We asked carers what they thought in our survey

Carers have access to the right information, the right range of support, in the right place, at the right time.

and this is what they told us

Suffolk Carers Steering Group
I, and others around me, including my employer if relevant, can identify and recognise my needs and rights as a carer. I can access a timely and comprehensive assessment and review of my needs as a carer. I can easily find and access good quality, clear information, advice and guidance to meet my specific needs as a carer.

I am aware of, and can easily access, a range of support options to meet my identified needs as a carer, including opportunities:

- to maintain or improve my health and wellbeing including my emotional support needs
- to meet the specific needs of the person I am caring for
- for replacement care/respite to meet both my needs and/or the needs of the person I care for

Carers have access to the right information, the right range of support, in the right place, at the right time.
I am aware of carers’ assessments but haven’t had one as I don’t seem to be being recognised as a carer.

You are just expected to know these things and the majority of people don’t.
Acknowledgements

The Carers Steering Group would like to acknowledge and extend their gratitude to every person who helped design the survey and especially those carers who responded.

The group would also like to thank Healthwatch Suffolk for undertaking analysis and collating comments and observations made in response to the survey.
Report Headlines

The survey was co-designed by members of the multi-agency steering group, including family carer representatives. The function of this group is to inform, shape and steer the co-design and co-production of a new model of support for family carers.

The survey was intended to hear the views of adult carers supporting people over the age of 18 years to understand what is working well, what is not working well and their priorities for future support.

Numbers of carers completing the survey

195 carers completed the survey during October and November 2018. The number included seven carers responding to the survey using an Easy Read format.

Carers profile in the Suffolk survey

- 50.7% of respondents were caring for someone over 65.
- The largest proportion of carers who completed the survey were aged between 51-64 years old (39.5%).
- 51.5% of respondents said that there were services they would like to keep the same.
- 50% said there were things that Suffolk could do differently or better.
- 60% said it was difficult or quite difficult to find the information they needed.
- 25.6% said they did not get the help and support they wanted or needed as a carer when they last looked for it.

What carers want

The top three key areas of help and support wanted were -

- Emotional support
- Information, advice and guidance
- Help or support to maintain health and wellbeing
1. Introduction

The Carers Steering Group was established in April 2018 to consider the support that is available to carers in Suffolk, with the intention of looking at how we can more effectively support carers in Suffolk by joining up our current resources.

The Steering Group comprises of adult carers and representatives from statutory health and care organisations in Suffolk (both adult’s and children’s services). The group shaped the survey together with representatives from the Family Carers Partnership Board in Suffolk and Suffolk Parent Carer Network (SPCN). In addition, carers from outside of these groups were asked to contribute and comment.

The survey featured in this report was designed by the Carers Steering Group in Autumn 2018 and took place between October and December 2018.

This was towards the end of the ‘Engaging and Informing’ stage of planning as indicated in the time line below:

<table>
<thead>
<tr>
<th>ESTABLISHING Governance</th>
<th>SCOPING &amp; PLANNING</th>
<th>ENGAGING &amp; INFORMING Literature Review</th>
<th>GOVERNANCE Funding stakeholder approval</th>
<th>ANALYSING Results &amp; planning of consultation</th>
</tr>
</thead>
<tbody>
<tr>
<td>April 2018</td>
<td>September 2018</td>
<td>November 2018</td>
<td>December 2018</td>
<td>January 2019</td>
</tr>
</tbody>
</table>

The survey contained 26 questions. Some of the questions asked carers to select a response from a list of options, and other questions asked for more information inviting other views and opinions. Where more information was recorded, Healthwatch Suffolk was invited to analyse these responses as an independent contributor of the analysis. The report blends analysis completed by Healthwatch Suffolk and statistical information provided from the selected responses.

The survey was shared with carers across Suffolk in a variety of ways. These included an invitation by letter to carers already receiving support from Suffolk County Council, personal invite, newsletters and articles online and by email to organisations. People known or assumed to have links with carers were contacted and invited to share the survey with potential carers, this included: local authorities; schools; and providers of healthcare services. It was available in several formats including easy read and large print versions.
2. Information about carers completing the survey

Question 1 in the survey asked carers to confirm that they met the definition chosen for the survey: “A carer is 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. The person cared for will be aged 18, or over for the purposes of this survey”. 195 carers said “yes” they met that description.

Carers were invited to select one description that best fitted the person or main person they cared for in question 2. The graph below sets out a summary of the recorded descriptions (number and %).

Description that best fits the person you care for

<table>
<thead>
<tr>
<th>Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long standing illness</td>
<td>17.4% (34)</td>
</tr>
<tr>
<td>A learning disability or difficulty</td>
<td>16.9% (33)</td>
</tr>
<tr>
<td>A mental health problem</td>
<td>16.4% (32)</td>
</tr>
<tr>
<td>Dementia</td>
<td>15.4% (30)</td>
</tr>
<tr>
<td>A physical disability</td>
<td>15.4% (30)</td>
</tr>
<tr>
<td>Problems connected to ageing</td>
<td>13.3% (26)</td>
</tr>
<tr>
<td>Terminal illness</td>
<td>2.1% (4)</td>
</tr>
<tr>
<td>Sight or hearing loss</td>
<td>2.1% (4)</td>
</tr>
<tr>
<td>Alcohol or drug dependency</td>
<td>1.0% (2)</td>
</tr>
</tbody>
</table>

Graph 1
Carers were invited to select the age band of person cared for in question 3. The graph below sets out a summary of the recorded descriptions.

**Please select by ticking the relevant age-band the person you are caring for:**

<table>
<thead>
<tr>
<th>Age</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>85+</td>
<td>12.8% (25)</td>
<td></td>
</tr>
<tr>
<td>65-84</td>
<td>37.9% (74)</td>
<td></td>
</tr>
<tr>
<td>51-64</td>
<td>15.4% (30)</td>
<td></td>
</tr>
<tr>
<td>37-50</td>
<td>12.3% (24)</td>
<td></td>
</tr>
<tr>
<td>26-36</td>
<td>11.8% (23)</td>
<td></td>
</tr>
<tr>
<td>18-25</td>
<td>9.7% (19)</td>
<td></td>
</tr>
<tr>
<td>Under 18</td>
<td>excluded from this analysis</td>
<td></td>
</tr>
</tbody>
</table>

**Please select the age-band of yourself as the carer**

<table>
<thead>
<tr>
<th>Age</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>85+</td>
<td>0.5% (1)</td>
<td></td>
</tr>
<tr>
<td>65-84</td>
<td>36.4% (71)</td>
<td></td>
</tr>
<tr>
<td>51-64</td>
<td>39.5% (77)</td>
<td></td>
</tr>
<tr>
<td>37-50</td>
<td>17.4% (34)</td>
<td></td>
</tr>
<tr>
<td>26-36</td>
<td>4.6% (9)</td>
<td></td>
</tr>
<tr>
<td>18-25</td>
<td>1.5% (3)</td>
<td></td>
</tr>
<tr>
<td>Under 18</td>
<td>Excluded from this analysis</td>
<td></td>
</tr>
</tbody>
</table>
The map contains circles of differing sizes. The larger the circle the larger the responses from that postcode area. These ranged from 1 carer up to 18 carers responding in a postcode area such as IP1. The extent of each postcode area represented is indicated in solid purple circle.
3. Knowing where to get help and support

Knowing where to go
There were 194 responses to the question ‘did you know where to go when you needed support in your caring role?: 49 carers said “yes”, 71 said “no”, and a further 74 said “only some of the time”.

Information, Advice & Guidance
I can easily find and access good quality, clear information, advice and guidance to meet my specific needs as a carer.

Did you know where to go when you needed support in your caring role?

<table>
<thead>
<tr>
<th>Only some of the time</th>
<th>38.1% (74)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>36.6% (71)</td>
</tr>
<tr>
<td>Yes</td>
<td>25.3% (49)</td>
</tr>
</tbody>
</table>

Graph 4
There were **86** comments received in response to this question. The most common themes in these responses were:

- **17 carers** referred to knowing that they could receive support from or accessing Suffolk Family Carers (SFC). However, 11 said that this was the only source of support that they were aware of.

- **15 carers** referred to not knowing where to go for support because of a general lack of support services being available for them or that services were difficult to access.

- **13 carers** said that they did not know what services were available or that there was poor information about services.

Examples of the comments received were:

> I know where to go but getting the help is more than difficult.

> I know where to go to get information: Suffolk Family Carers or to Social Worker for carers assessment.

> You are just expected to know these things and the majority of people don’t.
Services used by carers
Carers were asked which services they had received in the past. A total of 56% (111) confirmed that they had previously received a service. In these comments, there were 122 references to individual services or sources of support. The most common of these were:

- There were 41 references to receiving a service from Suffolk Family Carers (SFC).
- 28 referred to receiving domiciliary care services.
- 20 comments referred to using social services or a social worker. Often, carers said that social workers or social services organised their domiciliary carers for them.
- 13 stated that they had received a carer’s assessment.

Support
I am aware of, and can easily access, a range of support options to meet my identified needs as a carer, including opportunities:
- to maintain or improve my health and wellbeing including my emotional support needs
- to meet the specific needs of the person I am caring for
- for replacement care/respite to meet both my needs and/or the needs of the person I care for

Are you currently using any services to support you in your role as a carer?

There were 78 comments from carers which listed the services they were currently receiving. The most common services received:

- 29 carers referred to currently using domiciliary care services.
- 14 carers stated that they were currently receiving a service from Suffolk Family Carers.
- 8 carers comments referred to receiving funding for social care, day care or activities.
- 5 carers stated that they received direct payments.
4. What is working well, or less well?

What is working well?
Carers were asked ‘what support or services are working well or have worked well and why?’
There were 103 carers who responded. The most common themes in their comments were:

• **23 carers** said that their domiciliary care was working well.

• **10 carers** referred to support from Suffolk Family Carers working well.

• **9 carers** stated that support from health care services was working well for them, for example, hospitals (three), District Nurses (three), GPs (two) and other healthcare professionals like physiotherapists (two).

• **8 carers** referred to the funding or grants they received working well, including direct payments (two), and funding for respite (two).

Examples of comments on what is working well included:

“Excellent health care from hospital for both me and my husband.”

“Suffolk Family Carers and related carers group have been of great help and also my GP.”

“Only service received is a single one-off payment (which is now exhausted) in the last 12 months. It has been very helpful.”
What is working less well?

Carers were asked ‘what support or services are failing, or are less than satisfactory? Please say why you think this is or add N/A if you have good or positive experiences.’ There were 103 responses from carers. The most common themes in these responses were:

• **22 carers** responded with N/A, indicating that they were not dissatisfied with any services or did not feel that any services were failing.

• **11 carers** referred to not being able to find or access services appropriate to their needs. Three referred specifically to services for people with autism or Autistic Spectrum Disorder (ASD).

• **9 carers** referred to a lack of respite services or finding respite care difficult to access.

• **6 carers** referred to support from a social worker as failing or less than satisfactory. These comments described problems such as the high workload of social workers and a lack of understanding of the needs of carers.

Examples of comments about what support is failing or less than satisfactory:

"No idea of services or what services can help me. I’m constantly told my need is unique or no services exist or no money. There is no access to any info, I belong to nothing I get no support I can’t even find time for funding support."

"Respite. We have not had time away together (my husband and I) for YEARS!"

"Services approached with less than useful responses (respite care)"
Services which carers would like to keep the same

Question 12 asked carers ‘are there any existing support or services you receive as a carer, which you would prefer to keep the same?’ Just over half of the carers completing the survey indicated there were services they would want to keep the same.

Are there any existing support or services you receive as a carer, which you would prefer to keep the same?

72 carers answering this question provided a comment about the services that they would like to keep the same. Carers referred to wide variety of different services and themes, however, the most common responses were:

- **11 carers (21%)** said that they would like to keep services from Suffolk Family Carers the same.
- **11 carers (21%)** said that they would like to keep services from a domiciliary care agency the same.
- **Six carers (6.5%)** referenced wanting to keep respite or day care services the same.
Examples of comments from carers who said that there were services which they would like to keep the same included:

“Family Carers. I know they are there if I need them.”

“The carers’ phone line please.”

“Having a friendly carer support team based in the hospital has been excellent.”
5. Improving services available to family carers

Question 13 asked carers about support or services that might be missing and question 14 asked carers about things Suffolk could do differently or better to support them.

Support

I am aware of, and can easily access, a range of support options to meet my identified needs as a carer, including opportunities:

- to maintain or improve my health and wellbeing including my emotional support needs
- to meet the specific needs of the person I am caring for
- for replacement care/respite to meet both my needs and/or the needs of the person I care for

Is there any other support or services which could help you in your caring role which you think may not be available at present?

<table>
<thead>
<tr>
<th>Don’t know</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>49.7% (97)</td>
<td>40.5% (79)</td>
</tr>
</tbody>
</table>

Is there anything else relating to your caring role that Suffolk could do differently/better to support you?

<table>
<thead>
<tr>
<th>Don’t know</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>42.6% (81)</td>
<td>50% (95)</td>
</tr>
</tbody>
</table>

There were 119 carers who answered “yes” to one of the above two questions and stated what services could be made available or what could be done to better support them.
Carers’ comments on what could be done to better support them were varied, however, the most common themes were:

- **20 carers** said that access to respite or day care services could improve support for them.

- **11 carers** said that improved information and signposting could help to support them. Carers referred to wanting more information about what services are available, help with benefits and information about the diagnosis of the person who they cared for.

- **8 carers** referred to a general lack of support available in Suffolk. Five said that the person who they cared for required specialist services, including those for people with autism. Three said that there were no services available locally.

- **6 carers** referred to wanting to receive additional funding. Reasons for wanting funding included to pay for respite, or for day to day expenses.

Examples of comments about how carers could be better supported:

- “Sorry to say financial support, I take dad to all hospital, doctor’s app. Make all his phone calls, washing, ironing, cleaning and gardening.”

- “I would like some money to pay for respite for the person that I care for to enable me to have a break from my caring role. Everyone should be entitled to a break.”

- “There is very little available in or near Halesworth. Family carers do not offer courses or anything helpful near to Halesworth so I am unable to go.”
6. Help requested and received by family carers

Requesting support
In question 16 carers were asked whether they had previously tried to request support for their caring role. Over half of carers completing the survey said “yes”.

Support
I am aware of, and can easily access, a range of support options to meet my identified needs as a carer, including opportunities:
• to maintain or improve my health and wellbeing including my emotional support needs
• to meet the specific needs of the person I am caring for
• for replacement care/respite to meet both my needs and/or the needs of the person I care for

Have you previously tried to request support for your caring role?

<table>
<thead>
<tr>
<th></th>
<th>No</th>
<th>Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage</td>
<td>40% (78)</td>
<td>60% (117)</td>
</tr>
</tbody>
</table>

Graph 9
There were 113 comments from respondents who had previously tried to request support for their caring role. The most common themes in these comments included:

- **60 carers** referred to their own wellbeing when asked what led them to ask for support in their caring role. Carers reported feeling like they were finding it difficult to cope (13), feeling tired (nine), needing a break or respite (eight), stressed (six) or experiencing deterioration in their own mental health (six).

- **16 carers** said that they asked for support with their caring role because they were finding it difficult to balance their caring role with either their work or personal life.

- **11 carers** referred to the changing or complex health needs of the person who they cared from prompting them to ask for support.

- **10 carers** stated that another person or organisation had advised them to ask for support with their caring role. Of these, three were advised by Suffolk Family Carers. Other sources of advice given include a nurse, GP, friend, social worker or family member.

> "Due to being the only carer and feeling constant pressure and realising that I needed a break."

> "Increased demands on my time because of my daughter’s varying health needs. The fact that I am getting older and want to plan ahead for a time when I am no longer able or about to support my daughter."

> "When my wife’s circumstances changed I found I could not cope with the extra care that was needed on top of what she already had."

> "Suffolk Family Carers encouraged me to ask for a carer’s assessment."
Availability of information
In question 19 carers were asked how easy it was to find the information needed. More than half found it difficult or quite difficult.

Information, Advice & Guidance
I can easily find and access good quality, clear information, advice and guidance to meet my specific needs as a carer.

How easy was it for you to find the information you required?

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficult</td>
<td>19.4%</td>
<td>32</td>
</tr>
<tr>
<td>Quite difficult</td>
<td>40.6%</td>
<td>67</td>
</tr>
<tr>
<td>Quite easy</td>
<td>29.7%</td>
<td>49</td>
</tr>
<tr>
<td>Easy</td>
<td>10.3%</td>
<td>17</td>
</tr>
</tbody>
</table>

Graph 10
Carers were asked to identify where they got information from about services and were given the opportunity to identify more than one source.

**If you have asked for support before, where did you get the information about help and services from?**

45 carers mentioned where they received information about help and services. These included the following under other organisations and sources:

- **Age UK** (six)
- **GPs** (four)
- **Suffolk Family Carers** (three)
- Other services or sources of information mentioned included: Sue Ryder (three), nurses (three), including a disability nurse, Parkinson’s nurse and a practice nurse, Parkinson’s UK (three) and Social Services (three).

Note: The sum of responses in this table may not equal the number of total respondents as carers were allowed to select more than one answer.
7. What happens after support is requested

Receiving help and support

There were 112 responses to question 20 about what happened after carers had requested help or support.

Support

I am aware of, and can easily access, a range of support options to meet my identified needs as a carer, including opportunities:
- to maintain or improve my health and wellbeing including my emotional support needs
- to meet the specific needs of the person I am caring for
- for replacement care/respite to meet both my needs and/or the needs of the person I care for

Did you receive the help and support you wanted or needed as a carer when you last enquired about it, or looked for it?

<table>
<thead>
<tr>
<th>Response</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I haven’t looked for, or asked for anything as yet</td>
<td>22.6% (44)</td>
</tr>
<tr>
<td>No</td>
<td>25.6% (50)</td>
</tr>
<tr>
<td>Some of it</td>
<td>28.2% (55)</td>
</tr>
<tr>
<td>Yes</td>
<td>23.6% (46)</td>
</tr>
</tbody>
</table>

Graph 12
All of the carers who answered this question provided more detail about their experience. The most common themes in these responses were:

- **29 carers** referred finding that there was a general lack of support for carers or that it was difficult to get the support which they needed the last time that they looked for it.

- **11 carers** referred to receiving funding or grants the last time they sought support. This included two references to receiving a carer’s assessment. However, four carers said that the last time they looked for support that they had been declined a carer’s assessment or had experienced delays in receiving an assessment.

- **8 carers** said that they had received support from Suffolk Family Carers when they last looked for support.

Examples of comments about what help or support carers had received included:

> Suffolk Family Carers were very helpful, supportive and knowledgeable.

> I attended the caring with confidence course which was fantastic but had no support since. As carers we are just meant to cope alone which is really difficult.

> The cash sum enabled me to pay a cleaner and a gardener, which reduced my personal burden of work but I had no other advice or support.
**Carer’s Assessments**
A total of 64% of the carers responding to the survey were aware of or had received a carer’s assessment.

**Assessment & Review**
I can access a timely and comprehensive assessment and review of my needs as a carer.

**Are you aware of and have you had a Carer’s Assessment?**

<table>
<thead>
<tr>
<th></th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not sure</td>
<td>8.7% (17)</td>
</tr>
<tr>
<td>No</td>
<td>27.2% (53)</td>
</tr>
<tr>
<td>Yes</td>
<td>64.1% (125)</td>
</tr>
</tbody>
</table>

Graph13
There were 73 carers who chose to add more information to their response. The most common themes in these comments were:

- **17 carers** said that they were aware of carer’s assessments but had not had one. Of those who gave a reason: Two did not think they were eligible, three said that it was difficult to access an assessment and one said that their GP was dismissive of their eligibility for a carer’s assessment.

- **17 carers** were positive about the impact of their assessment. Included in those who were positive about the assessment were four carers who employed a gardener or cleaner and one who paid for chiropractic treatment.

- **14 carers** stated that they had received a carer’s assessment but were negative about the assessment’s impact. Of these, eight felt they were offered insufficient support following an assessment.

- **9 carers** stated that they experienced delays in receiving their funding or were negative about the timeliness of their assessment.

Examples of comments about carers’ assessments included:

”I’m still waiting for the payment so I can have a break. It’s taken a long time to get the assessment and now it’s 3 months and still no payment.”

”I am aware of carers’ assessments but haven’t had one as I don’t seem to be being recognised as a carer.”

”I have continuously asked for a carer’s assessment. Firstly, told I wasn’t entitled to anything then ignored.”
Barriers to asking for support
Carers were asked whether there is anything that puts them off asking for help. A third of carers completing the survey said “yes” and a slightly smaller proportion said “sometimes” (29.2%).

Is there anything that puts you off asking for help, or support as a carer?

<table>
<thead>
<tr>
<th></th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sometime</td>
<td>29.2% (57)</td>
</tr>
<tr>
<td>No</td>
<td>39.0% (76)</td>
</tr>
<tr>
<td>Yes</td>
<td>38.1% (62)</td>
</tr>
</tbody>
</table>

Support
I am aware of, and can easily access, a range of support options to meet my identified needs as a carer, including opportunities:

- to maintain or improve my health and wellbeing including my emotional support needs
- to meet the specific needs of the person I am caring for
- for replacement care/respites to meet both my needs and/or the needs of the person I care for
120 carers commented on what could put them off asking for help. Of these:

- **30 carers** referred to a lack of support services. Some stated that their past experiences of being unable to access help put them off asking.

- **22 carers** said that they felt that they should be able to cope on their own or felt that judged by others for not coping.

- **9 carers** said that the person who they cared for did not want support from anyone else.

Examples of comments about carers’ assessments included:

“**My husband would struggle to be in the company someone else, if I was to have respite as a carer.**”

“I think about asking for help but then I remember the hassle that I have had in the past. I just don’t have the energy to keep fighting services that should be there to help.”

“I feel that I should just get on with it on my own. It’s hard to get past this thought even though I know I need help.”
8. Support from professionals

Question 24 asked carers whether a professional had spoken to them about their caring role and who this was. Their responses can be seen in the graph below.

Support
I am aware of, and can easily access, a range of support options to meet my identified needs as a carer, including opportunities:
• to maintain or improve my health and wellbeing including my emotional support needs
• to meet the specific needs of the person I am caring for
• for replacement care/respite to meet both my needs and/or the needs of the person I care for

Identification
I, and others around me, including my employer if relevant, can identify and recognise my needs and rights as a carer.

If yes, who was it?

<table>
<thead>
<tr>
<th>Professional</th>
<th>Percentage</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>32.2%</td>
<td>49</td>
</tr>
<tr>
<td>Health Practitioner</td>
<td>13.2%</td>
<td>20</td>
</tr>
<tr>
<td>Social Care Practitioner</td>
<td>21.1%</td>
<td>32</td>
</tr>
<tr>
<td>Support worker e.g. SFC</td>
<td>9.2%</td>
<td>14</td>
</tr>
<tr>
<td>Other</td>
<td>24.3%</td>
<td>37</td>
</tr>
</tbody>
</table>

Note: The sum of responses in this table may not equal the number of total respondents as carers were allowed to select more than one answer.
Carers who selected “other” gave a free text response. The most common of these included

- GP (8)
- Suffolk Family Carers (6)
- Nurse (4)
- Social worker or social services (3)
- Counsellor (2)

There were nine comments classified as “other” who either did not say who they had received support from or commented on the support received from the service listed in question 24.

“Never knew I was a carer until someone in the hospital said I was. I am only looking after my husband through cancer and other illness never considered I was a carer.”
9. Priorities for future support

Carers were asked to rank their top three choices for further support. Their answers show how many times an option was placed in the top 3 choices for support.

**Support**

I am aware of, and can easily access, a range of support options to meet my identified needs as a carer, including opportunities:

- to maintain or improve my health and wellbeing including my emotional support needs
- to meet the specific needs of the person I am caring for
- for replacement care/respite to meet both my needs and/or the needs of the person I care for

**What carers want**

The top three priorities for future support most frequently chosen were:

- **Emotional support**
- **Information, advice and guidance**
- **Help or support to maintain health and wellbeing**
Carers were also advised that they could add their choices in the extra space provided. There were 32 responses from carers in the “other” section of this question.

- **6 carers** said that they wanted or needed respite or a break. Four said that they found it difficult to have time away from their caring responsibilities.

- **2 respondents** highlighted the need for more information about services and said that there should be a central place to receive information relevant to their role. Others said they would like general advice (one) and advice about benefits.

- **3 respondents** expressed that they would like more recognition at work of their role as a carer. One said that they would like flexible working.

Other options for support which people mentioned in response to this question included:

- Support from a gardener **(three)**

- To be able to keep up hobbies and interests **(two)**

- Better support for the person the respondent cares for **(two)**

- More funding or grants **(two)**
10. Conclusions

The survey revealed a wealth of insights into how challenging it is to be a carer, and how difficult it can be to access support in Suffolk when this is needed. The main themes highlighted were:

- When needs are unmet it remains unsatisfactory
- There can be delays for assessment or support
- Access to good information is frequently assessed as being ‘poor’, or as being too difficult to find

Where support is found or provided, experiences are reported as good or excellent in many cases.

The results are consistent with reported experiences in other areas of the UK when considered alongside other local and national surveys, and research about carers. Whilst those completing the survey represent a small sample of carers across the county, the similarity with findings elsewhere provides confidence in the findings of the survey. It is important to note that the challenges highlighted in this survey remain broadly the same as other research carried out locally in 2014 including access to information and access to replacement or respite care being cited.¹

This survey provides valuable information about the types of support many carers want. It highlights key areas to focus on in order to improve the range and flexibility of support to meet the current and future needs of carers’ and their cared for person.

Events have since been held with carers to share and check that the issues and themes raised are at the heart of the change carers want and need in Suffolk.

¹ Health and Wellbeing Suffolk Joint Strategic Needs Assessment – Dec 2014
11. What happens next?

The Carers Steering Group met to review the findings from the survey alongside other work they had initiated in 2018.

Literature

The literature review continues to grow where the Carers Steering Group have reviewed over 100 documents, articles, reports and statistical information found referencing carers – sourced both nationally and locally.

The word cloud represents the most frequently used words in the summary of the literature review showing the main points of consideration.

Review

At three events in Suffolk for carers in April and May 2019 the Carers Steering Group sharing with carers how the group has made sense of the information carers had shared. Carers attending each event were given the following forward plan of action:

- **Consultation**
  - Full Stakeholder consultation
  - April/May 2019

- **Shaping**
  - Confirm model & delivery options
  - May/June 2019

- **Drafting**
  - Service specification & outcome measures
  - December 2019

- **Arranging**
  - Funding & processes to deliver on the specifications

- **Implementation**
  - New model implementation
  - September 2019
  - April 2020

A full set of slides from the carer events are available to view separately from this report.
The carers’ assessments have been a great help. I feel that both my husband and myself are grateful for having the opportunity to talk to someone.

I am also very lucky to have very supportive and helpful neighbours always ready to help if needed and also a very supportive family.