support young carers and help them achieve good education outcomes
- Department of Health and Social Care to run a project aimed at identifying effective practices to help young carers transition into adult services.

Funding reform to secure the long-term sustainability of care and support may also be in the pipeline with the long-awaited Government social care green paper. The LGA responded to the Government’s delay of its green paper by publishing our own in July 2018, ‘The Lives We Want To Lead’. We received more than 540 submissions to the consultation from across the general public, people who use services, councils and countless other interested organisations. The LGA's response to the consultation was published in November 2018 and puts forward a number of recommendations to Government, including:

- Urgently injecting genuinely new national investment to address the social care funding gap that builds to £3.56 billion by 2024/25. This must include additional investment to that announced in the 2018 Budget to help address serious provider market stability concerns in 2019/20.
- Making the case for national tax rises, such as increases in Income Tax and/or National Insurance.
- Reversing the cuts of £600 million to the public health budget between 2015 and 2020.
- Prioritising investment in prevention, community and primary health services within the £20.5 billion additional expenditure for the NHS.
- Launching a national campaign to raise awareness of what adult social care and support is, why it matters in its own right and what it could and should be with the right funding and investment.
The role of local government

The new legal rights given to carers by the 2014 Care Act led to a duty being placed on councils to make sure the care and support needs of carers were properly considered.

The duty relates mostly to adult carers who are caring for another adult. This is because young carers and adults who provide care to disabled children can be assessed and supported under children’s law.

However, the act does set out the need to look at the family circumstances when assessing the need for care, for example making sure that the position of a young carer within a family would not be overlooked.

The act gives councils responsibility to assess the carers’ need for support. The assessment must consider the impact of caring on the carer. It also needs to consider the things that the carer wants to achieve in their own day-to-day life as well as the other important issues, such as whether the carer is willing and able to carry on caring, whether they work or want to work, or whether they want to study or do more socially.

If both the carer and the person they care for agree, a combined assessment of both their needs can be undertaken. When the assessment is complete, the council must decide whether the carers’ needs are eligible for support. At the very least, they should be given information and advice. This approach is similar to that used for adults with care and support needs. The carer will be entitled to further support if:

- The need for support arises because they are providing necessary care.
- That care is having a significant impact on their well-being.
- If this is the case, a support plan must be agreed between the council and carer. This might include everything from arranging help with housework and respite care, to providing the funds to buy a laptop to keep in touch with family and friends or becoming a member of the gym so that the carer can look after their own health.
- Or, it may be the case that the best way to meet the carer’s needs is to provide care and support directly to the person being cared for by providing replacement care to allow the carer to take a break for example.
- In some cases councils do not charge for providing support carers. However, this is something that the council can decide to do and if it does it must carry out a financial assessment to decide if the carer can afford to pay.
Key learning points for councils

• Make sure carers’ services are accessible and flexible – consider weekend and evening opening or pop-up clinics in different locations.

• Communicate in a variety of ways - from text and email to more traditional methods, such as newsletters.

• Co-produce projects with carers themselves.

• Try to unlock the potential of small charities and groups that may be put off by a formal tendering process.

• Think about how to support carers with their health – carers can sometimes ignore their own needs.

• GPs can be important allies in reaching out to carers. Carers are likely to be frequent attenders with the people they are caring for.

• Bereavement for carers brings its own unique set of challenges. Ask how you are supporting carers once they have lost a loved one.

• Personal budgets, also known as direct payments, can be a great way of giving carers control over their support.

• Reach out to the public – shared lives schemes can be a great way to support carers and give them breaks.

• Remember many carers work so local employers are important partners. Seek to raise awareness about the needs of carers among employers and support carers to stay in work or get back into work.

• Ensure that your support teams are speaking to frontline services like libraries and leisure centres which are often in touch with carers and providing informal support.
Case studies

The following case studies show how local authorities are supporting carers across England. It identifies the challenges authorities face and how they address them, often in partnership. It highlights the impact of services and lessons learned that will be of interest to all councils. The cases studies were compiled following discussions with the lead officers and members in the areas.
Bournemouth, Poole and Dorset: creating a discount card for carers

Across Bournemouth, Poole and Dorset, local government and the NHS have worked together to launch a carers card to give people discounts and benefits at more than 200 local businesses. So far more than 7,000 carers have signed up to it.

The challenge

Carers UK and the Carers Trust have both been promoting the importance of creating carer-friendly communities. These are environments where the needs of carers are considered and accommodated.

The desire to do more for carers in this way prompted Bournemouth Borough Council, the Borough of Poole, Dorset County Council and the local NHS to start thinking about launching a carers card that would encourage businesses to think about the needs of carers, offering them discounts and making services more accessible.

The solution

Pilots first started to be run three years ago. A social care agency was appointed, but uptake was disappointing so a local company with experience in marketing was chosen and given a two-year contract.

The contract was carefully structured so that payments were incentivised to ensure certain targets were met. After some careful work planning, the carers card was officially launched in the summer of 2016.

The card entitles holders to discounts up to 25 per cent and even free products for all sorts of good and services. It includes everything from restaurants, cafes and pubs to leisure attractions, hair and beauty salons and health and wellbeing clinics.

There is an online directory listing them all and grouping them into regions so carers can see what discounts they can get near to them or if they are travelling to a new part of the county.

Debbie Hyde, Bournemouth’s Carers Commissioning Manager, said: “The only businesses we haven’t had joy with yet really are the big national chains – and that’s to do with a problem with their tills more than anything. The uptake has been really pleasing.”

But the carers card has also had the added benefit of boosting the numbers of people the carers service has on its books. When people sign up they are also registered by the council’s carers service so they get the regular information and advice that the service sends out by post and email.

Ms Hyde said: “It has worked well from that point of view. Not only have we created a card that gives carers all sorts of discounts and hopefully makes their lives that little bit easier, but we have also created a way of increasing our reach. People don’t have to join in with anything, they are under no obligations, but it just means they have the information about what is on offer if they want it. I would say close to half the people who contact the carers centre to join our information service have done so because they also want a card.”

The impact

The card has proved popular. Two years on from its launch over 7,000 people have signed up for the card and over 200 businesses are involved.

One of those who has benefited is Brenda, who cares for her husband. She said signing up for the card not only provided some great discounts, but also put her in touch with the carers service and what they had to offer.
She said: “Most people don’t see themselves as carers, however being aware of your role as a carer, sooner rather than later, is important - knowing what support may be available, before you need it, can be very reassuring.”

She found it particularly useful during her regular trips to Poole Hospital with her husband. The hospital offers discounts on meals at the canteen, which she found extremely useful. Brenda said: “It is one less thing to worry about.”

Lessons learned

A card like this is only successful if there is good interest from businesses. “We have thought carefully about how we market it to businesses,” said Ms Hyde. “Of course, many businesses want to help, but you still have to point out the benefits. It gives them free marketing to thousands of people and when they join we promote them on social media.

“We also encourage the card-holders to recruit businesses for us. They get leaflets that they can hand to the businesses they use letting them know how they can get involved. It is a good way to get people interested. The number of businesses signing up is growing all the time.”

How is the approach being sustained?

The type of businesses targeted has evolved since the card was launched. When it started there were no trade people, such as plumbers and carpenters, signed up because of concerns about how the quality of the work would be vetted.

“We keep in regular contact with carers through events and forums and there was an appetite for that. So we have been thinking about how we could introduce them. We decided to use the Buy With Confidence scheme, it is trading standards vetted and businesses pay to go on to it so over the last year we have been able to accept them.”

Thought is also being given into how the carers card could be merged with the carers emergency card to create a unified identification card. “We know having two cards is not ideal. If we could have just one that served both purposes it would be better for carers,” added Ms Hyde.

In the meantime, the contract for the card has been renewed for another two years.

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**Brent:** helping carers access services through a Hub

Brent Council commissioned a carers hub in 2013, providing a single-point-of-access to a whole range of services from information and advice to counselling. More than 3,000 local carers now use the service each year.

The range of services provided include:
- general information and advice, including referrals to specialist service
- advocacy and representation
- money and benefits advice, including help completing forms
- whole family assessments when children are involved as either carers or simply living in the house to see if the child needs support in any way
- access to employment and training support, including workshops and help with interview techniques and job application forms
- help accessing home adjustment support and specialist equipment.

Councillor Krupesh Hirani, Cabinet Member for Public Health, Culture and Leisure, said the centre was providing vital support. He points out providing care to family members and close friends can be isolating and cause stress and depression and so they need the easily-accessible help that the hub provides. “The staff at the centre have demonstrated hard work, dedication and commitment in supporting carers,” he added.

The challenge

Carers may need help in a variety of ways. It may be simple information and advice about caring or it can be specific help with everything from housing, finances to health.

It can lead to carers having to access a variety of services provided by different agencies, which can be both time-consuming and confusing for carers.

Brent Council has long had a commitment to supporting carers via Brent Carers Centre.

But five years ago it led a consultation exercise which set out a need for a more comprehensive range of support services including advocacy, information and advice and training workshops for carers.

The solution

The council decided to set up a carers hub to provide a single-point-of-access. The hub opened in 2013 in Wembley and moved to Willesden in 2016. It is open every weekday from 9am to 5pm.

There is a five-strong team of support officers who work with adult carers, while two people are employed to focus on cases involving children. The hub also employs a counsellor who can provide free therapy to carers who are struggling with their mental health.

They are supported by a team of volunteers who help with administration and organising events.

The impact

The hub has proved incredibly popular. Over 3,000 carers use it every year. Feedback from them is very positive.

Sam (not their real name) said: “The staff are kind plus very helpful. They know their stuff and provide useful advice. They always go above and beyond in helping to assist in whatever way. You are never left to struggle on your own.”

And another client, Alex (not their real name), believes the help she received prevented her having a breakdown. She said the staff had been patient, knowledgeable and thoughtful.
“It made an enormous difference and helped me through a very stressful time. Without Brent Carers help I’d have broken down,” she added.

The centre has also received recognition elsewhere. It has been London’s Carer Support Charity of the Year for the last two years in the Global Health and Pharma Awards and was nominated in 2018 for the Care and Compassion Award at the NHS 70 Parliamentary Awards.

Brent Carers Centre Chief Executive Anne-Marie Morris said: “It is a really effective way of providing support. We have a small team at the hub but with the help of the volunteers they can provide a really comprehensive service to carers.”

Lessons learned

As the hub has developed, Ms Morris said it became clear that making sure services were accessible was paramount. “It is not always possible for carers to get to our hub – some work, while others may find it difficult to travel – so we have taken a number of steps to make sure our services can be used.

“Once a month we have a late night opening and a Saturday morning session. We also have clinics out in community locations at seven different sites, such as libraries and health centres, and do home visits where needed. While having a hub is convenient and provides all the help people need in once place, we realise it is not always possible for people to come in.”

Communication is also important. The centre publishes a quarterly newsletter, monthly emails and even texts when they have events to promote. “When you are busy – as carers are – it can be easy to forget what is going on and not prioritise yourself. Keeping in touch is vital,” added Ms Morris.

How is the approach being sustained?

The funding the council provides for the hub is enough to pay for the core services. But Brent Careers Centre relies on fund-raising to pay for extras, such as organised activities for carer’s, respite grants and relaxation and massage therapies.

Currently about a third of the charity’s income comes from fundraising, but the centre has recently appointed a fundraising officer to increase that ratio.

“There is plenty more we want to do – and fundraising is going to be key to that. We hope by having a dedicated officer focusing on this we can do even more to support carers,” said Ms Morris.

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Cheshire East: modernising support for carers

Cheshire East Council has completely transformed its approach to supporting carers. Four years ago it started the process of closing its three respite units – and has replaced them with a modern service that utilises strategic purchasing of care home beds, shared lives, a community-based offer and a borough-wide carers hub.

The challenge

Cheshire East Council has always placed a high importance on providing carers with respite care. Up until 2014 it ran three mixed-use, short-stay units with around 40 beds where people needing care could stay to allow their carers some valuable time off. But the facilities were ageing – the rooms were not en-suite, there were no modern facilities.

Councillor Janet Clowes, the council’s Cabinet Member for Adult Social Care and Health Integration, said: “These units dated back to the 1970s. It was going to cost us £1 million to renovate and remodel each one and when we consulted with carers we realised it did not make sense. While they used the units and valued them and the staff in them, many carers admitted that they were not ideal. They wanted a more flexible approach to respite care.

“One carer explained that whilst she had booked carer respite at one unit for her husband with dementia, she would not do it again. She had enjoyed her break but it had taken her weeks to get her husband settled back at home. It was clear we needed to modernise.”

The solution

The council decided to close all three units and block purchase beds in local care homes. It was done in a phased way with the first unit closing in early 2014 and the other two following as contracts ended.

All three were shut by January 2016. The block purchase of care home places means carers can easily pre-book places for up to a year in advance using a dedicated booking number.

Staff from the respite units were re-deployed into other care roles within the council, including two reablement teams – one dedicated to supporting people discharged from hospital and one to supporting residents newly-diagnosed with dementia.

The council has also invested in expanding its shared lives network. These are members of the public who are trained and paid to offer short and long-term respite care.

Meanwhile, the council and its clinical commissioning group partners took the decision to “pool” their resources for carers and establish an Integrated Carers Hub, which was launched earlier this year. The hub is delivered by n-compass northwest, in partnership with Child Action Northwest and the Alzheimer’s Society, and provides a single point of access for all carers including adult, parent and young carers.

Councillor Clowes said: “We realised that although we all had allocations of money to support carers, we were duplicating effort and administration which in turn meant that carers were not always sure where best to get the support they needed. By pooling our resources we have been able to provide much more for carers.”

The impact

One of the benefits of the carers hub is that the council and NHS have been able to commission much smaller-scale providers to run innovative support services. They have a “dynamic purchasing system”, which reduces the administration.
The council’s communities team and npower have also run a Dragon’s Den-style event for local organisations to bid for small pots of money to support services for carers in their communities. The event saw £88,000 of funding split between 10 projects, including a buddying scheme for young carers.

The benefits can also be seen in the growing numbers of carers who have been registering with the council. Before the changes took place, the council was in touch with about 3,000 carers. But that has now grown by over 500 new carers registering with the Hub, including about 90 young carers. What is more, over the past few years, the number of shared lives volunteers has grown ten-fold to 250.

Councillor Clowes said: “What’s happened has been very dynamic, exciting and is delivering real benefits for carers of all ages. For example, we had very limited contact with young carers, but are now seeing more registering with us and getting the support they need.”

Lessons learned

Cheshire East Council has modified its approach as the new ways of working have been rolled out. Initially, the council block-booked 24 beds at 20 care homes. But over the past two years the council realised carers were choosing to use the other forms of residential and community-based respite care that better met their needs and reduced the need to block-book as many residential places. The council now purchases 10 beds from seven homes with two of the beds reserved for emergency placements.

Councillor Clowes said: “We can spot purchase extra beds if we need to, but with everything else we have to offer we have found that we do not need so many places.

“The crucial thing has been to co-produce this with carers themselves. When we tendered for the contract for the carers hub, carers and service users sat on the interview panels with us and in the end, we actually went for the provider that carers and service users preferred. It is easy to assume when you commission services you know best, but that is not always the case.”

How the approach is being sustained?

That co-production ethos is leading Cheshire East to change the way it commissions services in the future. To date it has aimed to get a good geographical spread of places so people do not have to travel very far.

Councillor Clowes said: “What we have found is that whilst carers prefer respite to be close to home, they do not mind travelling a little further if the place is right for the people they care for.

“With that in mind, we are looking to commission more specialist places to ensure people with dementia are cared for in homes where there are dementia specialists and that young people with learning disabilities or physical disabilities are with other people with similar conditions.”

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Coventry: working with schools to meet the needs of young carers

Young Carers Service Coventry works closely with schools to support young carers. It has a dedicated schools worker and runs an awards scheme, while the council has funded an online training course that is promoted to staff.

She also delivers the Young Carers in Schools Programme. This allows schools to achieve bronze, silver and gold national status for the work they do in supporting young carers, encourages steps such as appointing young carers leads and providing dedicated resources for staff, families and young carers.

Ms Kaur said: “Schools are busy environments, and many may not have considered the needs of young carers. By working with them we can help ensure young carers have the support they need to thrive.

“Some of it is just about helping schools accommodate them, such as being flexible with homework or supporting with attendance and timekeeping.”

School staff are also encouraged to complete an online course offered by Coventry City Council. Young Carer Aware is broken down into four bite-sized sections, covering what a young carer is, legislation and children’s rights and their needs.

The challenge

There are an estimated 5,000 children and young people under the age of 25 with caring responsibilities in Coventry. But young carers do not always identify themselves as a carer because they see it as part of their everyday life and something they have always done.

Often young carers are reluctant to tell anyone about their caring responsibilities. This can lead to young carers becoming isolated and not getting the right support. The impact on their lives can be huge. Juggling all their responsibilities can make it hard to find time for homework, activities after school and friends.

Nationally, more than one in four miss school or experience difficulties such as bullying at school, according to the Carers Trust, while GCSE results are lower than the national average by nine grades.

The solution

Over recent years, Young Carers Service Coventry, part of the Carers Trust Heart of England, has focused efforts on working with schools as a way of helping young carers.

The service has a Primary Schools Education Worker, Rhupinder Kaur, who is funded by the Big Lottery. She works with schools in a variety of ways. She holds awareness assemblies, refers young carers into the service, attends meetings and parent’s evenings, run drop-in sessions as well as training staff to identify and support young carers.

Regular youth clubs are run for different age groups – five to seven, eight to 11 and 12 to 17. There are also activities and sessions during school holidays, including arts, music, movie nights, cooking and other life skills sessions.

The impact

Those that need support from the service are referred on for an initial assessment meeting with the Family Information, Advice and Support Worker, Mark Graham, who is also funded by the Big Lottery. He then identifies whether emotional support is needed or if the carer would benefit from a taking part in some of the activities the service runs.
Mr Graham said: “We really tailor the support to the individual. I’ll go into schools, their homes, provide one-to-one support or they can come to our centre. Often it is easier for them to open up away from the home environment where the person they are caring for is.”

Schools are the major route of referrals, although some do also come in from council staff such as social workers, other professionals and some via self-referrals. The service currently has around 1,500 children and young people on its books.

Over the last year, 350 have received one-to-one support and over 500 have taken part in activities. Those that have been supported say it has had a major impact on their lives.

One young carer said: “Before speaking with you, I felt like nobody understood how I felt. Now I feel so much happier after talking to you”

Meanwhile another, who really enjoyed the youth club, said: “It's been wicked. I really look forward to coming here and hanging out with the other guys as well. There's no pressure and I can really chill out which takes my mind off things at home for a few hours.”

**Lessons learned**

Mr Graham said over the last two years some of the most popular activities have been the family events. “We took 150 people to Skegness for the day over the summer. The year before we went to Bournemouth. The families had great fun together. We also have a Christmas party every year

“It is easy to forget, that these families don’t always get to spend time together doing activities. It is not just about providing opportunities for young people to have time away from their family.”

Mr Graham said they have also found benefit in being flexible in their approach to activities. “We have funded drum lessons for one boy and a football trip for another. Sometimes what they need is not something we offer. But we see the value in helping young carers in any way we can.”

**How is the approach being sustained?**

The service currently has two full-time members of staff and a sessional worker to support with activities. Funding has recently been secured from Children in Need for a three-day a week activities worker to increase the opportunities the service can offer young carers.

Service Manager Michael Howard said: “The more staff we can employ the more we can do. There is so much we can do for young carers. We do have volunteers who help us with the activities, but there is only so much you can expect from them. There are lots of carers out there we would like to reach and there are lots more schools to work with.”

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Young Carer Aware course
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Dudley Metropolitan Borough Council has a strong track record in supporting carers. It has pioneered the use of direct payments to carers to allow them to take a break or pursue social or leisure activities and is now building on that by providing a range of other support, including helping to look after their health and wellbeing.

The challenge
All too often carers neglect their own health and wellbeing as they devote all their energies into looking after someone. Research shows the risk of physical and mental health problems increases for carers.

It is why Dudley has been running a carers direct payment scheme since 2004 to support carers. Carers are offered one if – based on national eligibility criteria – they qualify for help through a carers assessment. The one-off payments, normally between £200 and £500, enable carers to achieve their identified outcomes.

It has traditionally been used to allow people to take holidays or short breaks. The scheme proved popular, although some carers did report finding it difficult to get alternative care or reassure the person the cared for they would be looked after in their absence.

The solution
Over the last seven years, in addition to holidays and short breaks, direct payments have begun to be used for a more diverse range of activities.

These range from driving lessons and attending concerts to gym membership. This greater flexibility has allowed people more choice and control over how they spend the payment.

And with the introduction of the 2014 Care Act and the duty that placed on councils, Dudley has looked for other ways to support carers.

Dudley Carers Coordinator Nicola McGregor said: “The direct payments scheme has been really valued by those who benefit. But there are other ways we have supported carers.

“For some, ensuring the cared for person has a good package of care is enough. For others, the challenge maybe more to do with isolation and loneliness so we have supported them to access local groups to get them involved in the community.”

The impact
Over the years hundreds of carers have been helped in this way. In the last six months alone the council has carried out over 200 carers assessments. Whatever the support that has been given over time, carers report that has proved invaluable in helping them cope.

One individual used their direct payment to pay for gym membership. The gym was only two miles away from their father’s house, meaning they could go there after they had washed, dressed and fed him.

Other cases have included purchasing a new bed to help give a carer a better night’s sleep as they were relying on an easy bed and covering the costs of a training to course to enable her to start up her own business from home, allowing her to work and continue caring.

For one carer who could not drive the payment was used pay for the cost of travelling to Birmingham to enable her to access her church and religious community to avoid isolation and socialise.
Lessons learned

For all the support and help that has been given, the council has recognised that sometimes the need cannot simply be addressed through a social solution. So in partnership with the council’s public health team, a course was launched to help improve the health of carers.

Looking After Me is the carers’ version of the Expert Patient Programme. It is a self-management course for adult carers with problems such as stress or tiredness.

There is a version for carers who are looking after someone with dementia and then a generic version for others. It aims to help carers learn new skills, develop the confidence to take more control of their life and meet with others who share similar experiences. Carers are offered one three-hour session a week for six weeks.

How is the approach being sustained?

A Carers Hub and Wellbeing Service has recently been launched in Dudley to build on the range of support that is on offer and make it easy for carers to access services.

It acts as a single-point-of-contact for carers to access information, advice and support.

The plan is to provide a health and wellbeing element similar to the Looking After Me programme as well as training programmes on everything from help getting back to work to first aid.

Users will also be able to ask for assessments and get a wide range of information and advice.

Ms McGregor said: “The Care Act has changed the way we support carers. Direct payments are still effective, but we also want to keep exploring new ways.”

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Bereavement for carers brings a unique set of challenges. The carers service in Hertfordshire is supporting carers dealing with the loss of their loved ones by running support groups and offering telephone support to help them rebuild their lives.

The challenge

Losing someone close to you can be devastating. If you have been caring for that person, the loss can seem even greater. Research by Carers UK has shown that as well as coping with the loss of the cared-for person, a carer may find themselves coping with the loss of the caring role.

Carers can also report significant problems with isolation. The contact and relationships they had with health and care staff come to an end and they may have lost touch with their own friends and wider family because they have had to devote so much of their time to caring.

The solution

Carers in Hertfordshire, which is commissioned by the county council, has always promised carers access to its services for three years following the death of the person they were caring for. But 10 years ago it recognised that something more needed to be done and so a bereavement service was launched.

The service is staffed by 16 volunteers and provides carers one-to-one support via telephone consultations or they can take part in a nine-month course. The course is done in a group setting and starts in September every year.

The group meets twice a month in the lead up to Christmas and then monthly afterwards. Participants take part in a variety of sessions, including in-depth discussions on grief and loss, coping strategies for dealing with anniversaries and other difficult times such as Christmas. Other services are also invited in so bereaved carers can hear about the opportunities that exist through volunteering and learning and development.

Carers in Hertfordshire Health and Wellbeing Manager Carole Whittle, who manages the volunteer-led bereavement service, says: “It really depends on what the individual wants. Older carers often feel isolated and many need some help getting to know people. They may want to take part in day trips for example, while younger carers wonder what next to do with their lives. They may want to change careers or do a course.

“We can help with that. We aim to get them into doing something that they enjoy and that helps them to adjust to the change in their lives. People will often say that when they become a carer their lives shrink. They don’t see people as often and they may have to cut back on work. We give them an opportunity to expand their lives again.”

The impact

In 2017, 38 people took part in a group, and another 176 were helped via telephone conversations. Feedback has proved extremely positive. All of those that took part said it increased their confidence, reduced their isolation and helped them to cope better with their grief.

One of those who has been helped is Margaret Stone. She joined the bereavement group after her husband, who she had been caring for for seven years, died.
She said: “When my husband died I knew that I had to work at dealing with my grief. I realised that for each death you have to come to terms with the particular situation you are in – because I had cared for my husband for so long it was a different kind of grief from when my parents died. That's why the Carers in Hertfordshire course appealed to me – it addressed my particular situation and gave me the chance to meet other people on a parallel journey.

“The course was structured, well-balanced and varied, and allowed plenty of time for people to talk and help each other through the process. It really has the right approach, acknowledging that grief is hard work, but that you can get through it. You feel cared for, accepted and supported, no matter what level you are at.”

Lessons learned

The service has found that uptake for the course can sometimes be a little low – around eight carers in some years. The traditional approach taken involves sending a letter and making a call soon after bereavement. The letter explains that the carers service will continue to be there for them for up to three years and that there is a bereavement service available to them if needed. But just over a year ago the service introduced a new three-month follow-up call.

Ms Whittle said: “Sometimes immediately after their loved one has died people are not quite ready to accept help. We have seen an increase in the numbers accepting help by doing the follow up call. And even those who still do not want help often say they appreciate the phone call.

“We are always trying to improve how we support carers following bereavement. There are other steps too. For example, the course changes each year off the back of feedback we receive.”

How is the approach being sustained?

The group support is run from a centre in Welwyn Garden City. But last year the service introduced a new element with the introduction of a drop-in clinic in Watford. It is run once a month and follows a similar pattern to the structured group course.

Ms Whittle said: “It has worked really well. We are getting about 12 each week. We are encouraging them to only use it for up to a year – we don't want them to become dependent. But it gives people another option if they don't want to sign up to the course or can't get to Welwyn Garden City. It is still bedding in, but we are pleased with how it is going.”

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Kirklees Council: how shared lives can help give carers a break

Summary

Kirklees Council is ensuring carers get a break by running a successful shared lives scheme. It sees families offer to care for people with disabilities, mental health problems or dementia when their family need respite care.

The challenge

Being a carer is hard work. One in five provide over 50 hours of care a week. Being able to take a break, therefore, is critical to the health and wellbeing of carers.

If during the carers assessment, this is identified as a specific need for the carer it will be the duty of the council to provide support so they can take a break. This can take the form of a short-holiday or just day care to help the carer pursue a hobby or leisure activity.

There are a number of ways this can be done – through paid carers coming in or via a short placement in residential care for example. Shared lives is another option. This is where a family agree to take in a person in need of care either for a short-break, in an emergency situation or for a long-term placement.

The solution

Kirklees Council has been running a successful shared lives scheme for people with learning disabilities for over 30 years. Five years ago the council decided to give it a “reboot” by including people with physical disabilities, dementia and mental health problems. This has been accompanied by a recruitment drive to get more shared lives carers signed up.

Each shared lives carer undergoes an assessment and training and are then entitled to an allowance when they provide care. There are currently over 50 families offering short-term shared care and another 40 involved in long-term arrangements.

Shared Lives Team Manager David Maxted said: “It had a bit of a low profile, but we knew there was more we could do and we now see it as a really important part of providing support for all the unpaid carers who need a break. But as well as providing them with a break, it is better for the individual in need of care. They are going to another family in the community rather than to a residential care setting. They get to know the family over time and join in in all the activities they do.”

Mr Maxted said in some cases the relationship has got so close between the shared lives carer and the individual that in situation where the unpaid carer is older a shared carer has taken on the responsibilities long-term. “The individual then goes back to their own family for breaks. It is lovely to see these relationships develop.”

The impact

The quality of the service has also been recognised by the Care Quality Commission. In a report in early 2018 inspectors praised the work of the scheme for providing valuable care. On all five measures – safety, effectiveness, caring, being well-led and responsiveness – the service was rated good.

Inspectors said it gave people “maximum choice and control” over their lives and said relatives of people using the service had told them it was “excellent”. Meanwhile, the shared lives carers interviewed were praised for their “passion, warmth and affection”.

Supporting carers Guidance and case studies
Margaret and John are two carers who receive support through the scheme. Their daughter, Rachel, has a learning disability and is partially sighted. She has been going to another family for the past four years.

Margaret said she is delighted with the arrangement. “Rachel loves going. She talks about it for days before and after. They’re a lovely couple - very helpful and supportive. We make the arrangements between us and this can be very short notice. It works really well.”

Lessons learned

Running a shared lives scheme requires a lot of patience, assessment and vetting, according to Mr Maxted. Only about one in 10 people who apply end up qualifying to be a shared carer.

“You have to be prepared for people to drop out or decide it’s not for them. We send a social worker round to carry out a thorough assessment. Once they have got through that there is a two-day induction course and then they can do specific training in areas such as epilepsy, medication, dementia and autism depending on the sort of care they are going to provide.”

How is the approach being sustained?

The scheme is proving so popular that the team is being inundated with requests for help. At the moment, they can only help about one in five that come in, but Mr Maxted hopes that will change in the future.

“We’re always looking to recruit more carers. We have run advertising campaigns on billboards and posters, but we’re now exploring other avenues. The existing carers on our books are really good ambassadors – we take them to talks and events so they can give people that first-hand view of what it is like. We are also beginning to do some things on social media and in the press.”

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Leeds: helping GPs identify carers

Carers Leeds works with GP practices to identify carers. As well as referring carers to the service, GP surgeries are encouraged to put in place their own additional support for carers by offering things such as annual health checks and flexible appointments. The initiative has led to an increasing number of referrals from local practices.

The challenge

Identifying carers and making sure they get support is tricky. Not everyone who cares for someone necessarily identifies themselves as a carer or they can remain unaware of the stress, strains and risks of caring.

What is more, new carers are being created all the time. Every year approximately a third of carers find themselves no longer caring. In Leeds there are an estimated 74,000 carers, according to the 2011 census. Carers Leeds is in touch with over 11,000 of them.

Carers Leeds identified GPs as a key group to work with – it is estimated 70 per cent carers come into contact with the NHS on a regular basis yet only seven per cent are identified by GPs.

Health Development Manager Siân Cartwright said: “Carers may contact their GP about their own health needs but for many carers their contact with primary care will be as a result of the health needs of the person they are caring for. This means that primary care is an ideal opportunity to identify carers and to offer them support”

The solution

Carers Leeds, which is funded by both Leeds City Council and the local CCG, set up a scheme to encourage staff working in GP surgeries to refer patients to them over a decade ago. Known as the Yellow Card scheme, surgeries are provided with simple forms for carers to fill out. These are then sent by the GP practice to the service by Freepost and Carers Leeds then contacts the carer to tell them more about the services and support available.

GP practices are also encouraged to record that the person is a carer on their patient records, which enables the practice to offer carers targeted services such as annual health checks, flu vaccinations and flexible appointments.

The impact

Every GP practice in Leeds – over 100 of them – now have access to the Yellow Card scheme. Between them they are responsible for referring over 500 carers a year into the Leeds service, making them one of the core referrers.

Alison Stewart is Business Manager at Hillfoot Surgery. She felt that her practice had low rates of patients registered as carers and so wanted to do something to address that along with four other practices in the locality. They now are routinely identifying carers, offering them annual health checks and have worked with Carers Leeds to establish GP-based “carer clinics”.

She said: “Carers are unsung heroes and without them, health and care services would struggle to cope. It’s vital that we look after them and help make sure they are able to continue, so it’s been great to work with our colleagues in other practices and with Carers Leeds to put measures in place that will make a difference.”

Val Hewison, Chief Executive at Carers Leeds, is delighted with how the scheme is working out. “We recognise that people don’t often identify themselves as carers so it is our job to work across different organisations and communities to ensure that we are all able to recognise carers and let them know we have a range of support services to help them.”
This work with GPs has been a great success and we hope to continue building on this which benefits carers as well as the wider health and social care system. It’s a win-win.”

Carers Leeds also offers all GP practices Carer Awareness Training, which includes information about how the Yellow Card scheme works and can provide practices with feedback about the number of referrals they have made in any time period.

**Lessons learned**

Ms Cartwright said there are a number of key lessons she has learnt. She recommends “starting small” which allows you to work with practices that are really interested in looking at how they can improve support to carers.

“One once you have established a working model this can be used to influence other practices. The support and endorsement from staff has been key to generating interest in locality based working in other parts of the city,” she said.

She also said having a dedicated member of staff is vital to build relationships with the practice and keep promoting the scheme, while keeping schemes simple like the Yellow Card project helps to engage practices.

**How is the approach being sustained?**

Running a project like the Yellow Card scheme requires constant renewal, said Ms Cartwright.

“While every practice in Leeds has signed up to the scheme, staff change so we are currently re-contacing all practices in the city to offer them Carer Awareness Training and to make sure staff are still aware of the scheme and understand how it works.”

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Nottingham: developing a young carers app

An app has been developed for young carers in Nottingham. Helping them to access advice and support and find out when activities are taking place.

The challenge

Young carers can often feel isolated and alone. Their caring responsibilities mean they have little time for themselves.

Research by the Children's Society has shown that a third of young carers are providing more than five hours of care a week, with one in 20 doing over 15.

Take into account the time they spend at school and it can be difficult to engage them with services, even if those services are there to help them.

The solution

Nottingham City Council has turned to digital technology to help engage young carers. Research suggests three-quarters of children aged over nine have a mobile phone so the council and its young carers service provider, Action for Young Carers (AYC), decided to look at how they could reach out to young people via them.

A working group of young carers and AYC staff was established and together they developed the idea of an app. It was launched in October 2014 and can be accessed via smart phones as well as desktops.

The app can be used to help young people monitor their own mental and physical health and includes information about the activities and help available through the service from days out to when and where the support groups are taking place. Users can also ask questions and receive advice from the AYC team.

Councillor David Mellen, Nottingham’s Portfolio Holder for Early Intervention and Early Years, said: “We wanted to find a new way to engage with young people. We know people, especially young people, are using their phones for lots of things so we felt developing an app would help them access support - and that has proved to be the case.”

The impact

Since the app was introduced the numbers using the young carers service has increased. In the year following launch, the service saw the numbers increase by nearly a third. There are now just under 400 people receiving support with 150 regularly using the app at any one time. It has proved particularly popular among the 10 to 15 age group.

Those who have signed up report how it has helped them get the help from AYC that they need. One young carer, aged 12, says they find it really useful for keeping in touch with what is going on in regards to activities and knowing the support is there when they need it is really reassuring.

“AYC supports me and they’ve helped me to see that there are other young carers just like me and I’m not alone.

“They give me a break from being a young carer and listen to me. I like going to AYC because I feel I can be myself.”

Lessons learned

One of the benefits of the app has been that it provides an immediate idea of what help people need, said Councillor Mellen. “We have found that we have been responding and developing the service in reaction to what people are using the app for.
“It has helped to highlight where there is a need. So, for example, we have issued a card with advice about where to go when there is an emergency. It is not always possible to provide an immediate response via the app so we have made sure young carers are aware of where they can go for help.”

The advice issued includes information about where to go for help from the NHS, social care and basic home safety in the event of a fire or burglary.

**How is the approach being sustained?**

The app continues to be actively promoted. Young carers are encouraged to sign up to it when they have their full assessments. It is also available in schools.

But Councillor Mellen said there are two clear priorities for the future – helping young people transition to adult services and identifying more young carers. “As young people get older they tend to outgrow the young people’s services and using the app. That is understandable. What you want and need at 21 is quite different from the support you require in your teenage years. But these young carers are still vulnerable and we know we have to do more to help them as they get caught between the young people’s service and adult’s service.

“But we also know we need to do more to reach out to younger carers. The latest census suggests there are more carers out there than are being helped. That is a challenge for all services so we want to work closely with schools in particular to make sure we are providing help to all the people who would benefit from it.”

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Summary
A series of one-day events have been held across Norfolk and Suffolk for carers. The forums include talks by experts and advice stalls to provide information about local services.

The challenge
In 2013 the Carers Trust published a report, A Road Less Rocky, that found carers of people with dementia were not getting the support and advice they needed.

The research found that only 51 per cent of carers questioned said that they were given an opportunity to talk separately about their needs and how much care they felt able to provide.

Another 56 per cent of carers questioned said that they had not received information about managing the medication of those they cared for and 52 per cent of carers said that they had been given no information on how to cope with incontinence.

The solution
Mental health provider Norfolk and Suffolk NHS Foundation Trust has worked with the county councils and voluntary sector bodies across the region to run one-day forums where carers, health and care staff and patients themselves can come and find out information about caring for someone with the condition.

The forums called A Road Less Rocky involve a “marketplace” of advice stalls along with talks from experts, such as pharmacists, solicitors and doctors. The first event was held in 2013 and a number have been held since in local halls and conference facilities across the region.

Organiser Howard Tidman, a senior mental health nurse, said: “I know how hard it is caring for people with dementia. I do it for a job, but at the end of the day I am finished. For people caring for loved ones, it never stops.

“We know they don’t always get the advice and support they need so wanted to create something that was really informative and useful. As well as carers, we get professionals and even patients attending. There is a real mix.

“The talks are really popular and people can get referred to specialist services on the spot. It is a great way of reaching out to carers who may be struggling on their own.”

The impact
Mr Tidman said the events have proved very popular and have been going from strength to strength. “We got something like 140 at one point and are now running three or four a year. It is not just on dementia – we have been doing forums on diabetes and mental health problems too. They are all conditions that are becoming more common and people caring for them really need help and support in caring for people.”

Feedback from those who have attended is really positive. Some 98 per cent reported they found a recent mental health forum “really useful”, while 89 per cent said it had made them more confident dealing with situations as a carer.

Kevin Vaughan, Service Manager at Carers Matter Norfolk, said the events have worked extremely well and is full of praise for the way they have been developed. “They provide unpaid carers with vital information and advice. They are a great opportunity.”
Lessons learned

The way the events are communicated is really important. For example, the one on mental health is very much about schizophrenia, but is called Hearing Voices.

Mr Tidman said: “People can be sensitive about how you describe things. We have tried to create events that are inclusive and break down the stigma that surrounds these issues.

“People really do want to find out more information so we have now started putting some of the talks on a You Tube channel that we have set up to ensure the information goes to as many people as possible.”

How is the approach being sustained?

Alongside the forums, a series of roadshows are now held on a regular basis. These are more based around delivering services in local communities and are held in everything from local libraries to supermarkets.

Staff from councils, the NHS and voluntary sector representatives are available at the roadshows.

Mr Tidman said: “There’s an assumption that people are mobile but in our experience that is not always the case which is why we are so keen to get out into the community.

“The reality is that many people and their carers live on low incomes, do not have a car and have to rely on public transport which in some parts of Norfolk and Suffolk is either very poor or non-existent.

“We encourage people to ask us questions and to share their stories with us. We’re able to give them advice, hand out useful information and signpost them to the services that can best meet their individual needs.”

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Recent Road Less Rocky event
www.nsft.nhs.uk/Pages/A-Road-Less-Rocky-supporting-people-on-the-dementia-journey.aspx
West Midlands: creating carer-friendly employers

Councils in the West Midlands are working to encourage employers to support carers. An employment guide has been produced and now councils are changing their own practices as well as encouraging others to do so.

The challenge

Approximately half of carers are in employment, many in their prime years of employment. But research suggests many find it difficult to balance their working life with their caring commitments.

Research shows 70 per cent reduce their hours or quit with 60 per cent of those left working reporting they worry about losing their jobs. Those that give up work altogether tend to be in the 50 to 64 age range, depriving the workplace of valuable experience.

The solution

West Midlands Association of Directors of Adult Social Services (WM ADASS) represents 14 local authorities. It has a Carers Leads Network. Last year the network produced a guide on encourage employer friendly practices.

It sets out what rights carers are entitled to – such as asking for flexible working, time off for caring and the right not to be discriminated against. It also includes advice to carers about how to approach their employers as well as suggestions for changing practices, including shift swaps, staggered hours, self-rostering or even just simple steps like providing places for personal phone calls.

WM ADASS Co-Chair Andy Begley said it was designed to benefit both individual carers and employers. “We cannot underestimate the huge contribution carers make to our local communities and understand the many challenges they face on a day-to-day basis. For carers in employment this brings further challenges around juggling their care and work responsibilities.

“Knowing the experience of a carer can bring benefits to employers and their staff, because they are empathic and understanding of the juggling of roles that is required. Carers are invaluable and with the numbers of carers growing, we wanted to produce something in the West Midlands that would help guide both employers and working-age carers to help address these competing demands. Not only will this improve the work life balance of the carer, but also bring significant benefits to the employer.”

The impact

The 14 local authorities that are part of the WMADASS have signed up to making themselves carer friendly. All are at different stages, but steps being taken include identifying carers in the workforce, changing HR protocols, appointing carers champions and setting up carers groups so they can offer each other support and represent carers in the workplace.

Some have started to take this a step further by encouraging their contractors to sign up to being a carer friendly employer, while Birmingham City Council is looking to introduce a clause in its tenders. And talks are underway with local NHS bodies and big employer’s, such as Sainsbury’s and Tesco.
Meanwhile, Forward Carers, a local social enterprise, has recently set up an accreditation scheme for employers to sign up to. The Working for Carers scheme gives businesses access to online training for their staff, advice on how to support carers and free jobs advertising.

Birmingham Strategic Service Lead for Public Health Safina Mistry, who is also the regional carers lead for the West Midlands, said: “We are beginning to see some real progress. Employers are coming on board – and that is good for carers. “There is such a strong businesses case for this. If you support people, they will give you 110 per cent commitment. It is good for morale and good for retention and loyalty.”

Lessons learned
Ms Mistry said there has been two key lessons from the work that has been done. The first is to co-produce such projects with carers. We consulted our local carers forums and networks all the way. You cannot just assume what you are doing is right,” she said. “They gave us some valuable ideas and insights into what it is like for carers who work.”

She also feels it is important for local government – and the wider public sector to take a lead. “You have to get your own house in order. The 14 local authorities have all started to do that and we are now working with the NHS. Together we employ a huge number of people so the impact you can have is tremendous.

“How is the approach being sustained?

The work so far has been focussed on improving the working lives of carers in employment. But Ms Mistry accepts there is a challenge to get those who have left work back in to jobs.

“There are plenty of local people who have given up work, but want to get back. It can be difficult once you have had time out of the workplace so carers assessments are now routinely looking at this issue. It is something as a region we want to work on in the future and help carers more with.”

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**Want to know more**

**LGA social care green paper – The Lives We Want To Lead (2018)**

**Carers UK report – Valuing Carers (2015)**

**Carers UK report – State of Caring (2018)**

**Parliamentary Office for Science and Technology briefing on unpaid care (2018)**
https://researchbriefings.parliament.uk/ResearchBriefing/Summary/POST-PN-0582

**Carers UK briefing – Facts About Carers (2015)**

**Carers Action Plan 2018-2020**