Key messages

Through the Adult Social Care Survey, the Community JSNA and engagement activities to shape new carer services carers have told us that previous service delivery arrangements were confusing, they often had to contact numerous organisations, repeating their story before accessing the help and support that they need, which could lead to them feeling overwhelmed and contribute to their exhaustion. The carers hub has therefore been commissioned to improve early identification of carers (including carers of people who pay for their own care), enable effective signposting to the right support, increase numbers of carers receiving a Carers Assessment and accessing the support they need, when they need it.

Further work is needed to develop links between the carer’s hub, schools, colleges, health professionals and other VCFS organisations to ensure that carers’ experiences of service delivery and their outcomes improve. Support is also needed to help carers develop their knowledge and understanding of the health conditions of the person they care for.

A new respite offer is being commissioned from December 2018 to provide bed-based respite (including support for people with disabilities, challenging behaviour, mental health and nursing needs) and community based support to enable carers to take a break from caring.

Cheshire East Council also has umbrella membership to Carers UK Employers for Carers (EfC) scheme, which offers support and guidance to carers who are in employment or wanting to get back into employment. The umbrella membership can also be rolled out by Cheshire East Council to small and medium-sized businesses (SMEs) within Cheshire East, including providers in the voluntary sector. Work is currently underway to promote this scheme and to get a better understanding of the number of working carers employed by Cheshire East Council.

We need to understand what happens to young people’s caring responsibilities as they become adults. Another important factor we need to consider for future need, is the potential increase in carer numbers, due the ageing population of Cheshire East.
There are many definitions of what a ‘carer’ is. A carer is generally described as a person of any age providing unpaid care to an ill, frail or disabled family member, friend or partner. This may include physical or emotional support, advice and advocacy. The 2014 Care Act defines a carer as: ‘someone who helps another person, usually a relative or friend, in their day-to-day life’. Carers Trust describes a carer as; “anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support”. Often carers care for more than one person and there may be family situations where, for example, a couple mutually care for each other and there is no main carer.

The Care Act 2014 came into force in April 2015 and sets out the legal rights to assessment and support carers now have. The Care Act relates mostly to adult carers – people aged 18 and over who are caring for another adult. Young carers (aged under 18) and parent carers have the right to be assessed and supported under the Children’s and Families Act.

The provision of unpaid care in England and Wales is becoming more common due to an ageing population and there is an expectation that the demand for carers will more than double over the next thirty years.

Key facts about carers in the UK:
- There are around seven million carers of all ages – that is one in ten people. This is rising.
- Three in five people will be carers at some point in their lives.
- The economic value of the contribution made by carers is £132bn a year.
- By 2030, the number of carers will increase by 3.4 million (around 60%).

Young carers across the UK:
- Following a survey in 2010, the BBC estimated that there are 700,000 Young Carers.
- Only half of young carers have a particular person in school who recognises that they are a carer and helps them.
- Young carers responding to a survey missed or cut short many school days every year. The average was 48 school days missed or cut short because of their caring role.
- Many services are only funded to work with young carers up to the age of 18. In a survey, 79% of young carers said they were worried about moving on as they felt there was no support for them.

Data Source: Carers Trust

Estimated Total Number of Carers in Cheshire East

The 2011 Census results state that there were around 40,000 people in Cheshire East providing unpaid care. It is, however, likely that Census figures are underestimating the number of young carers. The figure for those providing unpaid care in Cheshire East, therefore, is estimated to be around 5,200 carers.

There is estimated to be around 5,200 carers currently supported in Cheshire East. Of this figure, about 450 are Young Carers.

Estimated Total Number of Carers in Cheshire East Who Need Support

It is estimated that there are around 8,300 carers that need support to help them cope in their caring role. This is estimated to be made up of 2,350 young carers (aged 0-17) and 5,900 adult carers (caring for adults or young people).

There is a further approximate 6,000 who are known to adult social care. An unknown proportion of these may need some form of support. These are all adult carers.

This leaves a further estimated 27,200 adult carers who are not known to the health, social care, and voluntary and community sectors. An unknown proportion of these may need some form of support.

Estimated Number of Carers Who Need Support but Not Currently Supported in Cheshire East

By comparing the number who are highly likely to need support with the number currently supported, it is possible to come up with the likely minimum number of carers who need support but are not being supported.

Using this calculation there are likely to be at least 3,000 carers who need support but are currently not being supported. Of this figure, the majority are young carers – about 1,900; the remaining 1,100 are adult carers.
Where do they live?

The table below shows that there are similar proportions of population providing unpaid care in each of the GP Clusters. However, there are some areas with slightly higher proportion of carers than the Cheshire East average: Bollington, Disley and Poynton (12.1%), Sandbach, Middlewich, Alsager, Scholar Green, and Haslington (SMASH) (11.6%) and Nantwich GP Cluster (11.0%). Although the Crewe GP Cluster has a slightly lower proportion at 10.0%, it does have a slightly higher proportion that are providing 50 hours or more unpaid care per week.

Although the distribution of carers in terms of rate or proportion of total population as illustrated in the table and map is interesting, it is also important to consider the distribution of carers across the borough in terms of actual numbers and the proportion of Cheshire East carers this represents. In terms of numbers, Crewe and SMASH GP Clusters in the south and Macclesfield in Eastern Cheshire CCG have the largest numbers of self reporting carers.

Future need

If we consider population changes only, this estimates that by 2030 there will be over 44,000 unpaid carers in Cheshire East; this represents a 10% increase.

If we also consider the expected increases in the numbers of people with ill-health or a physical disability that may impair their independence and mean that they are dependent on a carer to support their everyday living. This increases the estimate of carers to over 59,000 in Cheshire East.

Our findings suggest that nearly 20% of carers need support, this means that by 2030 over 11,700 carers will need some support to continue in their caring role. Again this does not consider that there is likely to be increased numbers of carers with health problems of their own.
Total number of carers in Cheshire East

Gender
Using the 2011 Census breakdown for the estimated total number of carers in Cheshire East, there are approximately 24,000 female carers (58%) and 17,500 male carers (42%).

Age
There are estimated to be around 1,600 carers aged under 16; and nearly 10,000 carers aged 65 and over. The 50-64 age band has the largest proportion that provide unpaid care (21%).

<table>
<thead>
<tr>
<th>Age group</th>
<th>Number of carers</th>
<th>Percentage of carers</th>
<th>Population</th>
<th>Percentage of age band population that are carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 to 15</td>
<td>1,573</td>
<td>4%</td>
<td>65,753</td>
<td>2%</td>
</tr>
<tr>
<td>16 to 24</td>
<td>1,962</td>
<td>5%</td>
<td>36,262</td>
<td>5%</td>
</tr>
<tr>
<td>25 to 34</td>
<td>2,282</td>
<td>6%</td>
<td>38,552</td>
<td>6%</td>
</tr>
<tr>
<td>35 to 49</td>
<td>9,681</td>
<td>23%</td>
<td>82,346</td>
<td>12%</td>
</tr>
<tr>
<td>50 to 64</td>
<td>16,120</td>
<td>39%</td>
<td>75,842</td>
<td>21%</td>
</tr>
<tr>
<td>65 and over</td>
<td>9,810</td>
<td>24%</td>
<td>71,372</td>
<td>14%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>41,428</strong></td>
<td></td>
<td><strong>370,127</strong></td>
<td><strong>11%</strong></td>
</tr>
</tbody>
</table>

Percentages may not add up to 100% due to rounding

Data source: 2011 Census. Age Groups 0-15 and 16-24 are modelled to reflect the findings of Hidden from view The Children’s Society May 2013 report

Carers currently supported in Cheshire East

Gender
The gender split is even more pronounced when we look at the Carers currently supported (Females 68%, Males 32%). However, due to the high number where gender is not known (46% of records), it is difficult to make any assumptions or establish the gender split of the gap.

Age
No age information was available on data from the voluntary and community sector. This accounts for 44% of carers currently supported. However, if we assume that the age breakdown of those carers accessing support where age is not known is the same as where age is known we can look at the potential age distribution and consider the age breakdown of those currently not accessing any support.

Carers in Cheshire East who need support

Age
Although the 50-64 age group were the largest grouping for all carers, they are not the largest group that need support; the 65 and over age group is the largest group and account for around a third of all those that need support. The 50-64 age group is still a significant proportion of those that need support, as are the 0-15 age group.

The 50-64 age group account for the largest percentage of unpaid carers (39%). This group, however, also has a lower proportion providing the highest hours of care and a high proportion providing under 20 hours of care per week. The 65 and over age group has the highest proportion amongst all the age groups that are providing the highest hours of unpaid care (50 or more hours per week). There is insufficient data on hours of care provided by young carers to give a breakdown for this age group.

The higher percentage of carers providing care of 50 hours or more per week in the Crewe GP cluster area.

The higher percentage of carers providing care of 20 hours or more per week have a higher likelihood of being in bad or very bad health.

Hours of care per week

See Community JSNA for further detail & assumptions
Carers who need support but not currently supported in Cheshire East

### Carers in Cheshire East who need support

<table>
<thead>
<tr>
<th>Age</th>
<th>Number of Carers</th>
<th>% Supported*</th>
<th>Gap</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 to 15</td>
<td>1,571</td>
<td>75.7%</td>
<td>1,189</td>
</tr>
<tr>
<td>16 to 24</td>
<td>852</td>
<td>91.3%</td>
<td>778</td>
</tr>
<tr>
<td>25 to 34</td>
<td>292</td>
<td>69.9%</td>
<td>204</td>
</tr>
<tr>
<td>35 to 49</td>
<td>955</td>
<td>40.2%</td>
<td>384</td>
</tr>
<tr>
<td>50 to 64</td>
<td>1,932</td>
<td>12.5%</td>
<td>241</td>
</tr>
<tr>
<td>65 and over</td>
<td>2,695</td>
<td>11%</td>
<td>296</td>
</tr>
</tbody>
</table>

* Estimated age breakdown

Data source - Carers needing support: GP carer registers; Eastern Cheshire CCG Jan 18, South Cheshire CCG Mar 18. Age Groups 0-15 and 16-24 are modelled estimates to include all young carers based on the findings of Hidden from view The Children’s Society May 2013 report.

### Age

A large proportion of the gap between those who need support and those currently supported is in the younger age groups, particularly the 0-15 and 16-24 age bands, where currently there appears to be a very low percentage currently being supported. Although the 25-34 and 35-49 age groups account for a smaller proportion of those that need support they do also have a significant gap as a percentage of their total.

Also, there appears to be a drop in the numbers of carers needing support in the 25-34 age group compared with the younger age groups. The ratio suggests that for every 5 young carers only 1 carer appears to continue to need support with a caring role in their twenties and thirties. **We need to gain a greater understanding of what is happping at this transition stage from young carer to adult.**

### What we don’t know but would like to know...

- For all carers: their age, gender, ethnicity, needs, how well these needs are being met and how many people each carer is caring for recorded in a way that can be easily analysed
- The age, health conditions and needs of each person they care for
- How well cared-for person’s needs are being met/barriers/opportunities for improvement
- More information about how the needs and experiences of carers with protected characteristics may differ
- Number of parent carers vs number of adult carers caring for adults plus those with overlapping responsibilities
- An understanding of the transition from young carer to adult.

### Opportunities for improvement / future developments...

- Carers are not a homogenous group: they have different hours of caring, caring roles, ethnicity, age, caring for people with different conditions, employment status etc. One size will not fit all
- Different approaches required to meet the needs of those that need support that are currently not accessing it e.g. large proportion of younger carers not accessing support
- Understand any barriers to accessing support experienced by carers from protected characteristics groups.
- Streamline data recording across the hub, GP carer registers and social care case management systems to more easily analyse how many carers need support and how many are accessing support (e.g. carer’s hub to record whether the carer has informed their GP that they are a carer or contacted social care as a carer and to develop a process for keeping these records up-to-date).
- Ask carers who else in the family has a carer role and whether they need support.
The impact of the caring role on Young Carers

Impact on health and quality of life of young carers – Results of the survey included:

- 61% of young carers surveyed felt that they could spend their time as they wished.
- Nearly 40% felt that they couldn't spend enough time doing the things that are important to them.
- 11 respondents (35%) felt that they struggled with school work because of their caring role.
- Nearly ¾ (74%) of respondents felt they could take part in after school clubs or activities if they wanted to.
- Nearly half (48%) of respondents felt that they had some control over their daily lives but not enough.
- 71% felt they looked after themselves, but 29% felt they couldn’t look after themselves well enough at least some of the time.
- 52% would like to be able to spend more time with friends and family.
- 48% of respondents found it hard to be part of friendship groups because of caring, at least sometimes.
- 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.

Community JSNA

The top 4 impacts on young carers’ health were: feeling tired; short-tempered & irritable; general feeling of stress and disturbed sleep.

Carers UK statistics state that 46% of young carers are getting up in the night to care for family members, missing out on their own sleep.

Impact of support

There is anecdotal evidence of the positive impact that support has had but there is a need to improve on the collection and analysis of impact; how well are carers needs are being met and outcomes achieved.

Opportunities for improvement / future developments...

- Measure the type of care young carers are providing (possibly by using the MACA analysis tool) and young carer quality of life and track these over time
- Tracking changes in quality of life for young carers over time.

Meeting the needs of Young Carers

The positives of caring

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

- “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.”

Developing friendships and sharing 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.

Mental health

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

Young carers who had accessed support said it had a positive impact, and reported benefits:

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.

Carers JSNA (page 6 of 20)
The impact of the caring role on adult Carers

Carers were asked, *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 Survey of Carers of Adults in Cheshire East 2016/17 report were: **feeling tired, disturbed sleep, general feeling of stress and feeling depressed.**

**Relationships**
Some carers told us that they have less time to develop and maintain relationships with others, due to their caring role. But they spoke about the positive impacts too, such as them learning new skills, the cared for receiving high quality care and maintaining their independence.

*“It can be very rewarding.”*

**Benefits, pensions and wider financial difficulties**
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. This situation drastically reduces the number of work opportunities available and can make finding a suitable working role unfeasible. The issue of Carers Allowance stopping when someone draws their pension was also raised.

**Over two-fifths of respondents to the Adult Social Care Survey (43%) said that they were not looking after themselves well enough.**

**Planning for the future**
The majority of carers had not thought about or planned for their futures or had regular feelings of worry. 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. Others stated that they were too busy dealing with their day to day caring role to plan ahead and a small number answered that the issue was something that was causing them great concern.

**Parent Carers**
Parent carers defined themselves by the impact of the caring role. They can often feel guilty and judged and are constantly on guard.

**Aspirations**
When carers were asked about their 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.*” Community JSNA

**Lack of flexibility and understanding at work**
An issue with which many working carers struggled with, was the lack of flexibility at work to enable them to fulfil their caring role. **39% of carers** said they were unable to balance these roles. Even with a supportive manager and a flexible work environment, carers often struggled with combining both roles and commented that it became so stressful for them that they left work and became self-employed.

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 carers role can become progressively more demanding as time goes on, several carers found that their capacity to work reduced as their caring role increased.

Caring and the financial impact
**71% of carers responding to the Adult Social Care Survey felt that their caring role has caused money worries or problems, with 21% of those saying it caused them ‘a lot of worries’.”**

**Returning to paid 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. In some cases, this need for support was due to the carers 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.

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Concerns with practical issues
For a small number of carers, maintaining their home and garden was a major concern.

For one respondent: “[having support]..has helped to allow me some free time to look after my own home.”

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

Community JSNA

Mental health
A recurring theme in Community JSNA 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: “Helped significantly with my mental health and taken some of the pressure off.” and “It has taken away a lot of the stress.”

Impact of support
There is anecdotal evidence of the positive impact that support has had but there is a need to improve on the collection and analysis of impact; how well are carers needs are being met and outcomes achieved.

How to improve the quality of life for 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.

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.

”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:

- The stress makes us more susceptible to health problems which impacts on all our children and our partners.
- 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.
- It is normal for us to not be able to get enough sleep or a toilet break at times.
- 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
- Small daily tasks are huge for our children.
- Carrying sadness around all the time
- Being more protective because they are so vulnerable.
- Have to be hypervigilant
- Comparing my child to other mainstream children

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Mental health
A recurring theme in Community JSNA 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: “Helped significantly with my mental health and taken some of the pressure off.” and “It has taken away a lot of the stress.”

Impact of support
There is anecdotal evidence of the positive impact that support has had but there is a need to improve on the collection and analysis of impact; how well are carers needs are being met and outcomes achieved.

How to improve the quality of life for 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.

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.
The Community JSNA asked Carers; “What would make your life easier at home?”

<table>
<thead>
<tr>
<th>What would make life easier at home for young carers?</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day care/carer breaks</td>
<td>14</td>
</tr>
<tr>
<td>Help around the house or garden (cleaner, gardener etc)</td>
<td>11</td>
</tr>
<tr>
<td>More free/me time</td>
<td>9</td>
</tr>
<tr>
<td>Respite care</td>
<td>7</td>
</tr>
<tr>
<td>Home modifications</td>
<td>5</td>
</tr>
<tr>
<td>Information</td>
<td>5</td>
</tr>
<tr>
<td>More money</td>
<td>5</td>
</tr>
<tr>
<td>Social services assistance</td>
<td>4</td>
</tr>
<tr>
<td>Less stress</td>
<td>3</td>
</tr>
<tr>
<td>Live in carer/24 hour care</td>
<td>3</td>
</tr>
<tr>
<td>Better links in an emergency</td>
<td>2</td>
</tr>
<tr>
<td>Better sleep</td>
<td>2</td>
</tr>
<tr>
<td>Help with transport</td>
<td>2</td>
</tr>
<tr>
<td>Less admin/easier system</td>
<td>2</td>
</tr>
<tr>
<td>More family support</td>
<td>2</td>
</tr>
<tr>
<td>Someone to talk to</td>
<td>2</td>
</tr>
<tr>
<td>Assistance to study/retrain</td>
<td>1</td>
</tr>
<tr>
<td>Proximity to cared-for person</td>
<td>1</td>
</tr>
</tbody>
</table>

What changed to make carers realise they needed support?

| Carers need support to help them understand the condition of the person they cared for. From focus groups held at specific condition peer support groups, attendees said that they particularly valued the opportunity to share experiences and information with other people who understood the needs of the person they care for. Community JSNA

Carers need support to help them understand the condition of the person they cared for. From focus groups held at specific condition peer support groups, attendees said that they particularly valued the opportunity to share experiences and information with other people who understood the needs of the person they care for.

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. Community JSNA
How young carers access support

Young carers were asked how they found out about young carer support. The main signposts to young carer services were:

- Schools and teachers
- Friends already attending
- Social workers

66% of 29 young carers who responded to the survey, said that they had accessed ‘help or support for their caring role’. Community JSNA

School

The vast majority of young carers felt that it would be helpful for their schools and teachers to be aware of their caring roles. They felt strongly they would not want to be questioned about their situation, they just wanted teachers to be aware: "It would be good to have people to speak to if you need to."

A number of young carers felt that they needed more support at school because of their caring roles at home, with some struggling with homework and tiredness: "I can’t do the homework. It’s difficult as a young carer because you’ve got someone to look after. School could be more supportive. I’ve been given detention because of my caring responsibilities." At least two of the young carers would value a designated space at school to have respite and be able to catch up with work.

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. Community JSNA

Residential Respite - Young carers

When asked about residential respite, none of the 29 young carers were aware of this support provision. Young carers said they would find it really helpful to have longer trips away from home, so they could switch off and have a proper break from their caring duties. More group/peer support sessions during the daytime at weekends. The main benefit would be to go to the shops or go for a coffee, which they would not be able to do during the usual week night group sessions.

More age relevant activities would be welcome at group support sessions. More indoor resources at the support group sessions, e.g. new art equipment for craft sessions, a table tennis table, and a facility whereby they could safely leave their own equipment at the venues. Community JSNA

Young carers said it would be helpful to have some clubs at lunchtimes for those who had to go home at the end of the school day.

Limited awareness of crisis support

When asked as part of the Community JSNA, only 54% of 31 young carers were aware that there is support enabling them to take a break at short notice or in an emergency. 67% of the young carers were unaware of the Alert Card for Emergencies. Of those who have had a crisis, the vast majority would call 999 for an ambulance or for the police. A small minority would rely upon family and friends.

Young carers in the UK:

- The caring role can affect a young person’s health, social life and self-confidence.
- Many young carers struggle to juggle their education and caring which can cause pressure and stress.
- In a survey, 39% said that nobody in their school was aware of their caring role.
- 26% have been bullied at school because of their caring role.
- 1 in 20 miss school because of their caring role.

Statistics from: https://carers.org/about-us/about-young-carers

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Young carers experiences of doctors and hospitals

The young carers at the two support groups did not have much to say about their experiences of doctors and hospitals, aside from a number of young carers who felt that they had not been asked about their caring role by medical professionals or offered support e.g. at doctor appointments with their cared-for person or at hospital. They were more forthcoming about support from social workers and schools.

Regarding social workers, the young carers who referred to them commented that they were provided with support from their social worker (or 'link worker') and that they could talk to them if they needed to talk about issues. Community JSNA

Young Carers - What could we do better and where are there gaps in services?

Transition

The main issue raised by service-providers about the needs of young carers was their transition at age 18 from being young carers to adult carers. There were reports by some service-providers that young carers could be left "high and dry" during the transition process. It was felt that the preparation of young carers to go through the transition should start well before the age of 18, to enable the young person to be as prepared and supported as possible. It was also recognised that young carers may need additional support when their caring role comes to an end, for example due to bereavement. Community JSNA

27% of 30 young carers said that they did not know where to go if they needed help.

Carers JSNA (page 10 of 20)
Too much and inconsistent information

Cheshire East Council’s November 2016 Survey of Carers of Adults in Cheshire East 2016/17 Report (which surveyed adult carers who had a social care assessment or accessed commissioned support in the previous 12 months) found that 24% of the respondents had found it fairly difficult to find information, with 11% finding it very difficult to find information (see below).

![Pie chart showing difficulty in finding information](chart1.png)

**Difficulties securing support for the cared-for person, for example support at night.**

Difficulties sourcing carers and/or professionals with detailed knowledge of the cared for person’s condition. A large number of adult respondents commented that they would particularly value support that was more tailored to specific conditions. More generally, 55% of the adult survey respondents said that they would welcome support to help them understand the condition of the person they cared for.

From focus groups held at specific condition peer support groups, attendees said that they particularly valued the opportunity to share experiences and information with other people who understood the needs of the person they care for.

**Opportunities for improvement / future developments**

- Provide feedback to carers and engagement participants to show how their input has been valued and listened to prior to any decisions being made, even if difficult decisions still have to be made.
- Ensure co-production around Equality Impact Assessments and encourage a consistent approach.
- Carers want to be signposted to specific organisations that will suit their individual needs, rather than a list of providers to work through.
- Option to speak to someone face-to-face - several carers stressed that not everyone is online, and that some people will always value having a person to speak to.
- Carers want information to be consistent e.g. a checklist of options and support provided to all carers, whichever pathway they have taken.
- Stronger partnership-working between support organisations.
- Provide tailored support for the specific needs of the carer and help carers to plan for the future. Develop a wellbeing plan, linked to the carer’s assessment, to help prevent crises. The plan should include the carer and cared-for person’s needs, who to contact if additional support is needed and 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.

**Co-production/consultation and carers**

From the Survey of Carers of Adults in Cheshire East 2016/17 Report 6.8% of the 279 respondents felt that they were never involved or consulted, and 71.3% saying that always or usually felt involved or consulted in discussions about support or services for the person they care for.

"Stop ‘consulting and engaging’ and start genuine co-production. Have conversations about how people can get a life that’s worth living. Give us free choice of what will work for us.”

**Figure 38: Carer involvement in discussion about the support or services provided to the person they care for**

```
<table>
<thead>
<tr>
<th>Carer Survey 2016/17: &quot;In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of responses = 279</td>
</tr>
<tr>
<td>I never felt involved or consulted</td>
</tr>
<tr>
<td>Sometimes felt involved or consulted</td>
</tr>
<tr>
<td>Usually felt involved or consulted</td>
</tr>
<tr>
<td>I always felt involved or consulted</td>
</tr>
</tbody>
</table>
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June 2018
Mental Health and Emotional Support
A number of adult carers felt that there was not enough mental health support and that carers have to be at breaking point before being offered mental health support: “It’s not geared for mental health, you have no help from social services unless you have a crisis.” Cheshire East Parent Carer Forum Members’ Survey (2017) also found that being a carer could impact upon the parent carers’ mental health. As well as the physical and mental strain of being a carer, it was reported that this can be made worse by the “constant battling for support” for the person they care for.

Limited awareness of crisis support
A number use the Alert Card for Emergencies (ACE) which gives some carers peace of mind – but only 42% of respondents were aware of the ACE scheme. Out of 20 carers interviewed, a few of the people they care for had a pendant alarm system, and two had contact details for relevant crisis teams. 73% of adult respondents were unaware of the short notice/emergency break support available, and the majority of carers had no crisis plans in place, and would use 999 in an emergency.

Opportunities for improvement / future developments...
- Raise awareness of the alert card and what support is available in an emergency. Raise awareness of short notice/emergency break support available and of the crisis support scheme.
- GP practices and pharmacies to provide more information, advice and guidance regarding online appointment booking and the ordering, collection and delivery of prescriptions.
- Provision of post-diagnosis support for carers quickly and not having to wait weeks for information, taking into account the presence of young carers.
- Provide home visits when the cared-for person is unable to go out, for either the cared-for person or the carer.
- Offer flexible appointments to those who are limited by when they can leave the house (e.g. provide home visits when the cared-for person is unable to go out, for either the cared-for person or the carer.
- Development of a clear offer for carers that is promoted to the public and professionals and encourage GPs to refer to the Carers Hub.
- Continue to identify whether patients and their family or friends have a caring role and whether the carers may need support. Understand any current barriers to doing this and identify ways of overcoming them.
- Instructing health professionals to consider if the cared-for person will need help taking medication, and how this could best be provided.
Experience of social care

Social Care input was mainly valued by the carers, however, a common response was that social workers could be hard to contact, that carers had to deal with too many different social workers, and that support could take some time to arrange.

From the Survey of carers of Adults in Cheshire East 2016/17, Support from social work staff and good social work practice was listed both in the top 5 of services and support most valued by carers, as well as the top 5 areas of support that could be improved:

"Social services promised to send information out but never did. I had to do my own internet research."

"Had a number of social workers and each one had to visit and ask the same questions which was quite disruptive for a person with dementia."

A number of carers were also concerned about ‘getting things wrong’ and ‘using the correct terminology’ to clearly convey their situation when filling in documentation and responding to social care workers.

Inconsistent experiences of Carer Assessments

There was a wide disparity between carers who were aware of Carer Assessments, and those who were not. There did not appear to be any consistent approach, and carers had found out about the assessments through different pathways. "I had to get a Carer’s Assessment before I could receive a service. The assessment was only provided when I asked for it, not as a matter of process."

Of those who had had a Carer Assessment, a number felt that it had not helped them at all and they felt there was little point in having one. However, some felt that the assessment had been an important gateway to accessing other services. More than one carer had reported a significant wait between requesting an assessment and receiving one (more than one had been waiting for up to 2 years). However, others reported a quick turnaround time, which highlights again inconsistent experiences between carers.

Difficulties taking a break during the day or evening

From the Survey of Carers of Adults in Cheshire East 2016/17, provision of breaks for the carer and 'help to have a life outside of caring' were in the top 5 of services and support that carers most valued. A number of carers who responded to the Community JSNA adult survey, paid for private carer breaks during the week to enable them to have some time to themselves and to leave the house. Some carers reported that they had difficulty in persuading the person they cared for to accept 'strangers' coming into their home to allow them to have a break. Another carer whose cared-for person had complex needs was told that they did not have sufficiently skilled staff available to provide for their carer breaks.

A number of carers use day-care provision to enable them to have a break or to go to work. These are often highly valued services that the person they care for enjoys and which have a positive impact on the carers wellbeing. Carers who attended some support groups were more aware of telecare and assistive technology whereas a proportion of those taking part in phone interviews who were not accessing any additional support, were not aware of this help available.
What could we do better and where are there gaps in services? Continued:

Adult Carers - Residential respite

The Community JSNA told us that 55% of 86 adult carers were not aware of residential respite and several presumed that if payment was required they would be unable to afford it or that they would not be eligible. It was mentioned more than once that some respite care could not be booked more than a fortnight in advance, which made planning a trip or break well in advance an impossibility. Others, however, said that they can book in advance, so there appears to be variation in experience. The cost of residential respite can be prohibitive; one carer reported that the cost of residential respite was three times the cost of their holiday break.

The majority of those carers who could arrange residential respite found that it made a significant difference to their own health and wellbeing. This is a finding which is supported by the Cheshire East Parent Carer Forum Members’ Survey, which found that "respite is very highly valued by those that get it — supporting a child with additional needs can impact on the whole family". However, they also found that "many respondents were unsure about what is available, where and when".

Most who used residential respite appeared to be happy with the care home/facility used to provide the care, with only occasional mentions that sometimes the facility provided wasn’t entirely appropriate e.g. a cared-for person with a stroke staying in a care home primarily supporting dementia patients, or a young woman being offered respite care with elderly dementia patients. Parent Carer also reported that it was too hard to find provision that met the Early Help Individual Payments (EHIPS)/Direct Payments (DP) criteria. There is limited support available for cared-for people with challenging behaviour in Cheshire East, particularly the lack of respite beds.

Carers told us that the provision of carer breaks and respite helped to sustain other close relationships.

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. 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.” This could suggest that we are we missing opportunities for early intervention. Are self funders accessing support and if not, what are the barriers? Community JSNA

Opportunities for improvement / future developments

- Develop, implement and evaluate a clear process for offering Carer Assessments and clearly publicise this, together with the benefits of having an assessment.
- Develop one point of contact for Adult Social Care
- Raise awareness of respite options, eligibility and costs involved.
- Carer respite to include, provision for cared-for people with challenging behaviour with appropriately skilled staff.
- Support carers and the person that they care for to identify options that both are happy with to enable carers to take a break, including telecare and assistive technology or advice on home adaptations and equipment. [See the Technology support to improve health and wellbeing JSNA]
- Raise awareness of short-notice care available in an emergency.
- Consider how to identify carers of people who pay for their own care (self-funders).
- Raise awareness of services that can provide practical help and advice via the Carers Hub.
- Raise awareness of the Employers for Carers scheme.

A carer had the following suggestion to make: “I’ve had a letter saying that respite beds are not being utilised properly so they are considering closing them. I’m surprised if they’re not used more. They could do with revitalising places, having respite homes where disabled people go and they do things and activities.”

Community JSNA
Why do we need to redesign services for carers in Cheshire East?
Carers have told us that Carers Services in Cheshire East need to be improved. Common themes include:

- Having better and clear access to information about what support is available
- Single point of access so carers only have to tell their story once
- Having improved transition arrangements between child and adult services
- Employer support for carers to enable them to balance work/caring
- Information for carers at point of diagnosis
- Better access to respite for cared for person
- More recognition for the role carers do
- More time for carers to build relationships/have a life outside caring
- Awareness raising in schools and better recognition of young carers

Key Challenges
A number of key challenges have been identified based on feedback from carers, local need, and national guidance. Future Carer Services must deliver:

- Prevention, early intervention, and ongoing community based support to improve outcomes through support to carers to maintain and sustain their caring role;
- Improved access, via a single point, using a flexible, community and assets based approach, as well as innovative solutions such as technological approaches to address the different needs and assets across the vast geography of the borough;
- A person centred approach, understanding that carers may have multiple needs, with responsibilities such as employment, education, being a parent, partner or within a wider family context. The service must take a ‘holistic’ ‘whole family’ approach. Partnership working for improved transition and pathways is essential;
- Increasing, promoting, strengthening and empowering the carers voice to ensure that the service meets the needs and aspirations of local people.
- A clear early intervention and prevention programme for young carers, including working with schools and colleges, building on existing infrastructure such as the Cheshire East Emotionally Healthy Schools programme, which has a focus on building resilience;
- A strong, seamless transition and pathway from children and young people’s services to adult services must be developed;
- Support plans are co-produced with individuals, with regular ‘meaningful’ review and a core focus on the achievement of goals and outcomes.

Live Well Cheshire East is a new online resource developed by the Council launched Spring 2017, providing an asset map of local services and support, giving residents choice and control of available services and information on:

- Staying healthy;
- Community activities;
- Living independently;
- Care and Support for Adults;
- Care and Support for Children;
- Local offer for special educational needs and disability;
- Education and employment.

Live Well Cheshire East is a platform that the Council will build on further providing self-assessment of care needs, and people portals linking services to people. Residents can access Live Well via the dedicated ‘live well’ web address. [http://www.cheshireeast.gov.uk/livewell/livewell.aspx](http://www.cheshireeast.gov.uk/livewell/livewell.aspx)
Cheshire East Council, NHS South Cheshire CCG and NHS Eastern Cheshire CCG, have commissioned a new Integrated Carers Hub service, that went live on 1st April 2018. The Carers Hub will replace and enhance existing services for carers and will be delivered by n-compass, in conjunction with The Alzheimer’s Society and Child Action North West. The Carers Hub is a joint, all age service for adult, parent and young carers across Cheshire East. The development of an Integrated Carer’s Hub model was a key objective of Cheshire East Council’s Carers Strategy and Delivery Plan and contributed to a ‘Whole System Redesign’ for carers outcomes, services and pathways. The Hub model is a key element of the Council’s statutory obligations under the Care Act 2014, the Children and Families Act 2014 and ensures compliance with the Council’s strategic aims and policies for adult and young carers including legal rights to assessment and support.

The Carers Hub model’s new whole system, all age approach to delivering services for carers in Cheshire East, will ensure that their needs and outcomes are met to support them in their caring role. This brings all carers services under one integrated approach thereby ensuring a clear referral pathway for all carers through one single access point so that they access the support they need, at the time when they need it most. It was clear from the feedback that we received, this was important to carers. Carers will be assessed for their needs and will be directed to the most appropriate help, advice and support. The Hub will also be expected to identify ‘hidden’ carers to ensure that they also receive the right type of support. It is hoped that by providing improved access to information and support, it will assist to reduce the impact the caring role can have on a carer’s own health and wellbeing.

The Carers Hub will ensure that young carers are identified and provided with the right support in their caring role. Part of the Hub Model approach will involve engaging with schools, GP services and the local community to form strong partnerships to support young carers. We envisage that the Carers Hub will help young carers in many ways, including; helping them to take a break from their caring role, getting help, advice and support for the person they care for, introducing them to other young carers and getting them support in school or college. Young carers will be offered support in a range of different ways, such as; support to access community, health and wellbeing services, one-to-one support, group based support, peer support, workshops, training, access to activities and providing information and guidance.

Support the hub can offer includes...

- Peer support
- 1-2-1 or group based support
- Access to activities, training and much more
- Information, advice and guidance
- Living Well Fund (criteria applies)
- Specialist support for carers of people with dementia
- Support to access community, health and wellbeing services
- Support to take a break
- Access to a 24 hour chat line manned by other carers

The Carers Hub will ensure that carers are identified and provided with support in their caring role, whilst improving and maintaining their own health and wellbeing so that they continue in their caring role for as long as they chose.

Contact the Carers Hub:
Telephone: 0300 303 0208
enquiries@cheshireeastcarershub.co.uk
www.cheshireeastcarershub.co.uk
Background

In December 2015, the Council launched a new Carer Respite Service, moving away from the internal provision which had been located in Crewe and Macclesfield. The new service offered residential carer respite in a number of different care homes across the borough, providing a more local offer for the cared for person. The number of beds available was 21, which included 2 emergency beds. The new Carer Respite Service was primarily focused on meeting the support needs of older people and the location of the respite beds confirmed this.

In 2016, occupancy rates for the residential placements was at 53%, which was not as high as anticipated; therefore, early in 2017, the number of available beds was reduced to 18. (Including 2 emergency beds). During 2017, the occupancy rate was at 63%. Again, this was lower than anticipated. Therefore, the number of available beds was reduced in February 2018. There are now 10 beds available, this includes 2 emergency beds. Occupancy rates continue to be closely monitored.

Next Steps

Based on the evidence to date, we are anticipating that the new service (which will be launched on 1st December 2018), is likely to include a range of community based services, including access to the Carers’ Hub for information, advice and guidance, support services which can be provided in the cared for person’s home and a range of bed based provision, including support for people with physical disabilities, learning difficulties, challenging behaviour, mental health needs, dementia and nursing needs.

78 carers said they would like a sitting service at home.
53 carers said they would like support from a domiciliary care provider (Care at Home).
59 carers said they would like support in a residential care home.

“IT made it possible for me to have a break away – I would like you to know the peace of mind I was able to have”.

Carers providing 50 or more hours per week are more likely to say they do not do anything they value or enjoy, had less control over their daily life and felt more socially isolated.

Adult Social Care Carers Survey

Here is an illustration of the Council’s proposed model of Carer Respite support for the future.

Carers Hub – services for all Carers
Information Advice and Guidance
Carers Living Well Fund

In a recent survey of 585 carers, we received 175 responses.
Further information is available at...
Opportunities for Improvement

Carers Hub to:
• Promote the hub to carers of all ages and in rural areas, not just in towns. Identify any barriers to accessing support and work to resolve these.
• Develop links to schools, colleges, GPs and other health professionals to agree how partners can help identify carers, support them and promote the hub
• Consider how to identify carers of people who pay for their own care (self-funders).
• Measure the type of care young carers are providing (possibly by using the MACA analysis tool) and young carer quality of life and track these over time
• Develop, implement and evaluate a clear process for offering Carer Assessments and clearly publicise this, together with the benefits of having an assessment.
• Streamline data recording across the hub, GP carer registers and social care case management systems to more easily analyse how many carers need support and how many are accessing support (e.g. carer’s hub to record whether the carer has informed their GP that they are a carer or contacted social care as a carer and to develop a process for keeping these records up-to-date).
• Provide tailored support for the specific needs of the carer and help carers to plan for the future. Develop a wellbeing plan, linked to the carer’s assessment, to help prevent crises. The plan should include the carer and cared-for person’s needs, who to contact if additional support is needed and 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.
• Ensure access to condition-specific information and support. Help carers to plan for emergencies and raise awareness of emergency/crisis services.
• Support carers and the person that they care for to identify options that both are happy with to enable carers to take a break, including telecare and assistive technology or advice on home adaptations and equipment. [See the Technology support to improve health and wellbeing JSNA]
• Ask carers who else in the family has a carer role and whether they need support.

GPs and other health professionals to:
• Continue to identify whether patients and their family or friends have a caring role and whether the carers may need support. Understand any current barriers to doing this and identify ways of overcoming them.
• Promote/refer carers to the Carers’ Hub.
• Provide more information and advice and guidance regarding online booking of appointments and the ordering, collection or delivery of prescriptions.
• Offer flexible appointments to those who are limited by when they can leave the house (e.g. provide home visits when the cared-for person is unable to go out, for either the cared-for person or the carer).
• Commissioners (in CCGs and Council) to consider improving identification of carers, providing flexibility/support for carers and promoting the carers’ hub when recommissioning services.

Cheshire East Council to:
• Provide feedback to carers and engagement participants to show how their input has been valued and listened to prior to any decisions being made, even if difficult decisions still have to be made.
• Develop one point of contact for Adult Social Care
• Carer respite to include, provision for cared-for people with challenging behaviour with appropriately skilled staff.
• Raise awareness of respite options, eligibility and costs involved
• Raise awareness of the Employers for Carers scheme
What we don’t know but would like to know:

- For all carers: number of people they are caring for (age, gender, health, ethnicity)
- Cared-for person’s health condition(s) and needs
- How well cared-for person’s needs are being met / barriers / opportunities for improvement
- More information about carers with protected characteristics
- Number of parent carers vs number of adult carers caring for adults plus those with overlapping responsibilities.
- An understanding of the transition from young carer to adult.

Glossary:

- DP – Direct Payment
- SMASH – Sandbach, Middlewich, Alsager, Scholar Green & Haslington Adult Social Care Team
- CCG - Clinical Commissioning Group
- JSNA – Joint Strategic Needs Assessment
- ACE - Alert Card for Emergencies
- EHIPS - Early Help Individual Payments
- MACA - Multidimensional Assessment of Caring Activities
- CVS - Community & Voluntary Services
- BCF – Better Care Fund
- VCFS – Voluntary, Community & Faith Sector

Further Information:

Cheshire East Council People Live Well for Longer Commissioning Plan (2017)
https://carers.org/about-us/about-young-carers
https://carers.org/key-facts-about-carers-and-people-they-care
www.cheshireeastcarershub.co.uk
Carers Trust UK https://carers.org/

Assets:

- Cheshire East Carers Hub
- Living Well Fund
- Live Well Cheshire East
- Employers for Carers
- Cheshire East Carer Respite Services

References/Data Sources:

Community JSNA 2017 (Community & Voluntary Services - CVS)
Cheshire East Council Adult Carers Survey 2016/17
Cheshire East Parent Carer Forum Members’ Survey 2017
Cheshire East Council Carer Respite Survey November 2017
2013 mid-year population estimates, Office for National Statistics
2011 Census LC3304EW - Provision of unpaid care by age ONS Crown -Copyright Reserved [from Nomis on 7 November 2017]

Version control

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<td>June 2018</td>
<td>New all age carers JSNA created</td>
<td>Danielle Stuart</td>
<td>Shelley Brough</td>
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