

Cheshire East Community JSNA Carers' Project Report 2018

Question 5

How well are the needs of Carers being met?



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Question 5: How well are the needs of Carers being met?

Maintaining and developing relationships

The provision of carer breaks and respite helped to sustain other close relationships. One carer said:

"...gives me an opportunity to enjoy time with my partner, without it our relationship would disintegrate."

Another commented:

"I don't get time to spend with and develop a relationship with my grandchildren."

Concerns with practical issues

For a small number of carers, maintaining their households and gardens was of great concern. This issue was raised by at least six respondents who completed the survey.

For one respondent:

"[having support]..has helped to allow me some free time to look after my own home."

Another stated that the best support they had used was having a paid cleaner, that *"gives me one less thing to think about."*

Some service-providers are able to help carers to navigate a complex system by: helping carers to explore options; making referrals to services that best support their specific needs; and helping with administrative tasks like filling in forms.

Carers' feedback indicates that this service is of particular value to carers who are struggling to find the time and head-space to tackle these tasks alone:

"They've [Cheshire and Warrington Carers Trust] filled in forms for me, I didn't know which way to turn. I was thrilled when I found them. There's so many different numbers and literature and when you're in a tizz yourself,

having help was invaluable because I just went to pieces."

A number of female carers described having to take over the driving role due to their husbands' illness and were struggling with confidence issues. They were referred to the Cheshire Connect 'Driving Down Risk' safe driving workshop and were reported as coping much better.

Case Study: Cheshire and Warrington Carers Trust

Background information

CARER was very nervous on arrival and said that she nearly hadn't come as she didn't know anyone but wanted to find out if there was support out there for her, both practical and emotional.

The group facilitator spoke to CARER at length, introducing her to other carers who also helped by letting CARER know about other services available in the town. CARER was struggling with the enormity of her husband's diagnosis and said she felt completely lost and bereaved of the life they had. She was very open to talking to the group, many of whom could identify with her feelings. She swapped numbers with other group members, who arranged to meet up with her between groups. She was encouraged to look at other services, events and activities offered by CWCT and other local organisations. She engaged in a group outing in May and enjoyed making bracelets with the rest of the group and found it easy to open up in friendly company.

She commented that she was nervous about driving in a new area as her husband's diagnosis meant that he soon would be unable to drive. CWCT have now set up a skill donor arrangement via Cheshire Connect with Driving Down Risk, who have set up a driving safely workshop which CARER will be attending in September. She is now in touch with the dementia re-ablement team and Admiral Nurses at Leighton Hospital via a direct referral from CWCT.

Outcome

CARER has told us that she feels supported both emotionally and practically and is more connected to her community. She has now made friends in her town and tells us she now has people who she can talk to (be it friends or organisations) should she need further information or just a chat. She is looking forward to the Caring with Confidence course later this year and the driving workshop. When a new lady arrived at the group in June, CARER felt confident to welcome her to the group with the other carers and also passed on her own number offering the lady her support and friendship.

Mental health

A recurring theme in survey responses was around the positive impact on mental health of accessing support. In some cases, having a regular carer break was enough to relieve the pressure,

"Gives me a break and recharges my batteries. I have a life to live too."

Whereas a proportion of carers needed to access more specific and focused mental health support, such as counselling or other psychological therapies:

"Counselling helped me to come to terms with my cared-for person's condition in the early stages, and some techniques to deal with panic attacks, lack of confidence etc."

"Helped significantly with my mental health and taken some of the pressure off."

"It has taken away a lot of the stress."

Some carers have had the opportunity to access complementary therapies and, for one carer, being able to focus upon herself was highly valued:

"I was on a personal budget a few years ago and was given some money, but that's stopped now. You could use it for yourself. It was great,

a lovely feeling to think that people do care for me. That I'm important as well, really. I'd lost sight of that, because that's how it is really."

The majority of adult carers who completed the online survey, found the support they received to be of great value, and were very clear about the impact on their lives:

"So many good things - too many to say."

"Without the support I would be a very different person than I am today. It's nice knowing you are not alone and stuck in a complete rut."

"We would be in a dark place without it."

Some carers said that the support they received improved their understanding of the specific health condition of the person they care for, and enabled them to cope better.

Carers reported that peer-support groups offered many benefits to carers. Of those who attended peer-support groups, the following comments were made:

"It means that I don't feel alone and I know that there is always somebody there."

"...someone who listens to me and doesn't make me feel stupid for feeling how I do."

"Peer support is non-judgmental (they are more understanding as they have similar pressures) along with social contact."

Peer support can not only be of significant comfort to a carer, but also a source of information. Carers commented several times that they had discovered available support services through contact with peers, support that they would not have found out about otherwise:

"Finding out how other people manage the system. You find out how the system works from other people who have been through it."

The opportunity for respite

For some carers, residential respite can have an enormous impact on their own wellbeing:

"The impact of respite is massive. If I didn't have them I could just go crazy. Sometimes I just need to get out of the house. I couldn't have existed without those breaks, goodness knows how I'd managed if we couldn't have afforded it."

"I had a weekend away, it was marvellous, I came back feeling totally rejuvenated, not having to think about someone else's needs."

Young Carers:

The Community JSNA Project team attended two Cheshire Young Carer group sessions in Middlewich and Crewe and met 29 young carers at these sessions.

The young carers were all positive about the benefits of attending peer-support groups: time with peers who understand; a break from the caring environment; and the opportunity to take part in trips and activities.

"You can be yourself and talk to people who understand."

"There are lots of people you can socialise with, people in similar situations."

"It's a break from home. You can get away for a bit."

"I'd be overlooked for trips and things like that otherwise. I've done trampolining, the Christmas disco, a pantomime..."

"The activities are really good. The residentials are better, though, to switch off."

Young carers who had accessed support said it had a positive impact, and reported benefits that fall within the following themes:

Having time to yourself

One of the main benefits to young carers from accessing support has been the opportunity to have some free time away from their caring responsibilities:

"Gets me out of the house."

"Gives me time to play with friends."

"Takes my cared-for person out for a day trip so I don't have to always look after him."

Mental health

Several young carers commented that they felt that support helped them with their own mental health wellbeing:

"Help with confidence."

"Helps when I'm worried."

"Helps when I'm a tiny bit annoyed."

Having someone to talk to

Several of the young carers felt that using available support gave them someone to talk to. Whilst some could speak to their families about their caring roles, others valued having the space and support provided through peer-support groups - to be with other young people who understood their situation. Other young carers were enabled to develop new friendships and informal networks through facilitated peer-support.

Better information

Aside from developing new friendships and having the opportunity to have time away from their caring roles, some young carers also found that they learned more about being a carer from their support groups:

"It has helped me because I know how to look after people."

Cheshire Young Carers: Case Study: Child 2

Reason for referral:

Child 2 was referred to Cheshire Young Carers in summer of 2014 by a health visitor. She supports her mother who suffers with anxiety and panic attacks, meaning she rarely leaves the house. She recently disclosed that although her mother's new boyfriend is living in the family home, that he has recently lost his job and spends most of his time in bed. School mentioned that in the past the children have been 'put off' participating in activities (for example The Duke of Edinburgh Award) by their mother. She also prevents them from playing out in the street because of her own anxieties about being outside, advising them that it is 'too dangerous'. This results in 2 having next to nothing to do in her spare time. When asked what she does after school she replied 'I just watch TV until I go to bed'.

Support given:

2 attends the regular respite sessions run by CYC. The Link Worker arranged a 1-1 session with 2 in school to give her the opportunity to speak more freely as the group sessions are not very private.

Through conversation with the pastoral lead at the school, it was discovered that 2 and her brother had very low attendance and a large number of unauthorised absences. The school had been attempting to contact the mother to discover why the children were missing from school and see what they could do to support. They stated that they are never able to get through to the parent and that she never attends meetings/parent's evenings at the school. It was clear at this point that either they were not aware of or don't understand the mother's diagnosis of social anxiety. This means that meeting with or even speaking over the phone with strangers is incredibly stressful for her.

Outcome:

The Link Worker was able to explain why the parent was not engaging with the school and

that the children often stayed home to support their mother when she was feeling particularly low. The Link Worker's plan going forward, is to build a trusting relationship with the parent. This in turn will facilitate communication between herself and the school.

The Link Worker met with 2 in school and completed a wishes & feelings document. Through this, the Link Worker discovered that her older brother (who also attends the regular respite groups with CYC) spends the majority of his time playing video games in his room, not socialising with anybody. The Link Worker made sure that he was invited to all the upcoming activities that he was applicable for. The Link Worker will continue to make sure that both young people continue to attend the activities they are invited to, as these young carers are at risk of extreme social isolation.

Unmet Needs: What we could do better - themes from focus groups and 1-2-1 interviews with adult carers

Themes and concerns emerged from twenty 1-2-1 interviews with carers, and various focus groups, and are detailed below:

Lack of recognition:

Several carers felt very strongly that they had little or no recognition for their caring roles:

"There's no recognition really, for the role we play as carers."

"If you take it all into consideration, I'm keeping someone from going into care or assisted living and I feel that 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."

This sentiment was expressed at several focus groups, with a number of respondents feeling strongly that some sort of acknowledgement would be very much appreciated.

Carers who are self-funding

It was raised by one support group that they felt that self-funding carers are offered minimal support particularly from statutory services. Approximately half of the 11 support group attendees felt that self-funding carers can be overlooked and “left to their own devices”, with one commenting:

“People who are self-funding are the forgotten silent majority.”

Opportunities for improvement:

- There is a need to raise awareness of services that can provide practical help and advice.
- The Carers Hub to consider how to identify carers of self-funders.
- Encouraging referrals from GPs.

Planning for the future

The majority of carers had not thought about or planned for their futures. This could be because the end of their caring role can often be linked to the death of the person they care for, which is very difficult for many to contemplate. A number of carers felt that they could only see their caring role ending with their own death, or the death of their cared-for person:

“I don’t think it ever will [stop].”

“I can’t see it stopping.”

“I can never die! I don’t know how he will develop, he can’t be left alone so I can’t go out. I don’t know what would happen.”

Others stated that they were too busy dealing with their day to day caring role to plan ahead:

“To be honest, I haven’t thought about it too much. When it happens we’ll worry about it, which possibly isn’t the best thing.”

A small number answered honestly that the issue was something that was causing them great concern:

“I constantly think about it...I’m mindful of all that, but things are getting more and more difficult. She won’t sleep at night, so I can’t sleep. Sleep deprivation is terrible. I know at some point there will come a point where I’ll have to stop. It’s the impact on my health.”

“I’m having counselling to deal with this prospect.”

“She’s deteriorating. She won’t go into a home, and I wouldn’t put her in one. I’ve looked into 24/7 home care but we just can’t afford it. I’m stuck with it for the moment, unless she just goes. That’s where I am now. I’m not sure what I’d do then.”

“At the moment we’re managing, but we won’t be in the long term. I’m getting older and I have my own health issues.”

At least two carers were concerned about the changes to their way of life when the person they care for is no longer with them:

“I worry about what’s going to happen. When somebody dies, their whole way of life goes too. There are also practical things: mobility cars taken away and all sorts.”

“If we went into care, that would really hit me. We help and support each other. It will be much more isolating when he goes as all the activities we do together will go with him.”

Two respondents who were working carers were hopeful that they would be able to develop their working careers at some point:

“I’m trying to get my cared-for person to be a bit more independent. I could do a full day of work if I didn’t have to drop her off and pick her up from day care. I could get work and be paid, which would be nice. You can’t do anything without money.”

"I changed job as it was really stressful... So I'm not in the job I want to be in, but it suits me for now."

It is evident that there is a need to raise awareness of support available for carers looking to return to work, and to refer them to the service commissioned by Cheshire East Council to provide careers advice and improve employment opportunities for both young and adult carers.

Aspirations

A common response by a majority of carers was summed up by a repeated phrase, *"I feel my life has been put on hold"*. Other comments included:

"I'm not at home at the moment as I'm living with my mum, so I can't do anything."

"No, there's nothing. My whole life is on hold."

One respondent had gone as far as saying that there was *"no time to have goals."*

One carer had even contemplated whether the impact of her caring role was that she had not been able to have her own family:

"Life is put on hold. I don't have my own children. Is that because of my caring role? I don't know. I would have a better job."

When asked whether they had any plans or aspirations for themselves in the future, only one respondent answered positively, saying that she had booked a 'once in a lifetime holiday' which was keeping her going.

The remainder hadn't thought about their own futures in any detail, or had negative feelings and worries:

"No. The brakes have been put on that. I want to keep mentally and physically active, but... I have shut down in the last 6 months. I would love to go abroad. But I suppose I should be grateful for my health."

"It's not good. I try to have a positive outlook, you try to have a smile for people. Friends don't want to be hearing what it's like. It looks black for the future [crying]."

"I've had a bad year... I used to be a bubbly person, always laughing... but now I've been doing a lot of crying and I'm seeing a Counsellor."

Whilst some carers' mental health and wellbeing was clearly affected by negative thoughts about their futures, others had adopted a pragmatic outlook:

"If I'm honest, I think I'm already there, this is my life. I just want to be well enough to carry on doing it."

Unmet needs of Young Carers: What we could do better – themes from focus groups with 29 young carers

Identification/Recognition opportunities for improvement:

There is a need for improvement in identifying young carers, by schools (Cheshire Young Carers has a new schools engagement project) and through GP appointments and hospital visits.

Planning for the future:

There was a distinct lack of planning for the future among the young carers in the 2 focus groups. Some said their future would be based around their caring role. It was apparent that there was a lack of opportunity to explore options.

Aspirations:

There was again a lack of response, with a perceived or real lack of opportunity to focus on possibilities for the future and the constraints of the caring role.

Life at school opportunities for improvement:

- Raise awareness amongst all teaching staff of young carers in their class, and about the potential impact of the caring role on school life and aspirations.
- Work with schools to improve the identification of young carers and provision of appropriate support during the school day.

What we don't know but would like to know:

- The views and experiences of carers from minority communities.
- The views and experiences of young carers at the Macclesfield Young Carers' support group.
- More data from providers on outcomes, how well carer needs are being met and barriers to meeting needs.

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