

Cheshire East Community JSNA Carers' Project Report 2018

Questions 2 and 3

What is the impact of the caring role on health and quality of life and what do carers need?



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Everyone is different

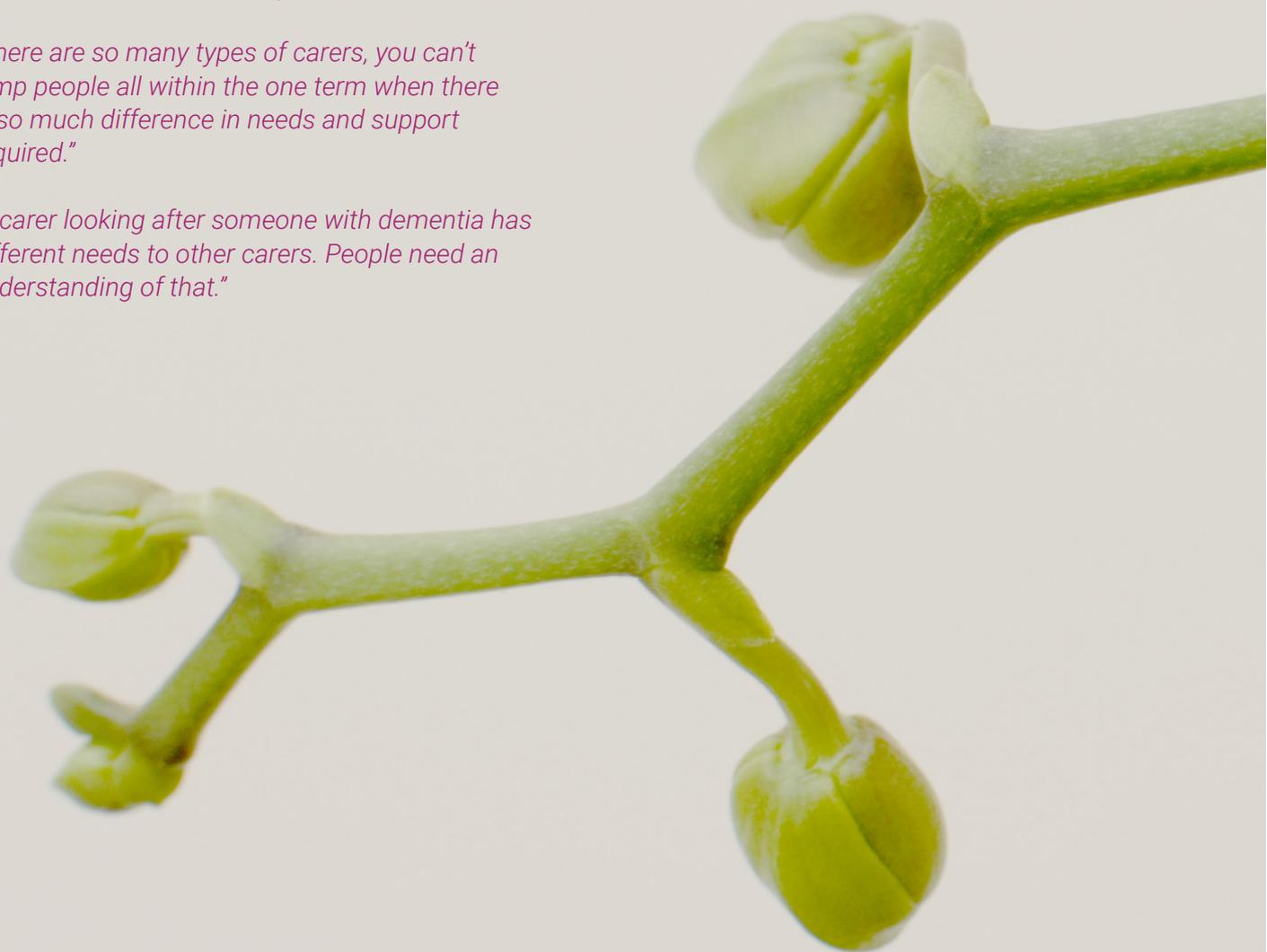
One clear theme that emerged from the Community JSNA work, is that carers feel very strongly that 'no one size fits all' in terms of experiences and needs. Some of the comments made include:

"They [funders] need to have a full understanding of the whole range of carers. There are so many initiatives where people haven't done enough research into what's needed. It's like having brilliant ideas based on a couple of viewpoints, rather than the full spectrum, as it does skew things."

*"It's support you need, it's not always money."
"I don't like the carer vouchers and cards, but that dictates where the money is spent. Some of the money you can spend on things tends to be for older people, or massages which I don't like. Or there's confidence workshops, which I don't need."*

"There are so many types of carers, you can't lump people all within the one term when there is so much difference in needs and support required."

"A carer looking after someone with dementia has different needs to other carers. People need an understanding of that."





What is Community JSNA in Cheshire East?

It's insight from people in our community, specifically from those who provide Voluntary Community and Faith Sector services, and the people who use them.

It's information about the health and wellbeing needs of our community, including evidence of what is working well and what people say are gaps in services.

What does JSNA mean?

Cheshire East Council's Joint Strategic Needs Assessment (JSNA) provides a picture of the current and future health and care needs of the local community. The JSNA provides the evidence that influences how public bodies plan for and buy in health and wellbeing services.

Who is the JSNA for?

- Commissioners who use it to plan for, and buy in services.
-
- The Voluntary Community and Faith Sector to help provide evidence for bids and business cases.
-
- Service providers to help them develop their services for the future.
-
- The public, who want to scrutinise local health and wellbeing information.

For More information on Community JSNA please visit:

www.cvsce.org.uk

The Impact Of The Caring Role (Young Carers)

Impact on health and quality of life of young carers (Young Carer Survey)

61% of young carers surveyed felt that they could spend their time as they wished, with none of the respondents feeling that they couldn't do anything that was important to them.

11 respondents (35%) felt that they struggled with school work because of their caring role.

Nearly $\frac{3}{4}$ (74%) of respondents felt they could take part in after school clubs or activities if they wanted to.

Nearly 40% felt that they couldn't spend enough time doing the things that are important to them.

Nearly half (48%) of respondents felt that they had some control over their daily lives but not enough. No respondents felt they had no control over their daily lives.

Just over half (52%) would like to be able to spend more time with friends and family, with the remaining 48% feeling they can spend as much time with friends and family as they like.

29% of respondents felt that they did not have enough encouragement and support in their caring role.

13 out of 17 young carers at one focus group had administered medication to their cared for person.

71% felt they looked after themselves, but 29% felt they couldn't look after themselves well enough at least some of the time.

29% of the 31 young carer survey respondents said that their health had not been affected by their caring role.

Of the 31, 29% stated that they felt depressed because of their caring role; 39% said they had experienced a general feeling of stress. The top 4 impacts on health were: (feeling tired; short-tempered irritable; general feeling of stress and disturbed sleep).

Fewer than 5 respondents developed their own health conditions, or said that their existing condition was made worse by their caring role.

48% of respondents found it hard to be part of friendship groups because of caring, at least sometimes.

Young carers appeared to concentrate very much upon their present situation and hadn't given much thought to future planning.

Young Carer Quality of life score:

A composite quality of life score has been calculated from young carers' responses to 5 of the survey questions. The maximum quality of life score was 10. The score for the 31 young carers who responded to the survey is 7.9. Due to the small number of respondents, this may not be representative of all young carers in Cheshire East.

Young carers in both focus group sessions were asked 'What would make a difference to your quality of life?' Young carers from both groups commented that they wished they could take away the pain of their cared-for person, or help them to be better. Otherwise, there were no other suggestions made, apart from one young carer who said:

"I'd like more support, like with the cleaning. And help with siblings and easier relationships within the household. A room of my own."

The positives of caring (Young carers)

Young carers attending the focus groups were also asked what they felt the positives of being a young carer were:

"I'm more mature as I have to deal with lots of issues."

"Adaptability to every situation."

"You feel good after helping."

"You feel more sensible, you know more what you should and shouldn't do."

"You have more understanding of people and situations."

Opportunities for Improvement

- Measuring understanding of what type of care young carers are providing (possibly by using the MACA analysis tool to record carer activity) and how this can be tracked going forwards e.g. through the Carer's Hub.
- Tracking changes in quality of life for young carers over time.

The Impact Of The Caring Role (Adult Carers)

Impact on health and quality of life (Adult Carer Survey)

How has your own health been affected because of your caring role?

The top four responses to this question from both the Community JSNA and Cheshire East Council's November 2016 'Survey of Carers of Adults in Cheshire East 2016/17' report were:

- feeling tired,
- disturbed sleep,
- general feeling of stress and feeling depressed.

A small percentage of carers surveyed reported that their health had not been affected (7.5% of adults caring for adults).

Key messages about the impact on health and quality of life:

The 2016 'Survey of Carers of Adults in Cheshire East 2016/17' report is also the source of the following figures.

The above survey found that 12% of their respondents felt that they didn't do anything they valued or enjoyed with their time.

86% of respondents felt that they had some control over their life, with 13% feeling they had no control.

Over two-fifths of respondents (43%) said that they were not looking after themselves well enough.

17% of respondents felt themselves to be socially isolated.

From the Community JSNA Survey of adult carers, nearly $\frac{3}{4}$ of respondents felt that they had some or sufficient encouragement and support

for their caring role, with 26% stating that they had no encouragement or support.

The Adult Social Care survey found that 22% developed health conditions and 19% said an existing condition was made worse.

Examples of health conditions in the Community JSNA survey included:

- An anxiety disorder (that manifests itself through physical symptoms e.g. chest pains and abdominal pain)
- Need for physiotherapy due to the physical demands of caring

Comments:

"The stress of constantly fighting the system has led to anxiety, PTSD and hypertension. Not the person I care for, but the system and the battles."

"Too many demands, psychological duress."

"Generally carers are just on their bottoms. There's not enough money. But the majority of carers have very little energy, space or time and just need support to help them as there is no space in their lives. It sometimes feel like people think 'job done' when they've directed you to the Wellbeing Fund, but you just need more than that. Services are disappearing, things like having lunches with others has

gone. People are stuck at home, they're isolated. You've got 80 year olds looking after other 80 year olds with dementia, who helps them? I find it very scary sometimes. There are some very vulnerable people out there. It's a real mess and we just need some back up. We save

Social Care and the NHS billions, but people are just on their knees."

"Have got to the point of thinking that I don't want to carry on. At this stage I saw my GP who was sympathetic and caring, but there's not much he can do."

"Things that affect your health and wellbeing, it makes you feel better. I'm not very good at focusing on what makes me feel better, what is good for me. So it's nice to have something for me."

Adult Carer quality of life score

A composite quality of life score has also been calculated from 6 of the survey questions in the 2016 Survey of Carers of Adults in Cheshire East. The maximum score was 12. The 2016/17 Cheshire East score was 7.6, similar to the average quality of life score in England (7.7; figures provided by NHS).

Balancing paid work and carer responsibilities (Adult Carer Survey):

Carers responded in the Community JSNA survey as follows:

26% said they could balance both roles
39% said they were unable to balance these roles
36% of respondents were retired.

"The Neuromuscular centre survey, undertaken annually, shows that between a third and a half of carers are in employment. Feedback suggests that to sustain working life, regular quality breaks are imperative."

- Quote from Crewe Alexandra focus group.

Feedback from focus groups and 1-2-1 interviews

Additional information, about trying to balance paid work with the caring role, from focus groups and 1-2-1 interviews are grouped thematically below:

- Lack of flexibility and understanding at work:

An issue with which many working carers struggled, was the lack of flexibility at work to enable them to fulfil their caring role:

"Lots of events are during the day. If you're working full time, it's impossible to attend. Can't get my cared-for person to them, or get them ready, transport etc."

Even with a supportive manager and a flexible work environment, carers often struggled with combining both roles:

"Very difficult... I could choose my hours. I had a brilliant manager; he would let me ring [cared-for person] to check he's all right. If I got no answer, I could just go. Once [cared-for person] had a hypo and I couldn't contact him, he'd have been dead if I hadn't popped home. In the end I was advised by DWP that it would be better to be a full time carer."

Another carer reported that unless they had a note from the hospital, or their cared-for person was in hospital, they were not allowed to take phone calls or have time to support their cared-for person. They were taken through a disciplinary process, and it became so stressful for them that they left work and became self-employed.

There was acknowledgement for this from another carer who commented that they would welcome "...support and understanding from work that it is now part of my life."

There was recognition from some working carers that they could only reasonably request so much time off before it became unsustainable, and some expressed guilt that their situation could make things difficult for others at work. The physical, mental and emotional demands of the caring role also had an impact on the ability of the carer to balance both roles. As a carer's role can become progressively more demanding as time goes on, several carers found that their capacity to work reduced as their caring role increased:

"It's very difficult, I often can't sleep through."

"I was making mistakes at work and my mental health was deteriorating."

- Increase in caring role:

A number of carers spoke about needing to leave paid employment as the demands of their caring roles increased:

"I was working, but had to leave to care for both of my parents, who used to help me with my daughter. Once my parents were gone, I became the sole carer for my daughter and was unable to work."

"I was a paramedic, I had to give up work to become a full time carer".

"Yes, I took voluntary redundancy as I couldn't cope with work and the caring."

"I had to give up work after 26 years to care for my child. I would like to work, I still have skills to offer."

In more than one case, carers reduced their hours to part-time working, before having to make the decision to become a full-time carer:

"I did work part-time but work tailed off as my caring role increased."

- Benefits:

There is an issue for some part-time working carers, that they can only work so many hours before it can affect the benefits they receive i.e. by working any number of hours over the limit, they can lose entitlement to benefits:

"I could only work and earn so much and still get a Carer's Allowance."

This situation drastically reduces the number of work opportunities available and can make finding a suitable working role unfeasible.

- Returning to work:

A number of carers were worried that once they were able to consider returning to work (as their caring circumstances changed or their caring

role ended), that they would need help and support to return to a work environment. One carer specifically said that they would need, and would welcome: *"retraining for when caring ends."*

In some cases, this need for support was due to the carer's lack of confidence in their skills and lack of recent experience. For others, there was a need to rely upon day-care provision to enable them to return to work. As one carer described:

"I owned my own house, had my own business. I had to move in with Mum to care for my mum and sister. 16 years of my savings have gone, I now have nothing. It's really difficult going from being a carer to going back to work, I really rely on day-care centres."

Another carer stated that they would like to have the option of working and earning money:

"It would be nice if I could get work and be paid. You can't do anything without money."

Whereas another carer felt that they had to return to work and could not remain in a full-time caring role:

"Future goals changed due to finances – I had to look for employment."

- Positive experiences:

Where carers have been given flexibility and understanding at work, it has been very much appreciated:

"I am lucky, my work has a flexible attitude to times of work and using flexi for crisis. We have a good employee assistance programme. I feel we still need to get into work to do a job and there is a limit to what employers can give."

What would make your life easier at work (Adult Community JSNA Survey responses):

| | |
|--|---|
| More understanding | 5 |
| Flexible hours | 4 |
| Less pressure for time off/emergencies | 3 |
| I have good support (flexibility due to situation) | 3 |
| To be able to become a full time carer | 2 |
| Working from home | 2 |
| Would like to work but can't | 2 |
| More money | 1 |
| To be open to employer about situation | 1 |

Understanding and flexibility were the two most common responses by carers to what would make their lives easier at work:

"Employers understanding I can only work certain hours and that I may have to leave work in an emergency"

"To be able to tell them what's going on as they don't know."

"More understanding and flexibility from the company"

"Less pressure if time off was required"

Opportunities for Improvement

- Raise awareness of carer rights regarding paid work and balancing carer roles.
- Encourage understanding and flexibility amongst employers and enable the carer to be honest about their caring role and its demands.
- Ensure support services are readily available outside of working hours.

What we don't know but would like to know

- How many carers have been supported into work by the service commissioned

by Cheshire East Council to provide careers advice and improve employment opportunities for both young and adult carers.

Achieving your goals and getting where you want to be in life

A number of carers were keen to convey that they felt they were living day to day and were unable to look to the future. The experience of being a carer was felt, by many, to be an unimaginable situation for those who had not experienced it for themselves:

"Unless you've worn the t-shirt, you'd never even begin to imagine what being a carer is like"

"Caring for someone with dementia is a horrible, soul-destroying job"

Some respondents explained that they felt they couldn't have goals due to the pressures of their caring role:

"It's difficult to answer. There are lots of things I can't do because of being a carer."

Whereas other carers said that being a carer for a loved-one changes personal perspectives on aspirations for the future:

"Goals have changed – the cared for person has become the goal."

Caring and the financial impact

71% of carers responding to the adult carer's survey felt that their caring role has caused money worries or problems, with 21% of those saying it caused them 'a lot' of worries.

Similarly, the majority of carers spoken to at focus groups and 1-2-1 interviews stated that caring for someone else had affected them financially in some way, and some said that it had a significant impact on their finances. The main issues are summarised under the following themes:

- Work

As already outlined, the issue of balancing work and caring can be problematic for carers, resulting in many carers leaving paid employment to become carers on a full-time basis. Some working carers felt that having to manage a caring role alongside a job negatively impacted upon their career progression:

"Yes. I would have had a better job, and done better at work."

"Carers who are working often have career progression compromised despite ability."

- Entitlement to financial assistance

The awareness of Carer's Allowance varied from carer to carer, and there did not seem to be a consistent route for carers to find out about the allowance payments:

"I get Carers Allowance. I didn't know until Cheshire & Warrington Carers Trust and Carers Trust 4 All told me about the allowance, I wouldn't have known otherwise."

It was raised at more than one focus group that some carers were frustrated when they reached pension age and their Carer's Allowance payments ceased:

"I've had Carers Allowance, but that's stopped now I'm drawing a pension. It seems very unfair as I haven't stopped being a carer."

For those carers who are ineligible for financial benefits, paying for private care can have a negative impact:

"Yes. We aren't eligible for anything and paying for private carers is so expensive, it really restricts what we can do."

"We're not well off. But I feel... I get other

people telling me things about financial help, but when I look into it, we're never entitled."

"We're not wealthy people, but we're not poor either. We have 2 hours care during the week, 1 hour on a Saturday through a private care agency."

One upset and frustrated carer at a focus group described their experience of trying to obtain power of attorney for their cared-for person to enable them to pay for care with their cared-for person's assets:

"Social services treat you like an imbecile. The premise is that you're guilty and trying to steal your relative's money. It's a sad way to look at things. The majority are not like that. People have enough guilt on without pointing the finger."

- Additional costs

The purchase of mobility aids and equipment and home adaptations can

result in large costs for some carers:

"Yes, we've had to buy all our equipment – scooters, bath chairs, wheelchair. None of that has been provided."

One carer at a focus group described paying over £100 per month for incontinence products for several months before discovering that they could be made available through the NHS.

Paying for assistance with household and garden maintenance can also impact upon finances:

"Yes it has, definitely. Because my husband can't do anything around the house or garden, I have to employ people to garden and clean. We have had to buy a lot of equipment. I bought new clothes for him to make it easier to dress him. We're struggling to find shoes with no grips, as they make him trip."

"We've only had Carers Allowance these last 12 months. No-one mentioned it to me all the years before then [14 years]."

Other carers described additional household costs that are required:

"I have increased costs e.g. convenience meals, increased utility costs."

At one focus group, a carer explained that they had to factor in additional funds to cover accompanying their cared-for person to activities and outings:

"Having the funds to do everything you need to do, it holds you back. I'm subsidising everything my cared-for person does, it's two of everything as I have to go too."

- Money Worries

Worry about finances was a consistent theme from carers at focus groups and in 1-2-1 interviews. They described the impact of the financial implications of their caring situation:

"People are worried to death about the money side of things. It needs to be transparent what you can and can't do. The main people it affects are those on the borderline."

"Yes, we are on a low income and with no savings. We couldn't even afford to continue with the telecare system. Now I'm on tenterhooks whenever I go out."

"Yes. I don't have a pension pot and we aren't financially secure. I spend time worrying about what will happen when my son turns 16 and PIP will decimate us."

"We're definitely well in debt. I've maxed out my credit cards and we can't cover the bills."

"We're really struggling, it gets worse every month."

"Every penny that you get, if used wisely, it's benefitting the carers 100%. Your life is pretty horrible as it is and anything that can brighten up your life helps."

More than one carer felt that they should be paid for their caring duties:

"Being paid for what I do – I find it offensive that I care for my cared-for person 24/7 and I don't get paid for it. I'm saving the country a lot of money, but I feel I'm being treated very badly. I don't know where to find the money for bills, it's a horrible feeling."

"Generally, carers should be paid lots more money to help reduce their stress and improve their mental and physical health."

- Not affected

Some carers, however, felt that they were in a stable financial position:

"No, we are lucky in that respect, I have a good pension and my cared-for person gets PIP and ESA".

Relationships with others

Being a carer can have a significant effect upon relationships with others, separate from the carer's relationship with their cared-for person. Some respondents struggled to find time for other family members, with one carer saying she felt unable to develop relationships with her grandchildren due to the pressures of her situation.

Another missed her friendship network and said she would really appreciate: "finding my friends again, finding myself again." Another respondent was concerned about arguments and their relationship with their partner because of the demands of their caring role.

"I had to change jobs as my job was too stressful and I couldn't manage both. Not that my cared-for person knows that, she'd be upset."

The positives of caring (Adult carers)

Focus groups and 1-2-1 interviews asked adult carers what they felt were the positives of caring.

The impact upon relationships, both for the cared-for person and wider relationships, was one area that was cited by some as being a positive:

"Smiles from my family member. Knowing you are making a difference."

"Close relationship with loved one."

(Since I became her carer) "I've seen her completely change personality. She was kept under wraps before, it's nice to see her personality develop"

"Knowing I'm helping her and her family"

"Magic moments"

"They're our loved ones, we love them."

"It can be very rewarding."

Being able to oversee and provide high-quality care to their cared-for person was another common response:

"Knowing they are receiving quality care"

"I feel I'm giving him the best quality of life at the moment. I try and enrich his life"

"Yes – in your own house and have the people (carers you employ) of your own choice."

"Control of care service being provided."

"The only positive side is that we feel he's getting the best care he can get"

A number of carers felt that they were able to maintain the independence of their cared-for person by caring for them themselves:

"Yes – you can keep the person at home for longer. What they worked hard to gain."

"Maintains their independence, builds resilience."

For some carers, it was not the caring role itself that caused issues, it

could be the restrictions resulting from caring, or the processes involved in asking for support that could be frustrating:

"I can't think of any negatives, it's all positive. Being tied 24/7 is the only issue"

"Don't find any negatives. It's not the caring, it's the administration that's the problem."

One carer felt that she had learned new skills and was now adept at time management, nursing and dispensing medication.

However, there were some carers who were surprised by this question and said that they felt hard-pressed to come up with any positives. One carer who was struggling with caring for their loved-one commented:

"No, it's very hard – I miss work, my friends. I feel isolated"

The impact of being a parent carer and the needs of parent carers, are powerfully summarised in the responses below when parent carers were asked, "How do we define ourselves?":

“Parent Carers – How do we define ourselves?”

When this question was put to parent carer representatives on the Cheshire East Parent Carer Forum steering group the following answers were given:

Feeling “guilty” and having more “baggage” than parents of mainstream children
Being a parent constantly, you can never switch off.

We are always advocating for our children. Even when we have all the support in place we can never take our eye off the ball, we must be constantly on guard

Have to be hypervigilant

Feeling constant anxiety, e.g. about social care.

Our parenting is always judged by others
Being the only person putting our child’s views across.

We are forced to focus on the negative to get any help for our child from professionals
We must always be collecting evidence about our children

Everything is weighed against a child with SEND

Bad parenting is seen as the cause of our children’s behaviour, when it wouldn’t be if they had physical disabilities.

We are always being sent on parenting courses.
The stress makes us more susceptible to health problems which impacts on all our children and our partners.

Doing everyday activities and routines with our children is much harder than for mainstream children – so this makes us doubt our own abilities.

It is normal for us to not be able to get enough sleep or a toilet break at times.
We give strategies for reasonable adjustments for our children to others and are then accused of being over protective or paranoid.

Small daily tasks are huge for our children.
We become totally isolated and lose our friends, unless we make contacts with other parents with children with SEND.

Coping with being heart broken, as my child is never invited to parties and other children stare and laugh at him.

Carrying sadness around all the time
Comparing my child to other mainstream children

Being more protective because they are so vulnerable.

What triggered the need for support? (Adult carers)

What changed to make Carers realise they needed support :

| | |
|--|----|
| Cared-for person's needs becoming greater | 36 |
| Carer mental health/inability to cope/exhaustion | 18 |
| Carer getting older | 6 |
| Own health needs/conditions (not mental health) | 5 |
| Cared-for person getting older | 4 |
| Needed more time for myself/other family members | 3 |
| Cared-for person needed more varied support | 2 |
| Lack of family support | 1 |
| Found out about available support | 1 |

The 'trigger' which received the highest number of responses in leading carers to request additional help and support, was the needs of their cared-for person becoming greater.

This was usually in relation to a worsening of the condition of the cared-for person and was typically linked with the caring role becoming more physically demanding, or with the carer being unable to leave their cared-for person unattended for any period of time.

The inability to cope, possibly through exhaustion and mental health, was another key trigger to seeking further assistance:

"Getting overwhelmed by quantity of care needed"

"There are times when I get to the point where I cannot cope"

"I felt like I was going to have a breakdown"

Needs

What extra help and support did you need?:

| | |
|---|----|
| Carer breaks within the home | 19 |
| Cared-for person activities/daycare | 15 |
| Residential respite | 12 |
| Talk to others who understand | 12 |
| Mental health support | 11 |
| Advice about support available | 10 |
| Personal care assistance | 10 |
| Advice about their cared-for person's condition/needs | 7 |
| Advice about financial help available and benefits | 6 |
| Help with the household: cleaning, gardening etc | 6 |
| More support in school for cared-for person | 3 |
| Mobility aids/emergency equipment e.g. pendants | 3 |
| Social care assistance | 3 |
| More flexibility with paid work | 2 |
| More money | 2 |

The top four sources of extra help and support needed once carers realised they needed support were to do with carer breaks (residential respite, daycare/activities for cared-for person and short carer breaks within the home), as well as talking to others who understood.

The impact of having a few hours to themselves was significant for some carers, who said they valued:

"A day to myself, or even an afternoon to myself, just something where I can take myself off and not have to worry about Mum..."

"Support workers who would take her out for a few hours and give me the break."

*"I just need to ensure I get time on my own."
"Personal care for my mum for mornings to enable me to get to work on time."*

'More free time/more me time' was also cited as the third most common response to the question 'what would make your life easier at home?', which is linked to short carer breaks.

Mental health support was next highest on the list, with a number of carers explaining how speaking to someone who 'understood what it's like' could make a difference to their mental wellbeing:

"Email and telephone support helping bring me forward from the brink of despair."

"To be able to talk to someone who understood the stressful situation I was under..."

"Adult conversation to know I wasn't the only one."

Opportunities for improvement

- Develop a holistic view of carers and their cared-for person.
- Develop a wellbeing plan to prevent crisis:
 - To link to Carer's Assessment
 - Include who to contact if additional support is needed
 - To be reviewed and updated with changes
 - Include carer and cared-for person needs
 - Include what life looks like when carers are well and when they are not well (to help them recognise when their wellbeing is deteriorating) and what makes them feel better.

(These plans need to be based on both individual and family circumstances and needs).

How to improve the quality of life for Carers (adult carers)

When asked what would make the biggest difference to quality of life, the following themes emerged:

- Carer breaks/residential respite
- Quality of external care provided
- Availability of support
- Information

- Greater awareness of their cared-for person's condition

55% of respondents to the Community JSNA Adult Carer survey felt that they would value help to understand their cared-for person's condition. Some carers felt that they were not sufficiently aware of specific conditions and that this could cause distress, and in some cases frustration, which complicated their caring role. It was suggested by a couple of carers that condition-specific advice and support from medical professionals would be useful, but that they would also welcome such advice from support organisations who have experience in dealing with that condition (e.g. Alzheimer's Society) and from condition-specific peer support carer groups.

- Recognition:

One issue which a number of carers felt about very strongly, was the issue of recognition for the role they undertake. It was raised on multiple occasions that the carer would find it easier to cope with their demanding caring role, if they were recognised for it, either by statutory agencies or by society at large. There was a tangible sense of frustration from some carers, who felt that their caring role was not appreciated as much as was warranted:

"I often feel that I don't have much understanding or appreciation of the role I must play in my cared-for person's life by services that we must deal with routinely e.g. hospitals, doctors, social services etc"

"Little support from the people supporting my daughter. I have felt I am an issue rather than being part of a team"

"If you take it all into consideration, I'm keeping someone from going into care or assisted living and I feel that I should be recognised sometimes. I don't think people realise, it would be nice to be acknowledged that you're doing it and doing a good job. I'm doing it because I want to and although I am struggling, the help I've had from Cheshire Carers has made all the difference to me."

What would make your life easier at home:

| | |
|---|----|
| Day care/carer breaks | 14 |
| Help around the house or garden (cleaner, gardener etc) | 11 |
| More free/me time | 9 |
| Respite care | 7 |
| Home modifications | 5 |
| Information | 5 |
| More money | 5 |
| Social services assistance | 4 |
| Less stress | 3 |
| Live in carer/24 hour care | 3 |
| Better links in an emergency | 2 |
| Better sleep | 2 |
| Help with transport | 2 |
| Less admin/easier system | 2 |
| More family support | 2 |
| Someone to talk to | 2 |
| Assistance to study/retrain | 1 |
| Proximity to cared-for person | 1 |

The most common response to 'what would currently make life easier at home' was similar to 'when carers realise they need support': the availability of day-care or short carer breaks.

Respondents made the following comments:

"More free time without guilt feeling."

"My cared-for person to agree to (a) use a wheelchair and (b) agree to attend day care centre activities to allow me to have time at home on my own."

"More day care and groups in my local area."

"Caring services trained to be able to attend to personal care as well as just companionship, as I have no-one to leave my cared-for person with on days he is not in care."

The second biggest expressed need for carers, is having help to maintain their homes and gardens and to keep on top of domestic chores.

5 respondents felt that they would welcome better or more information, particularly regarding what to do in an emergency.

The need for assistance from Social Services was raised by 4 respondents, and was mainly to do with the need for direct contact details for named social workers, and to improve consistency and access to social care professionals. [see Question 4: Current Services and Assets, p.10]

What support has been accessed by young carers?

Around half of the young carers spoken to at focus group sessions, felt that they did not know enough (or in some cases anything at all) about their cared-for person's health condition. Other issues raised included:

- Time to themselves
- Their own space at home
- Home modifications: "less steep stairs"
- "People taking my brother out for day trips"
- More help/hands
- Someone to talk to: "not being scared to talk to my friends/family", "a website to talk on"
- Calmer home environment: "no yelling", "no shouting"
- More family support/time with family
- Sleep: "I'd like to be able to have more sleep, with better sleep patterns, so I can get on better at home and school."

The 3 things would make life easier at school: themes

8 out of 15 young carers at one group said they had been bullied, but not all felt that this was because of their caring role. It was felt by some that at school they were often misunderstood by their peers, and this was a view that was also put forward by one of the service provider session leaders.

The main suggestions made were:

- Someone to talk to/go to at school: “time out if needed”, “quiet time if upset”
- Homework issues: “homework plan”, “no homework”, “less homework”, “teachers being a little more lenient on homework because I have bigger things on my mind”, “school work help”
- Teachers: “not shouting”, “all my teachers knowing what’s going on at home”, “teachers not forcing me to ask about things, just made aware that I can talk”, “more knowledge of situations”
- More support: “having more help”, “working with a 1 to 1”
- Peer relationships: “friends there”, “if the bully was gone”, “respect”, “my friends not asking questions”, “picking the right friends”

The caring role and protected characteristics:

There was very little evidence to suggest any additional needs or requirements due to protected characteristics of either the cared for person or the carer.

Only one carer mentioned the age of the cared-for person to be a factor in the type of support she needed e.g. she needed a parent-carer support group rather than a generic one.

Most comments were about age-related conditions of the cared-for person and about more help and support being needed as the cared-for person ages - as their needs increase - or the carer is also ageing and struggling to manage.

Cheshire Young Carers: Case study

Reason for referral:

Child 3 was referred into the service in November 2015 by a social worker. She supports her mother who suffers with Fibromyalgia; her mother struggles daily with musculoskeletal pain, fatigue and memory issues and has anxiety and depression. 3 was referred on the basis that she did not appear to have much drive and was becoming isolated from her friends. Last year she was dropped from her college course because of poor attendance. Consequently, this young person is currently NEET. She also struggles with severe depression and anxiety and often spends the entire day in her house.

Support given:

CYC invited this young carer on an Outward Bound residential trip to the Lake District. During the trip, 3 was also suffering with a bout of depression. She struggled to motivate herself to get up and out of bed to join in with the activities. The staff and volunteers on the trip were able to spend the time to encourage her to participate in almost every activity, showing her that she can achieve anything that she puts her mind to. In the middle of the week she was almost determined to leave and go home. During this time, 3 had been talking with her mother at home who had been saying how much she missed her and how hard it was not having her around.

When 3 was first referred, she didn't engage with the fortnightly group sessions because she was significantly more mature than the other members of her group and felt the games and activities were a bit too 'childish'. She had never really connected with any of the other members of the group because of the age gap. The first YAC (Young Adult Carer) activity that CYC invited her to was a day-long course on a narrowboat. Following this activity and the feedback from the young people, CYC launched Team YAC.

Outcome:

Taking the young person away from the home for an extended period of time is beneficial and an achievement in itself. In the end 3 really enjoyed the trip and got a lot out of it, including a new friendship group who she has met up with since. On the narrowboat trip, 3 met some of the young carers in the area that were her age. She told staff that 'it was great to be able to talk about real stuff', meaning that she appreciated the chance to have conversations about drugs, sex and relationships without worrying about the younger children being around.

Team YAC is aimed at encouraging young adult carers to be independent, to create new friendship groups, build confidence and provide them with 'once in a lifetime' opportunities. 3 attended the first drop-in session in Crewe this month and really engaged with the activity. Last year, 3 had been attacked in the street by a group of girls from her high school. Following this she rarely left the house alone. However, she managed to motivate herself to travel alone to this first session in the town centre and when asked how she found it she said it 'wasn't a big deal anymore'. This shows that something has changed in that she now has the confidence and courage to try something that had used to make her anxious.

This quarter CYC sent out invitations to Team YACs summer programme. CYC were incredibly pleased to see that 3 has signed up for all activities that she is able to attend. This is a huge achievement for her when compared to her almost total social isolation only 6 months ago.

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11 Hope Street
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 CVS Cheshire East  @cvsce

