Information and support for unpaid carers in Norfolk: feedback from local carers

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Acknowledgements

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Special thanks go to all the carers who took the time to be a part of this study.

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Who we are and what we do

Carers Council for Norfolk

Carers Council for Norfolk (CCN) represents the 99,419 unpaid carers in Norfolk (Carers UK, 2015). It is a user-led charitable organisation that exists to give carers a voice about the service they receive from adult health and social care and carers' services.

Our Vision is to ensure that unpaid carers throughout Norfolk are valued, recognised and supported with equal access to a good quality of life that is not prejudiced by their caring role.

Our Mission is to improve the health and wellbeing of all carers in Norfolk. Through partnership working we will ensure that the voice of carers is heard and listened to, enabling support and services to be designed and delivered that reflect carers' needs and interests.

Healthwatch Norfolk

Healthwatch Norfolk is the local consumer champion for health and social care in the county. Formed in April 2013, as a result of the Health and Social Care Act, we are an independent organisation with statutory powers. The people who make decisions about health and social care in Norfolk have to listen to you through us.

We have five main objectives:

1. Gather your views and experiences (good and bad)
2. Pay particular attention to underrepresented groups
3. Show how we contribute to making services better
4. Contribute to better signposting of services
5. Work with national organisations to help create better services

We are here to help you influence the way that health and social care services are planned and delivered in Norfolk.

1. Executive Summary

- This report sets out the findings from a survey looking at unpaid carers' experiences of Carers Assessments and information and support in Norfolk. The survey was conducted by Carers Council for Norfolk and Healthwatch Norfolk and was completed by 255 local carers.

- Seventy-three (73) respondents had received a Carers Assessment within the last two years. Their feedback was fairly positive; 56% rated the service as good or very good and staff were particularly praised. Many respondents valued the information and advice they received, but others were concerned that there had been no relevant outcome in terms of practical support or services.

- Feedback about Carers Assessments will be shared with Norfolk Older People's Strategic Partnership Board, who requested this information, for them to take forwards as part of the Living Longer Living Well strategy.

- Two hundred and fifty-five (255) respondents gave feedback about their experiences of accessing information and support in Norfolk. A significant minority (16%) said they did not currently know where to go for information or advice. More than two in three (68%) respondents felt confident continuing in their caring role but only 37% felt able to manage their health and wellbeing.

- When it came to increasing their confidence and health and wellbeing, respondents highlighted the importance of being supported to have a life outside of caring and stated their desire for more planned or unplanned respite care. Many respondents wanted more understanding, recognition and reassurance, and felt that they were currently being left to struggle on alone.

- A secondary analysis was undertaken to identify whether respondents' experiences differed according to their age and the number of hours they spent caring. Whilst there were no significant differences, a greater proportion of older carers (65+) felt that they were able to maintain their health and wellbeing. The results of this analysis should be treated with caution due to the size and nature of the sample.

- This report makes five main recommendations, which will be taken on by Carers Council for Norfolk as part of their role in the new service 'Carers Matter Norfolk':
    1. **Respite needs to be recognised to a greater extent in the cared for assessment and personal budget**
    2. **All carers to be supported to have plans for the future and emergencies**
    3. **Working with home care providers to improve outcomes for unpaid carers**
    4. **Carers are supported to manage their health and wellbeing**
    5. **Monitoring and evaluation of outcomes**

2. Why we looked at this

Today’s health and care system is struggling to overcome unprecedented challenges. An aging and increasingly unhealthy population is placing statutory services under immense pressure with more people in need of support than ever before. At the same time, real-term funding for health and care is at an historic low. Cuts to local authority budgets have been particularly severe, and, as formal social care services continue to decline, the burden of care falls more and more upon unpaid carers. An unpaid carer is anyone who cares, unpaid, for a friend or family member who, due to illness, disability, mental health problems or an addiction, could not cope without their support.

The number of unpaid carers has risen by 16.5% over the last 15 years (Carers UK, 2015), outstripping general population growth (6.2%). It is estimated that there are currently just under seven million unpaid carers across the UK, a figure that far exceeds the professional health and care workforce (Carers UK, 2015). These carers are a key part of the health and care economy and are thought to save statutory services £132 billion each year, which is equivalent to the total annual budget for the NHS (Carers UK, 2015). At a local level, it is recognised that Norfolk has 99,419 unpaid carers, whose contribution to services has been valued at £1.9 billion per year, or more than £60 a minute (Carers UK, 2015).

Caring for a friend or family member can be very demanding and may have a significant adverse impact on a carer’s health and wellbeing, as well as their life in general. Nationally, 83% of carers feel that caring has a negative impact on their physical health and 87% feel that it has a negative impact on their mental wellbeing (Carers UK, 2012). The great contribution made by unpaid carers is highlighted explicitly in the Care Act (British Government, 2014), which imposes an obligation on local authorities to offer Carers’ Assessments – whereby carers are assessed to see if they have any eligible needs arising from their caring role that may require information or support – to all unpaid carers within their area.

In 2015, Carers Council for Norfolk and Healthwatch Norfolk worked together to survey 226 local carers about their experiences of information and support services relating to their caring role. Whilst there were many positives, carers identified issues finding accessible and timely information and stressed the importance of being supported to have a life outside of caring (Healthwatch Norfolk, 2015). One of the recommendations from this piece of work was to conduct a further study to explore these issues in more detail. To that end, it was decided to launch another survey in summer 2017 in order to coincide with the development of Norfolk County Council’s commissioning intentions for carers.

Whilst designing this survey, Healthwatch Norfolk was asked by the Norfolk Older People’s Strategic Partnership Board to incorporate some questions that would measure carers’ satisfaction with Carers Assessments, with a particular focus on older people who had been assessed over the telephone. This piece of work was intended to contribute to the implementation of the Living Longer, Living Well strategy, which sets out the plan for the provision of care for older people and their carers in Norfolk from 2016 to 2018 (Norfolk Older People’s Strategic Partnership Board, 2015).

3. How we did this

3.1 Designing the survey

The survey consisted of a mixture of 30 open and closed questions to gather quantitative (numerical) and qualitative (narrative) feedback. The survey was divided into three sections, as follows:

1. Views and experiences of Carers Assessments
2. Feedback about information and support for carers
3. Personal information about the carer and the person they care for

The questions were developed by Healthwatch Norfolk and Carers Council for Norfolk. Questions were amended on the basis of feedback from local carers and professionals at Carers Council for Norfolk's Locality Network Meetings.

The full survey is included in the Appendix.

3.2 Data collection

The survey was primarily distributed through Carers Council for Norfolk's locality and organisational networks. Further promotion took place face-to-face, at libraries and engagement events as part of Carers' Week (June), and online, through established carer networks and Norfolk County Council's 'Your Voice' network. Norfolk County Council also agreed to publicise the survey to all new clients contacting their telephone assessment service, but there was no evidence of any successful referrals through this route.

In order to gather feedback about Carers Assessments that would be useful for Norfolk Older People's Strategic Partnership Board, a particular effort was made to sample older carers with the help of specialist organisations such as Age UK Norwich, Age UK Norfolk, Living Independently in Later Life (LILY) and Norfolk's Older People's Forums.

Surveys were available online and in hard copy. Completed hard copy surveys were kept in a locked drawer for the course of the project. Online responses were stored on a password protection system. All data (hard copy and online surveys) were destroyed with the publication of this report.

3.3 Analysis

Hard copy surveys were inputted alongside online responses to facilitate analysis. Responses to closed questions were counted and reported using descriptive statistics (e.g. percentages). Further analysis was conducted to identify whether responses to closed questions differed for respondents aged 65+ compared to younger respondents and respondents caring for 50+ hours per week compared to respondents caring for a shorter amount of time. The results of this analysis should be interpreted with great caution (see Section 3.4).

Open questions were analysed using qualitative content analysis. Two Healthwatch Norfolk Research Interns grouped feedback for each open question into categories consisting of similar responses and the numbers of responses relating to each category were counted as means of identifying which categories were the most important. External scrutiny and validation of the coding process was provided through a coding workshop, during which researchers from Healthwatch Norfolk helped to refine categorisation.

3.4 Strengths and limitations

This survey was not intended to provide an account of the experiences of all carers in Norfolk. The sample was not random, which means that the carers who volunteered to complete the survey may not be representative of the general caring population. Whilst the number of carers (255) who completed the survey was sufficient for general analysis, there were insufficient responses to support detailed investigation; e.g. comparisons of feedback from younger carers and older carers. It is important to be mindful of this point where such comparisons have been made.

The purpose of the survey was to capture feedback from local carers about their experiences of information and support in Norfolk. The survey featured several open questions, which enabled respondents to go into detail about what really matters to them. It is important that this qualitative feedback is taken seriously, and statutory services should recognise that even a single comment can be an important resource when it comes to improving the quality of local services.

3.5 Ethical considerations

Data were collected anonymously and stored securely according to the principles set out in the Data Protection Act 1998. As a statutory organisation, Healthwatch Norfolk has an obligation to ask various equality and diversity questions (e.g. age, gender, ethnicity) to ensure that the organisation is engaging with individuals from all of Norfolk's local communities. Recognising that these questions could potentially cause offence, Healthwatch Norfolk worked with local carers and professionals to ensure that appropriate wording was used.

All personal questions were clearly indicated as being optional and included a "prefer not to say" response.

Equality and diversity questions were further amended on the basis of feedback from initial respondents.

4. Who we spoke to

Altogether, 314 carers responded to the survey, of whom 216 (69%) responded online and 98 (31%) completed a hard copy survey. Fifty-nine (59) responses (19%) were excluded from analysis due to missing data. This section outlines some information about the 255 carers who *completed* the survey. For context, comparisons have been made with data from a recent Carers UK survey, which captured information from 5,682 carers across the UK (2016).

4.1 Information about carers (respondents)

Age

Most respondents were older people. Nearly two thirds (64%) were aged 55+ and 42% were aged 65+ (*Figure 1*). This contrasts with the national picture from the Carers UK survey (2016), in which 57% were aged 55+ and 22% were aged 65+ (*Figure 1*). The higher proportion of older carers in our sample is likely due to the fact that we specifically targeted this population during recruitment (Section 3.2).

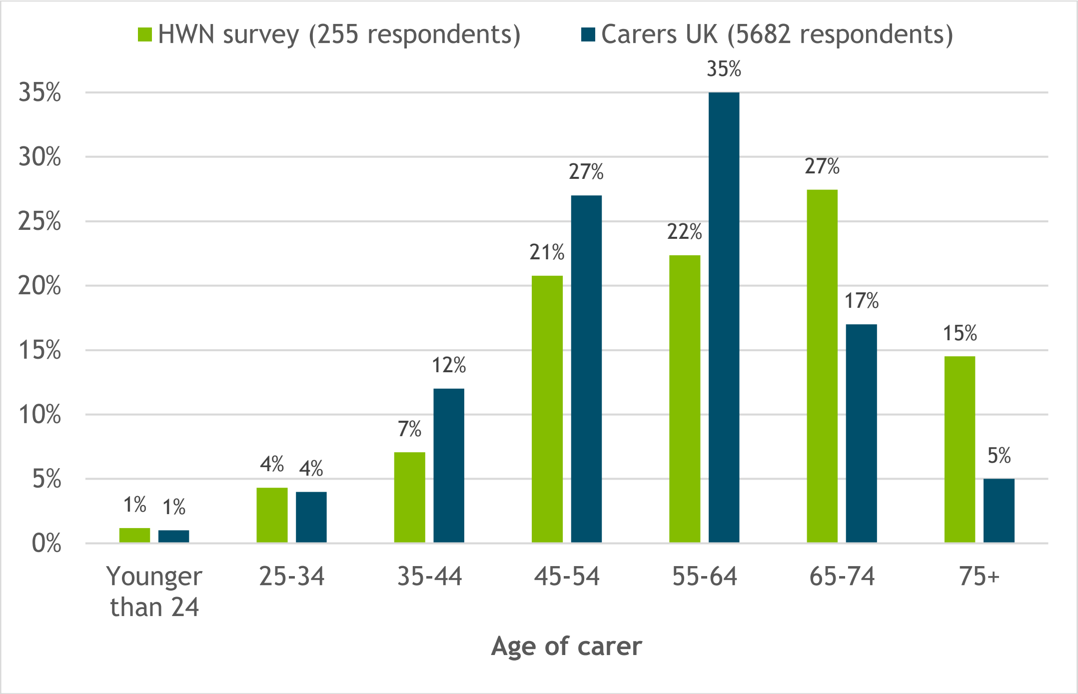

Figure 1. Age profile of HWN respondents compared to Carers UK data (2016).

Gender and ethnicity

More than three quarters (77%) of respondents were female, 21% were male and 2% did not specify. This finding matches the proportion of female carers (78%) who completed the Carers UK survey (2016). Ninety-two percent (92%) of respondents classified their ethnicity as being ‘White British’, which is reflective of local population data (Norfolk Insight, 2015).

Mental and physical health

The prevalence of ill-health was higher than expected. More than half (55%) of respondents (139 individuals) considered themselves to have a long-term physical or mental health condition(s), compared to 26% of the Carers UK sample (2016). The high prevalence may be due to the older age profile of our sample, as the incidence of long-term conditions increases with age. Indeed, respondents aged 65+ were more likely to report a disability (61% compared to 53%). Nearly two thirds (61%) of the 139 respondents who reported a disability said that they were living with a physical disability (*Figure 2*). Some respondents were living with more than one condition.

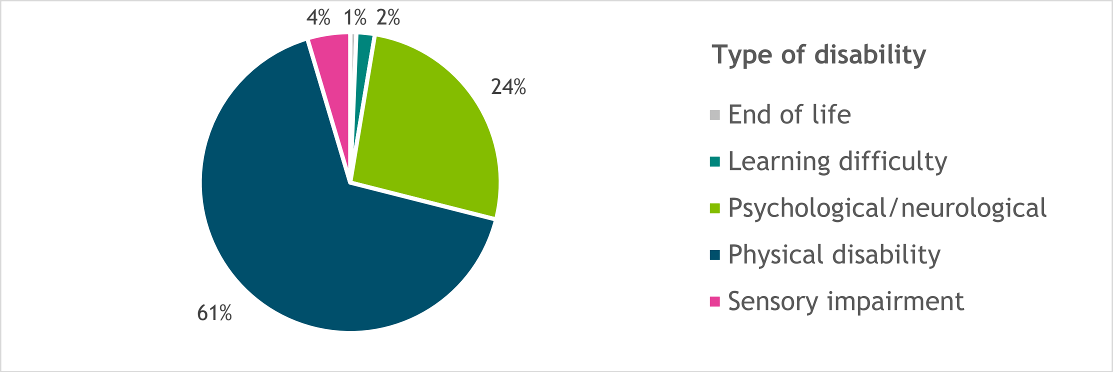

Figure 2. Type of condition(s) affecting long-term health of respondents.

Hours caring

More than half of respondents (56%) were caring for more than 50 hours a week, including carers who were providing care on a 24/7 basis (*Figure 3*). This is fairly consistent with Carers UK data (2016), in which 68% of respondents were caring for more than 50 hours.

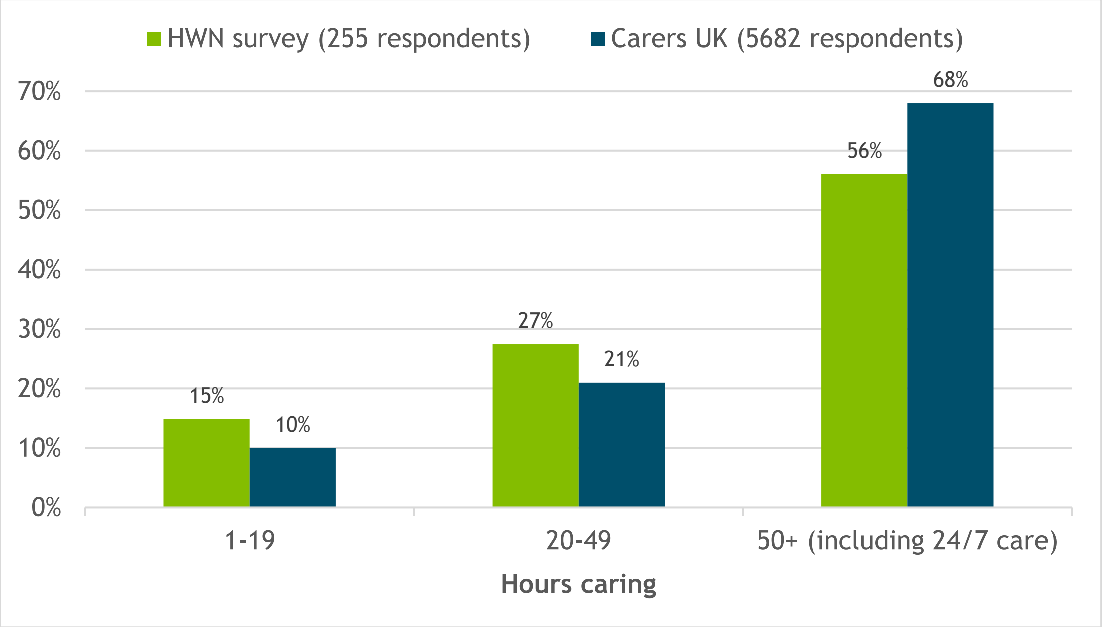

Figure 3. Hours caring per week for HWN respondents compared to Carers UK data.

Location

Two hundred and thirty-four (234) respondents provided the first half of their postcode (e.g. NR18). These respondents were located across Norfolk in a way that broadly reflects local population data (Norfolk Insight, 2015), as shown in *Figure 4*.

Figure 4. Location of respondents compared to Norfolk population data.

Figure 5 shows the location of respondents who provided postcodes:

Figure 5. Location of respondents based on the first half of their postcode.

4.2 Information about the people being cared for

Age

Fifty-five percent (55%) of respondents were caring for somebody aged 55+ and 43% were caring for somebody aged 65+ (*Figure 6*). Again, this is to be expected given the association between age and long-term ill-health. However, it is worth noting that more than a quarter (28%) of respondents were providing care for people aged younger than 25 (*Figure 6*). These respondents are likely to be parents caring for their children, as indicated in *Figure 7* (below).

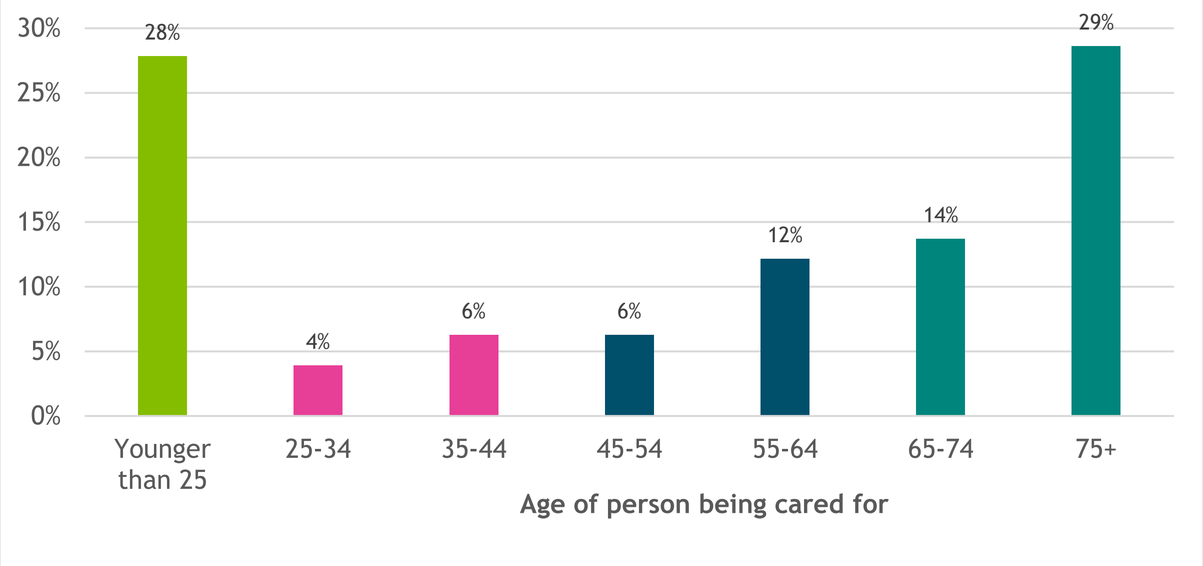

Figure 6. Age of person being cared for.

Generally speaking, older people were being cared for by older carers and younger people were being cared for by younger carers (*Figure 7*).

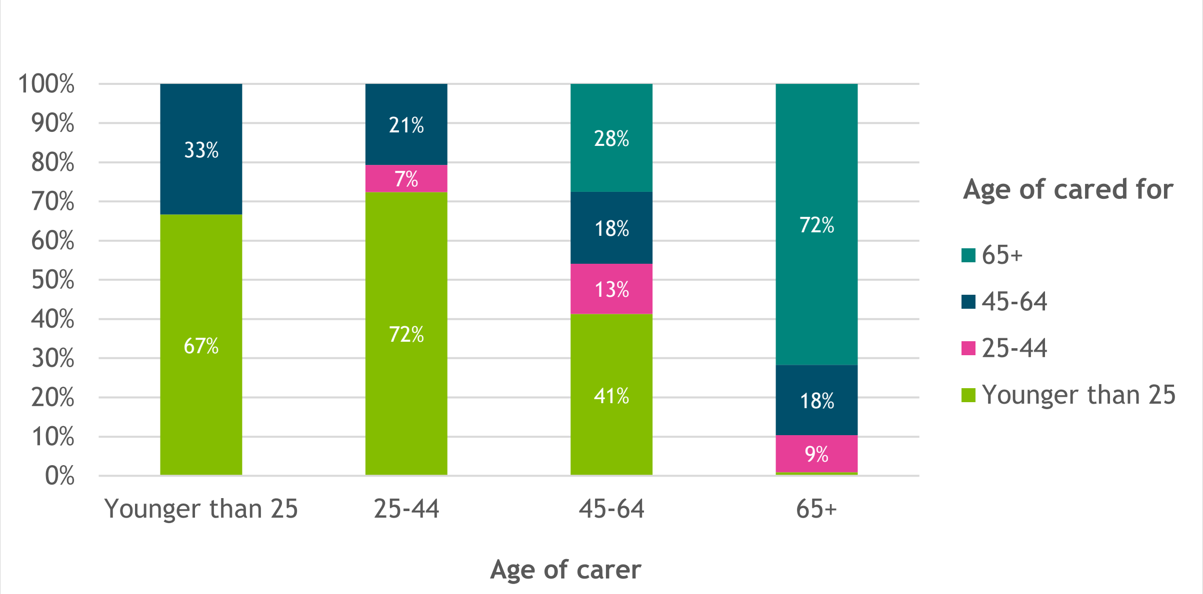

Figure 7. Age of carer by the age of the person they care for.

Mental and physical health

Respondents were primarily caring for people with a physical or psychological/neurological condition(s), as shown in *Figure 8*. Some respondents listed more than one condition.

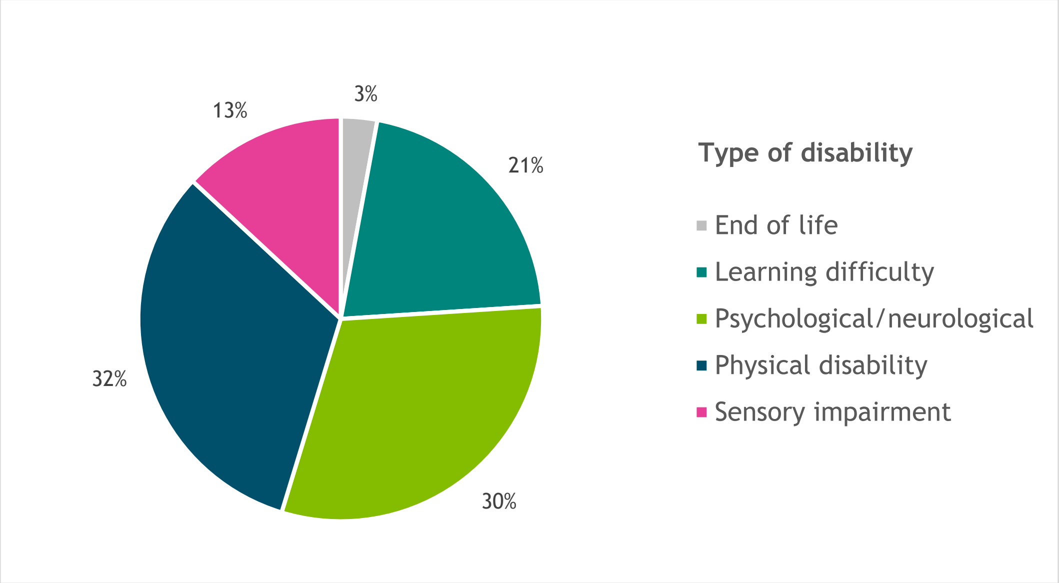

Figure 8. Type of condition(s) affecting person being cared for.

Different disabilities were more or less prevalent in different age groups. Physical disability was the most prevalent issue in older people (aged 45+), whilst younger people tended to be living with learning difficulties or psychological and neurological conditions (*Figure 9*).

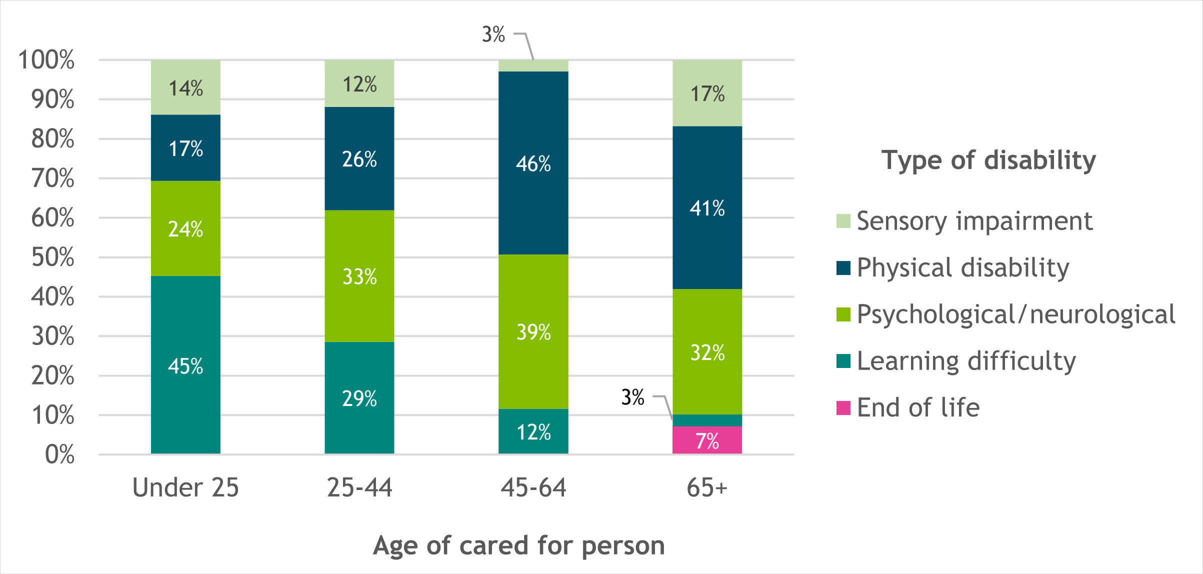

Figure 9. Prevalence of different conditions by aged of cared for person.

5. What we found out: Carers Assessments

This section was primarily completed by Healthwatch Norfolk.

5.1 Access and availability

One hundred and twenty (120) respondents (47%) said that they had received a Carers Assessment at some point during their time as a carer (*Figure 10*). The same number said that they had never received an assessment, whilst 15 respondents (6%) did not know or did not provide an answer (*Figure 10*).

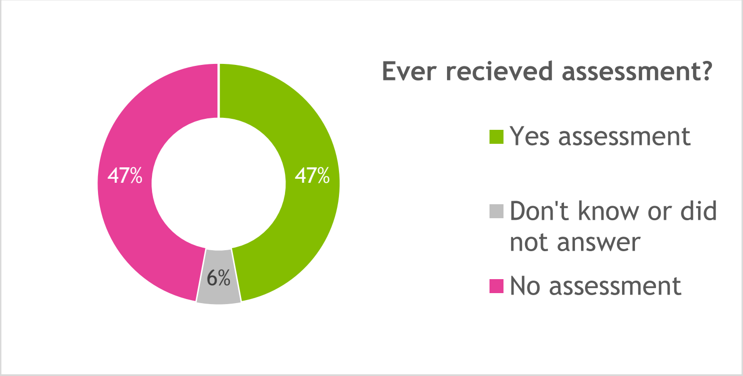

Figure 10. Proportion of respondents who have received a Carers Assessment.

Of the respondents who had received a Carers Assessment, 73 (61%) said that their assessment took place within the last two years. The other respondents had their assessments more than two years ago (43 individuals, 36%) or could not remember the date (4 individuals, 3%). Only the experiences of the 73 respondents who had their assessment *within the last two years* will be explored here, because the other responses are unlikely to be reflective of the current assessment service. All but two of these respondents (97%) were caring for a person aged 18+ and so would have accessed their assessment through Norfolk County Council's Adult Social Services. The respondents generally experienced a prompt service and 46 (63%) were assessed within three months (*Figure 11*). The longest delay was two years.

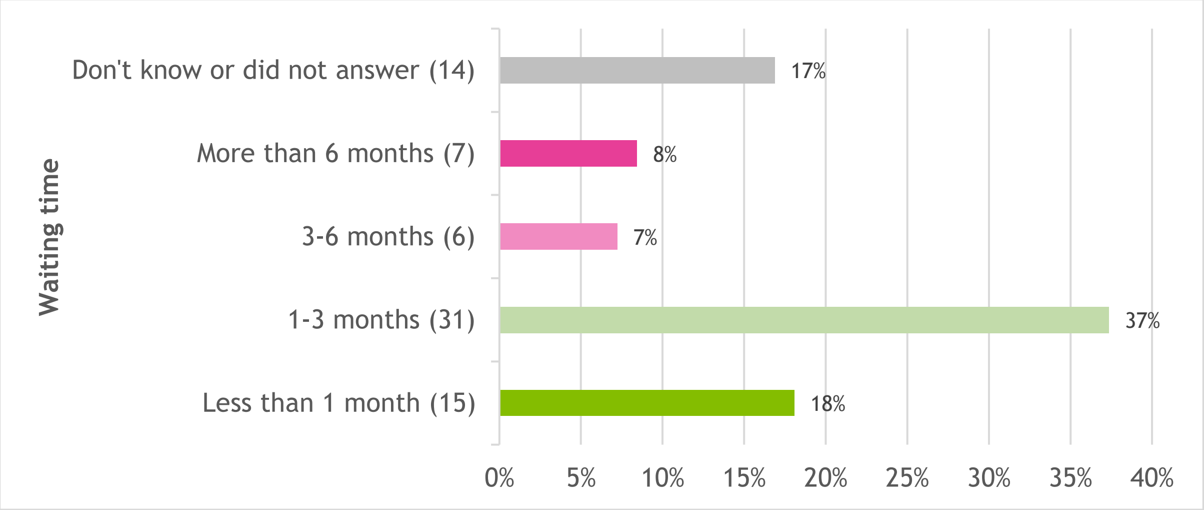

Figure 11. Length of time respondents waited for their Carers Assessment.

Fifty-eight (58) respondents (70%) had their assessment face-to-face inside their own home (*Figure 12*). Nine respondents (11%) were assessed over the telephone (*Figure 12*). Their experiences will be explored specifically in Section 5.4.

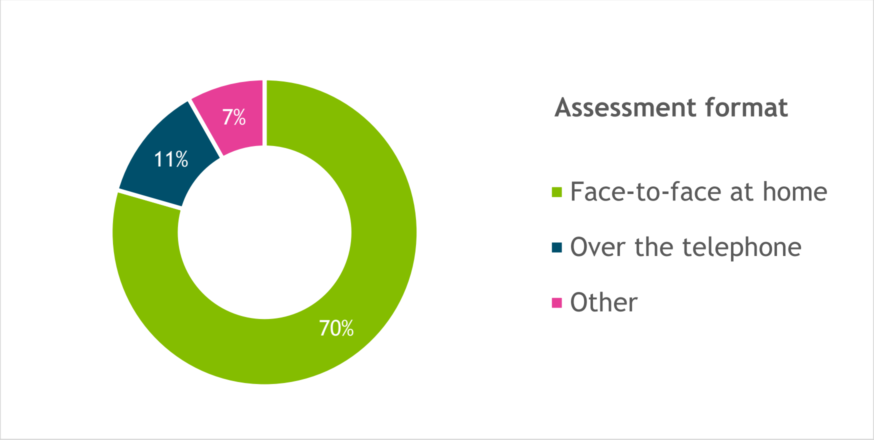

Figure 12. Format in which respondents were assessed.

5.2 Expectations and outcomes

Respondents were asked what they had hoped to get out of their assessment. This was an open question, allowing respondents to write whatever felt relevant to them. Seven respondents (8%) said they had no expectations or did not answer the question. The desired outcomes for the remaining respondents were grouped into five categories in analysis, as shown in *Figure 13*. Some responses were grouped into more than one category.

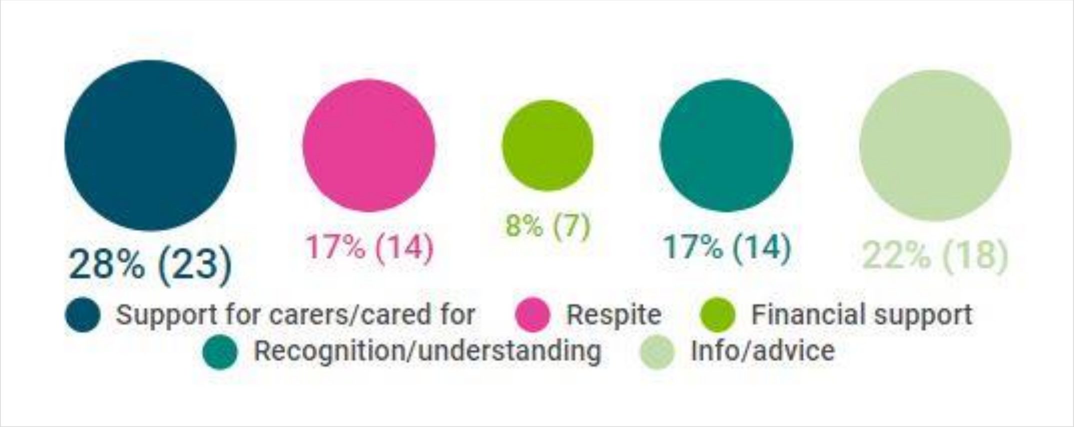

Figure 13. What did you hope to get out of your assessment?

These responses show that, although half of all respondents (53%) were hoping to receive some funding, support or services as a result of their assessment, more than one third (39%) were looking for “softer” outcomes in the way of information and advice or simply recognition and understanding.

Most respondents (44, 60%) felt that their assessment at least partly helped them to achieve the outcome they wanted (*Figure 14*). That being said, there were mixed responses, with more than one third of respondents (25, 36%) reporting that they did not find the assessment very helpful (*Figure 14*).

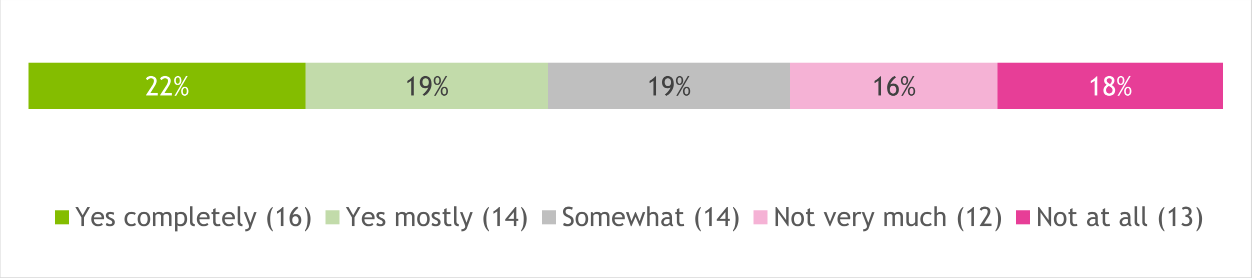

Figure 14. Did the assessment help you achieve your desired outcome?

Most respondents (60, 82%) had received some kind of outcome as a result of their assessment, as shown by *Figure 15*. Some respondents had received more than one outcome.

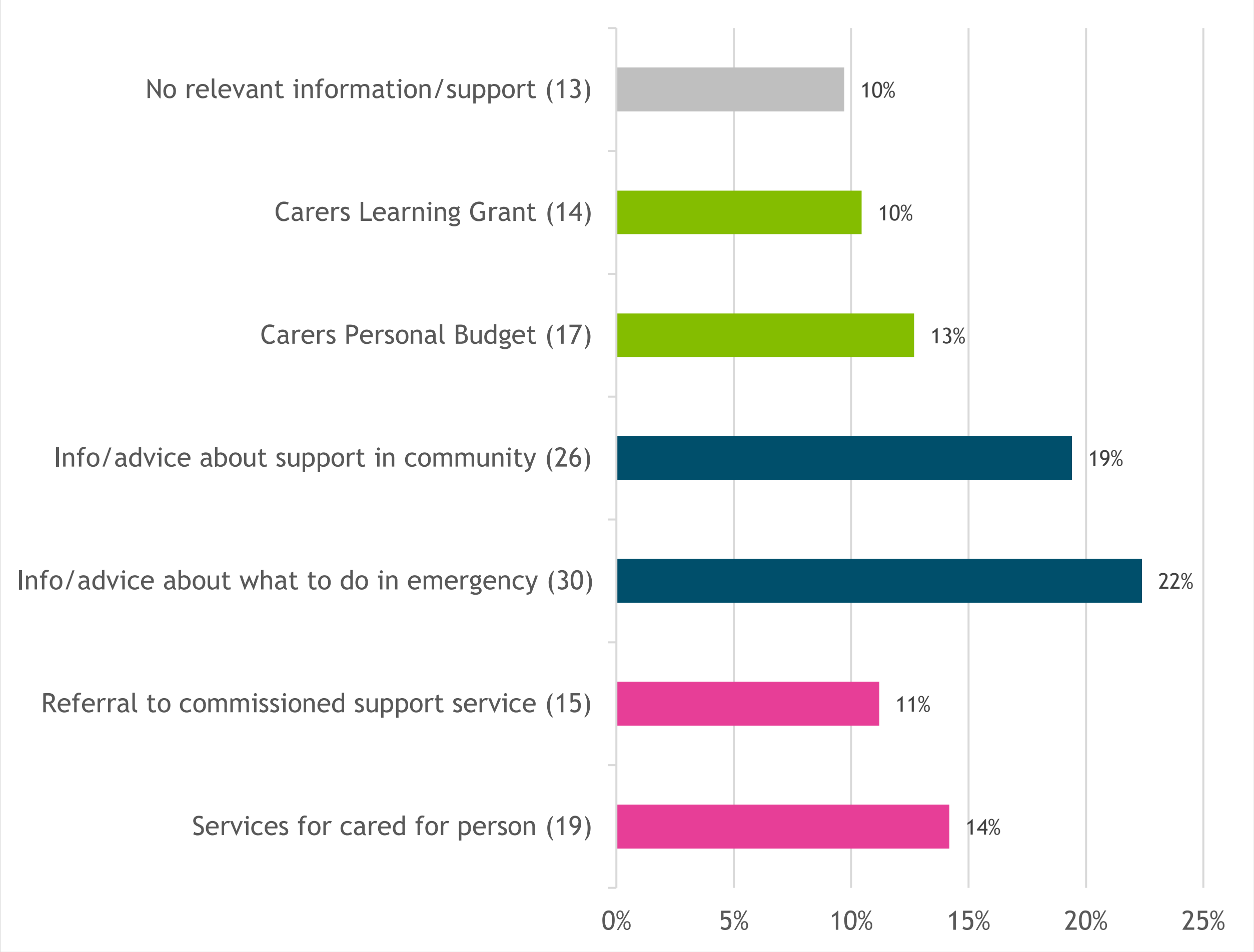

Figure 15. Reported outcomes following assessment.

There were mixed feelings as to whether the assessment, and any subsequent support, had helped respondents to continue caring. Forty-two percent (42%) of respondents (31 individuals) felt the assessment had not really helped them (*Figure 16*).

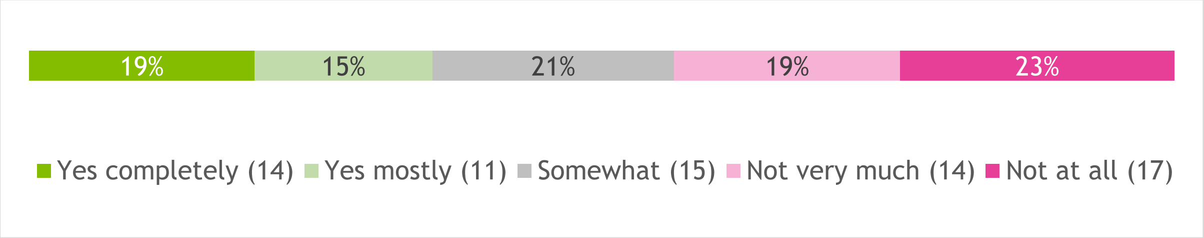

Figure 16. Has the assessment helped you continue in your caring role?

5.3 Overall rating

Respondents were generally positive about their overall experiences of the assessment process. More than half (56%) rated their experiences at 4 or 5 stars, compared to 19% who rated their experiences at 1 or 2 stars (*Figure 17*). A greater proportion of carers aged 65+ gave a positive rating (4-5 stars) than younger carers (53% compared to 42%). There were no differences in terms of hours spent caring and overall rating.

Figure 17. Respondents' ratings (1-5) of their experience with the assessment.

Respondents were asked to explain their rating. This was an open question, allowing respondents to write whatever felt relevant to them. Those who had given a rating of 1-3 highlighted a range of issues, which were grouped into four categories (*Figure 18*). Some responses were grouped into more than one category.

Figure 18. Reasons given by respondents who gave a rating of 1-3.

As shown in *Figure 18*, roughly half of all responses related to the outcome (or lack thereof) from the assessment, and the other half related to the experiences of the assessment itself.

Nothing really changed

Fifteen (15) respondents had given a negative or neutral rating because they felt that nothing had really changed for them following the assessment:

> “ We spent about two hour talking though things which turned out to be no help to me at all with my hobbies / down time from caring. Waste of our time. ”

> “ Although the small amount of cash provided me with some new craft items which I greatly appreciated and enjoyed, it did nothing to tackle the everyday issues of being a carer. ”

> “ The person was understanding and pretty good but there was little to offer me in my situation. ”

Lost in system

Six respondents felt that they had become lost in processes and procedures:

> “ I am still not very happy and still worried, social service visitor said she would get back to me but did not say she would send information for my son to phone them. Two weeks later I phoned social services and more or less told we know nothing about it, just phone when anything happens. My son is worried sick and his mental state isn’t good, on top of that a lot of physical and medical problems. ”

> “ I get no support for myself or my daughter. She had a speech therapy referral a year ago and still waiting. Feel alone. ”

Mistakes

Three respondents described mistakes that they felt had been made during their assessment:

> “ It didn’t provide anything for ME at all… I have never even received a copy of the assessment. Since then NCC has written to tell me that they forgot to let me know that from April we had to contribute [some money] towards my husband’s care and they have sent me an invoice for 11 week's arrears which I can’t pay... I think the whole thing was a waste of public money and it annoys me that they have ticked a box to say they have dealt with me when all they have done is treated me as if I was worthless and dropped me in the financial ordure. ”

Impersonal

Eight respondents felt that the assessment process was a bit impersonal and was not tailored to their particular needs:

> It appears that now you don't have a named social worker, as everything is task orientated. This is no good in an emergency, as the new person may not know the carers or their situation.

> [The assessor] just seemed to go through the motions to fill their quota. Same questions as always.

Respondents who had given a rating of 4 or 5 stars highlighted several positive aspects of their assessment, which were grouped into four categories (*Figure 19*). Some responses were grouped into more than one category.

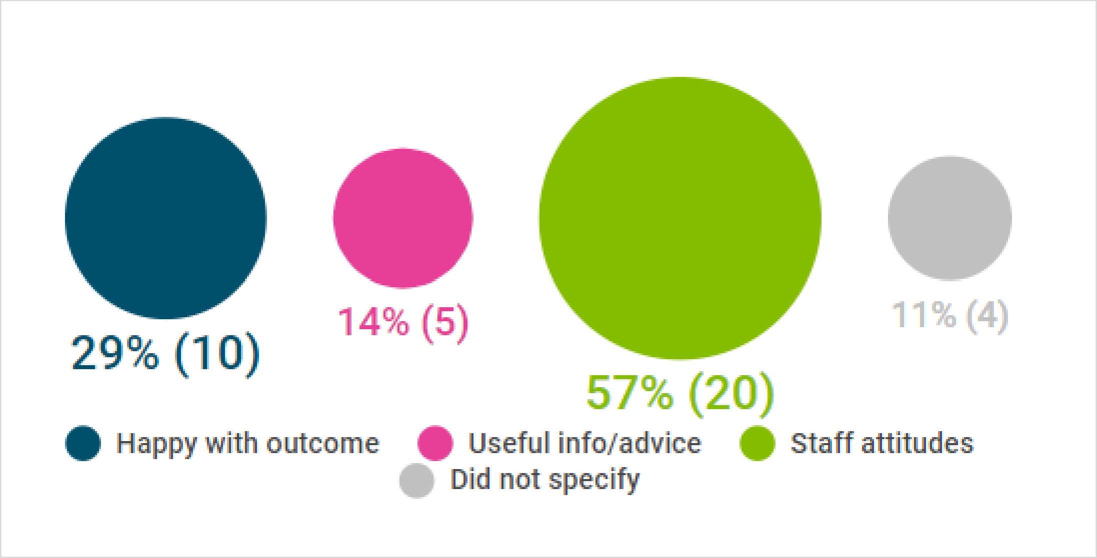

Figure 19. Reasons given by respondents who gave a rating of 4 or 5.

Happy with outcome

As before, some participants rated their experiences of the assessment in terms of the outcome rather than the actual process. Ten respondents gave a positive rating because they were pleased with the outcome they had received:

> My son requires a high level of care and I feel we have been supported and respite has been put in place.

> We were very pleased with our monetary outcome. As I love my garden it was a large form of relaxation from my caring role and I had been worried about the overgrown tree.

Useful information and advice

Five respondents were happy with the information and advice that they had received during the assessment:

- “ I had no info prior to assessment, now I have contacts to [the commissioned service (formerly Norfolk Carers)], West Norfolk Carers, Swifts and District nurses. ”

- “ They explained everything to me and gave me books and information about dementia. ”

Staff attitudes

Respondents who gave a rating of 4-5 stars overwhelmingly did so because of the attitudes of the staff members who had been involved in their assessment. In total, there were 20 positive comments about staff from the assessment service:

- “ The assessor was a good listener and heard what I had to say and offered me her support in getting respite care. ”

- “ The assessor was caring and listened to my needs rather than my husband’s. For the first time for a long while I felt someone cared for me. ”

- “ They are very informative and strive to help the best they can. ”

- “ I was listened to and my concerns were understood. I felt that the assessor had empathy. ”

Respondents were also asked how they felt the assessment service could be improved. Twenty-four (24) respondents (33%) said that they did not know or did not specify and answer. The suggestions from the remaining respondents were grouped into six categories, as shown in *Figure 20*.

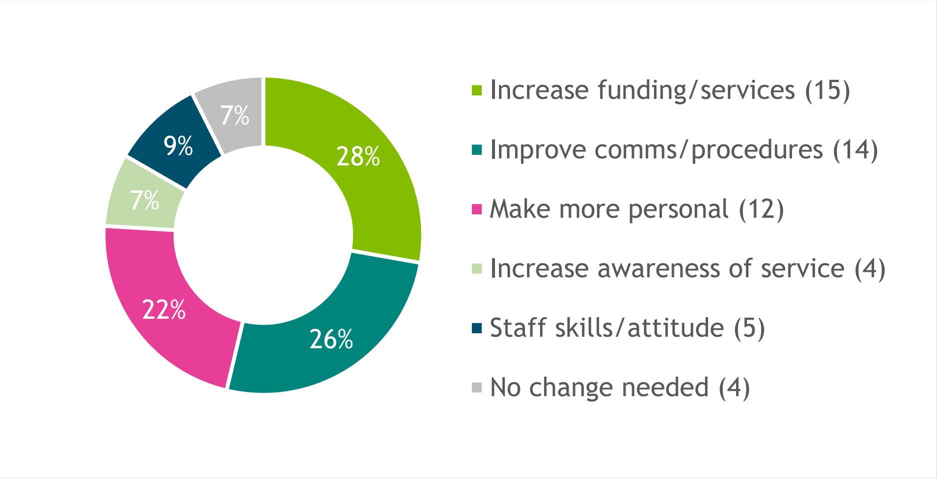

Figure 20. Suggested improvements for the Carers Assessment.

Increase funding/services

Fifteen (15) respondents highlighted their concerns with the lack of funding for carers’ services:

- “[I need] actual help with an actual person who could take my charges out/visit and generally relieve me of the constant race against time. Information and booklets are somewhat of a help but I need a REAL person. I just don’t have time to keep on top of running a home/garden/outside activities, etc.”

- “More help - not just money I would have liked to have found groups I could go to - to meet people my own age outside of caring completely to try and feel like a normal teenager.”

- “We need more respite caring day and night is exhausting.”

Improve communications/procedures

Fourteen (14) respondents suggested some ways to improve communication and procedural aspects of the assessment processes:

- “An annual follow up telephone call would be helpful and show support.”

- “If you know when you would get one it would be a ray of hope, whether you got what you needed or not. Also personal touch would help.”

- “After the assessment the notes taken should be reviewed. Officers should ensure they carry out all the promises made.”

- “Carry out the carers assessment first and then the cared for persons assessment - so that time the carer away can be taken account of in the cared for persons assessment.”

Make more personal

Twelve (12) respondents felt that the assessment should be made more personal:

- “To listen what the client needs are and if there need to have it in easy read or on audio for people who are blind. Especially if you are dealing with a young carers because not everyone does always fit in to the boxes and that is very important to the person who is caring for someone.”

- “I thought the assessment itself was a little demoralising, just few little tick box questions to decide if you’re worth a small cash donation. We as carers put our lives on hold to provide a good standard of care to our loved ones, some more than others. Yet all we get is a little bit of cash once a year if we’re lucky! A few suggestions of support, local groups and mental health support would go a long way.”

Increase awareness of service

Four respondents felt there was a need to do more to promote the service so that carers were aware of it:

> “By advertising it more because it was just by chance I spotted it in the Norfolk Carer magazine & never heard of a Carers Assessment before!”

Staff skills/attitudes

Five responses related to a need for staff to have better support and training:

> “Would be good if all carers were made aware and contacted each year to ask if they would like an appointment. More training so that the assessor was able to give more advice on other services available and how to access this and any other financial help.”

5.4 Older people and experiences of telephone assessments

Thirteen (13) respondents had been assessed over the telephone (this includes four respondents who did not complete the survey). Eight of these respondents (62%) were aged 65+ and 12 (92%) were caring for an older person.

Only one respondent said that they had been offered a face-to-face assessment; the others were not given a choice (eight) or did not know (four).

With so few respondents assessed over the telephone there is little value in making detailed comparisons with respondents who had face-to-face assessments. However, it may be of interest to note that carers who were assessed over the telephone tended to be less positive about the assessment. Only three (23%) said that the assessment (and any subsequent care plan) had completely or mostly helped them to continue in their caring role, compared to 40% of carers who had been assessed face-to-face (*Figure 21*).

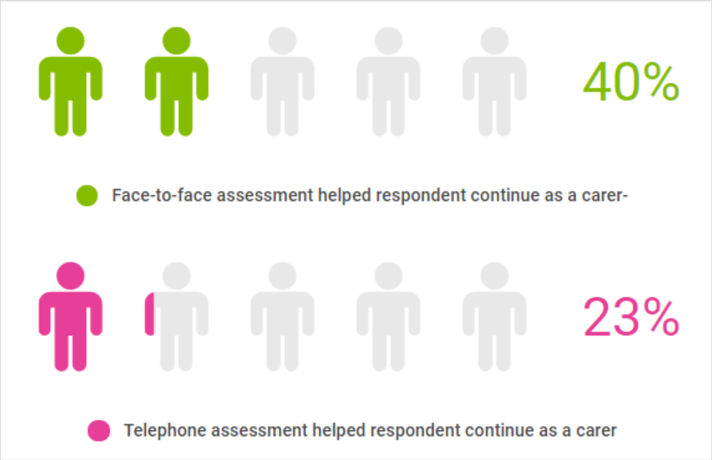

Figure 21. Did the assessment help? Comparison of telephone and face-to-face.

Carers who had been assessed over the telephone were also less likely to leave a positive overall rating of their experiences (*Figure 22*).

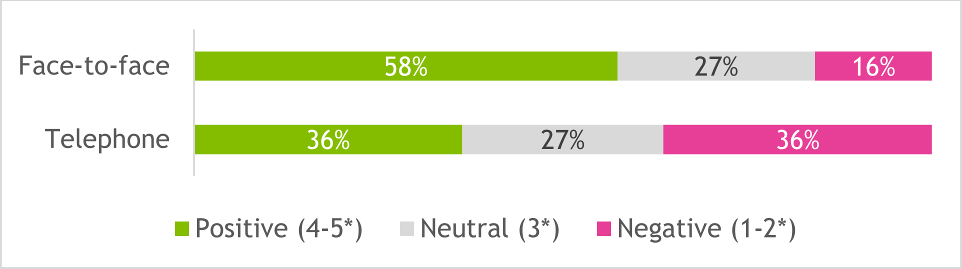

Figure 22. Overall 1-5* rating. Comparison of telephone and face-to-face.

Two respondents left comments that directly referred to the assessment format:

> Had to pester for an assessment and then only by phone when I wear hearing aids. I am not good on phone.

> I think all assessments should be face-to-face.

Again, given the small sample size of carers who had recent experiences of assessments, especially telephone assessments, it is important not to make too much of these findings.

5.5 Summing up

In general, feedback about the assessment service was fairly positive. It should be noted that staff were particularly highly praised. It is clear that some respondents really appreciated the information and advice that they were given and they also valued having the opportunity to talk to somebody about their life and needs as a carer. In this way, the importance of the assessment as an intervention in its own right should not be underestimated.

However, a significant proportion of respondents felt that they needed more than information and advice and were disappointed that their assessment seemed to have no real outcome for them, highlighting what they perceived to be a lack of support and services for carers in Norfolk. To that end, information and advice should not be regarded as a substitute for formal provision and the function of the assessment as a gateway to support and services must not be forgotten.

At the time of writing, Norfolk County Council was running an internal evaluation of their assessment service. Healthwatch Norfolk was not able to be involved in this evaluation and has not seen the results. As the Council continues to look for ways of operating with more and more restrictive resources, it will become increasingly important to ensure that Carers Assessments strike the right balance between the information and advice and gateway functions, so that formal services continue to be provided for all those who need them.

6. What we found out: Information and support for carers

This section was primarily completed by Carers Council for Norfolk.

6.1 Information and advice about caring

All 255 respondents were asked where they went for information and advice. Around one third (30%) said that they approached health and care professionals (*Figure 23*). One in five respondents (20%) were receiving information from a voluntary or community organisation, whilst a further 16% said that they would contact the commissioned support service (formerly Norfolk Carers) (*Figure 23*). Some respondents were receiving information and advice from more than one organisation.

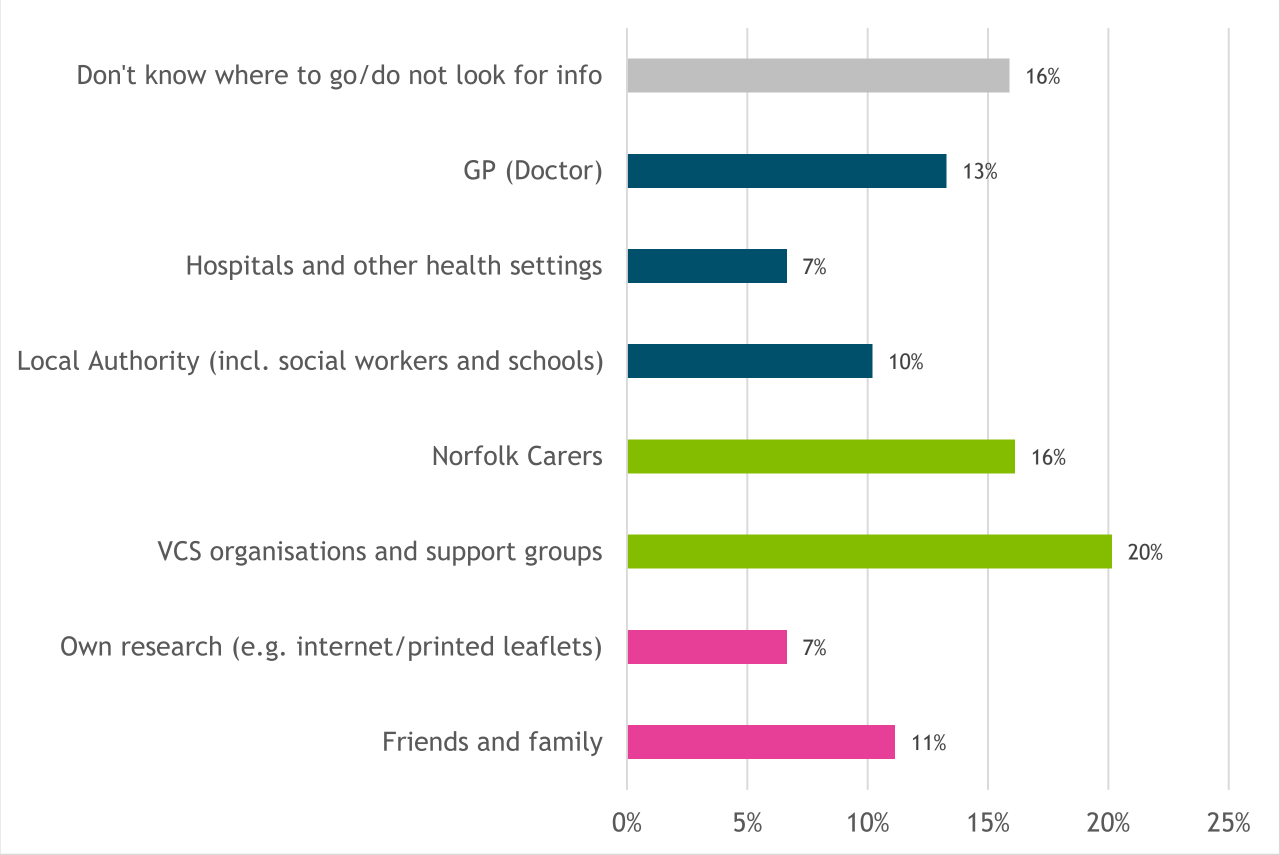

Figure 23. Where carers are looking for information and advice.

As *Figure 23* shows, a significant minority of respondents either did not know where to go or did not look for information (16%), whilst others said they relied upon their own research (7%) or friends and family (11%). Several respondents highlighted their frustration with their experiences of information and advice for carers in Norfolk:

> I have given up bothering. Everyone finds a way to make sure that I don't get anything and I am fed up with continually being signposted to another useless organisation.

Respondents were asked to specify which voluntary organisations they received information from, and the following were commonly referenced (Table 1).

Table 1

List of voluntary organisations commonly approached for information.

Organisation	Times referenced
MIND	15
Age UK	9
Family Voice	8
Local Offer	7
Local dementia café	6
Alzheimer's Society	5
Carers Council for Norfolk	5
Age Concern	4
Admiral Nurses	3
ASD Helping Hands	3
Equal Lives	3
National Autistic Society	3
Sensational families	3

One hundred and fifty-eight (158) respondents (62%) listed the places that they would like to access information in future. Their responses were grouped into eight categories (*Figure 24.*) Some responses were grouped into more than one category.

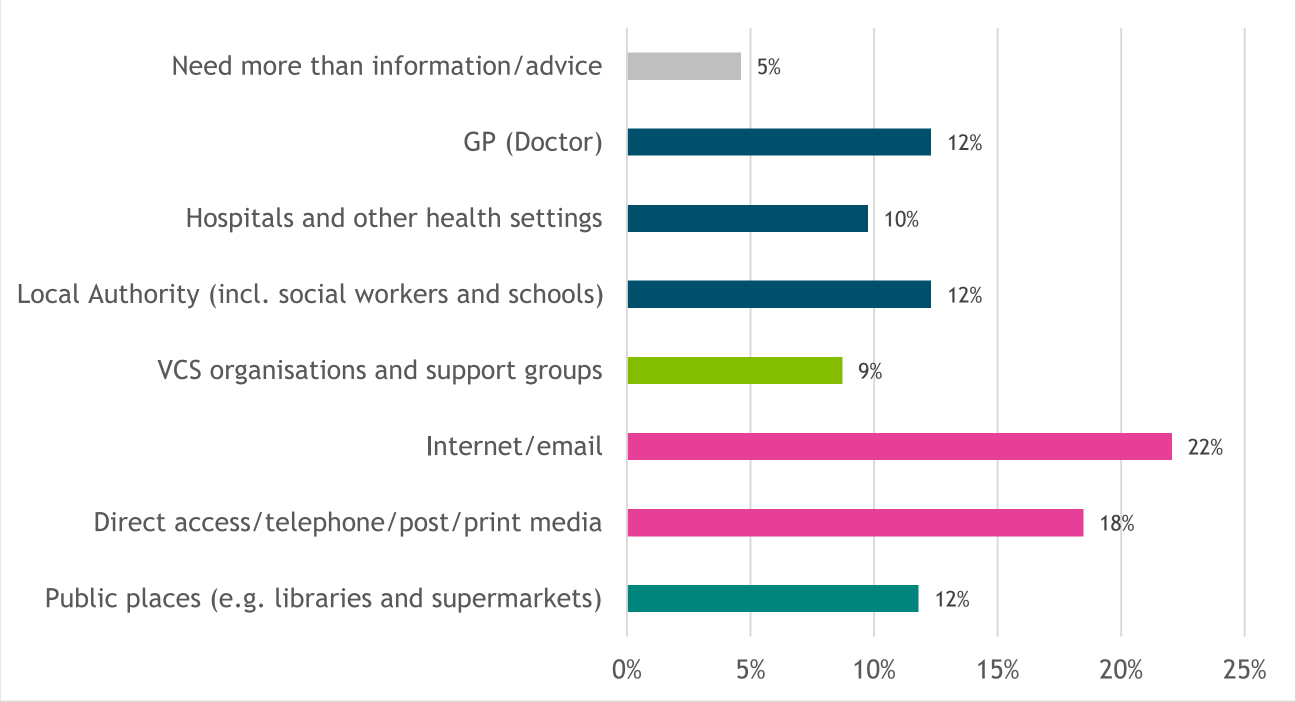

Figure 24. List of people/places where respondents want to receive information.

Figure 24 (previous page) shows that respondents expected health and care professionals, especially GPs, to continue to be key sources of information and advice in the future. It was also suggested by some (12%) that information should be provided in public places such as libraries and supermarkets. Many comments (22%) identified the internet as an important resource, but it is worth noting that 18% of feedback related to traditional channels such as the telephone or post:

> Happy with current situation, would be very unhappy if all info eventually crossed to internet only, since do not use a computer (nor ever will do in the future through choice, not technophobia! eg. very disturbed to hear that some official carers allowance claim forms etc. can only be accessed online now! (Paper and telephone can reach 100% of carers- computers only ??%?)

> My ability to attend monthly meetings is limited. Information is now online and I cannot access it due to poor eyesight. I need paper information which is no longer available. I can read, but I have to pay someone to download online info and send emails etc. My poor eyesight and age make using the computer difficult so I miss out. I never became competent on my computer. I could also benefit from information on the telephone but do not know who to call.

As before, some respondents (nine individuals, 5%) left general feedback as to their concerns about information and advice for carers in Norfolk:

> Information is so much harder to obtain now sub groups (service planning groups) and carer groups have been disbanded in LD. Nobody is allocated as a nominated social worker anymore. It’s time consuming and frustrating phoning and explaining all your difficulties over the telephone or internet to then be lost in an uncaring system.

> I don’t want information I want help and money. It is cynical for organisations to say that the provision of information is helping a carer - my experience is that everyone is bending over backwards not to spend money and it is insulting my intelligence to pretend otherwise.

6.2 Health and wellbeing and confidence to continue caring

Two hundred and fifty-two (252) respondents responded to questions about whether they felt able to maintain their health and wellbeing and whether they felt confident continuing in their caring role. More than two in three respondents (68%) felt completely or mostly confident about continuing caring, whereas 37% felt completely or mostly able to maintain their own health and wellbeing (*Figure 25*, overleaf).

Respondents aged 65+ were more likely to feel able to maintain their health and wellbeing than younger respondents (49% compared to 30%). There were no differences in hours cared for. There were no differences in confidence when considering respondent age or hours cared for.

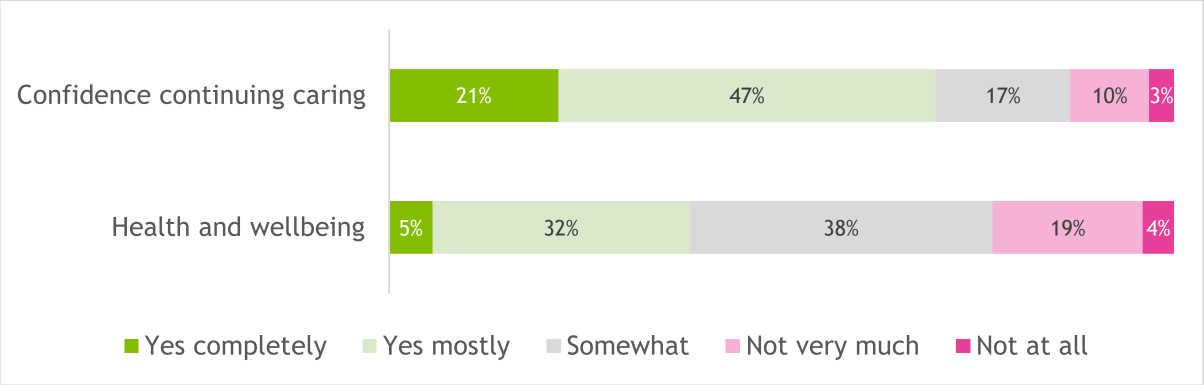

Figure 25. Do you feel able to maintain your own health and wellbeing?

Two hundred and twenty-four (224) respondents responded to a question asking what would help them to better maintain their health and wellbeing and 221 responded to a question asking what would help them to feel more confident continuing in their caring role. Both of these questions were open, enabling respondents to put their own words what they considered would actually help them, rather than choosing from a list of options. *Figures 26* and *27* show the words that were most frequently used; the larger the word, the more times it occurred in responses.

Figure 26. What would help you to better maintain your health and wellbeing?

Figure 27. What would help you feel more confident continuing in your caring role?

Analysis was initially undertaken for each question separately. However, as the above word clouds indicate, respondents were highlighting similar issues in both questions. To that end, responses were combined and categorised together. Six categories were identified, as shown in *Figure 28.*

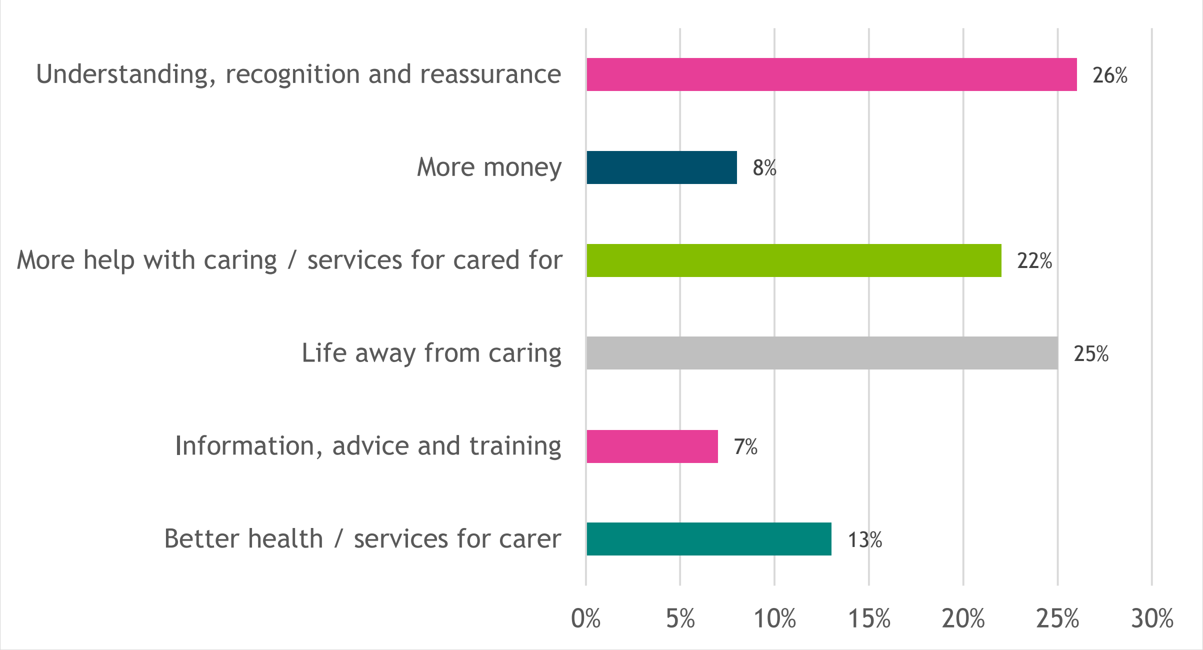

Figure 28. List of things that would help carers maintain their health and wellbeing and make them more confident to continue caring.

Understanding, recognition and reassurance

The responses most commonly related to the need for more understanding, recognition and reassurance, both from statutory services and elsewhere. It was clear that some carers felt as though they had been left to struggle on alone:

> We have no children and no close relatives - so I'm on my own and have been for the past 5 years.

> Reliable support from professional bodies, as I feel like doing this all alone.

Respondents expressed the importance of having “someone to talk to” and “being really listened to” and valued being able to meet with other carers:

> Well-being groups, exercises and classes of like-minded carers who share a common interest in the role of a carer.

> More information and follow up in the role of the carer and group discussion on a regular basis.

Some respondents were particularly concerned about the future, and wanted to know that the person they cared for would be safe and happy if they were unable to continue caring. This was particularly true for parents, who voiced some very real worries about their children:

“Not have to worry about the future for my young person when I am old, frail or dead.”

“Knowing that my child will be cared for in adulthood.”

“Knowing that the light at the end of the tunnel will be reached before I myself am too old to see it.”

Life away from caring

Respite is known to be a hugely significant factor in the health and wellbeing of carers, and 25% of all responses related to the importance of being able to have a life outside of caring:

“[I don’t want] to be trapped in this caring role.”

“A decent break knowing that (the cared for) is being cared for properly.”

For some respondents, it was a simple as finding a couple of hours to spend on themselves:

“Time to be able to go to the gym or enjoy a hobby without having to worry about finances or the person I care for.”

“More 'me' time / More help in home and garden / Financial support to maintain garden and home.”

Other respondents were looking for planned respite breaks, either regular or occasional. Whilst many organisations recognise the need for future care planning, it is not generally considered to be high on the preventative list for safeguarding the wellbeing of carers:

“Opportunity for respite care for my husband so I can have a break or for us both to go together for respite.”

“A break now and again but that won't be happening, I do get tired and fed up sometimes. My son is demanding so I get run off my feet no one else to look after him if I did go away for couple of days.”

On the other hand, for some respondents, the real issue was finding unplanned respite at short notice, for example in the event of an emergency:

- To know that there is back up support available if our situation were to change – long term not short notice.
- Knowing that someone could step in and support my husband at short notice if I needed a break away.

More help with caring / services for cared for

Twenty-two percent (22%) of respondents felt that it would help their health and wellbeing and confidence if they could have more practical help with caring:

- More efficient help from outside carers.
- Carers that are more helpful and not always in a hurry.
- Too many short-time/leaving carers… plus lack of communication.

Some respondents were looking for flexibility from paid caring services:

- Support from carers at weekends.
- Having help at night so as a carer I could get a good night's sleep.
- Carers coming in at weekends, I have asked twice and they have not had the staff to provide any carers at present.

Several respondents identified the importance of having support that was reliable and consistent:

- Appropriate services being available for the person I care for. People working within those services doing the things that they said they would. Not having to do extra things because others are not available or have not done as agreed in regard of services for person I care for. Making hoops easier that have to be jumped through… Back up on request not 4 – 5 days down the line.

Some respondents were mutual carers:

- I care for my husband and he cares for me, we both have disabilities and both need mutual help.
- We are both 80 and have disabilities where we need to help one another as best we can.

It was recognised that things could be difficult for carers whose loved ones refused to accept care:

- “My mother wouldn’t accept care so there was nothing to be done to help me.”
- “I wish the person I care for was more co-operative – won’t accept care.”
- “For the person I am caring for to accept more help from other people and rely on me less.”

Better health / services for carers

Many respondents (13%) highlighted the difficulties with looking after their own health and wellbeing on top of the health and wellbeing of the person they cared for:

- “Not having to worry so much about both my son who we look after but also my husband who shares the care, he has significant health issues.”
- “I am a disabled carer looking after a disabled mum.”
- “If I had my hips knees and back done then I might be able to get about more. I have osteo arthritis and crumbling bones in my back.”

There was a feeling that local health services could do more to respond to their needs:

- “A carers health check at the GP surgery. Carers tend to neglect their own health to care for others as I did when I had breast cancer but was too tired and too busy to notice. GP practices do not have the GP's or time in ordinary appointments to examine you.”
- “I have osteoarthritis and spondylitis. A pain free day and a full night's sleep would be great.”
- “Cannot bend down low because of problems so find it very difficult to remove shoes and clothing. Found myself the other day not being able to stand up in the kitchen as my legs kept going under me… have other problems for which I am under the N & N hospital. A couple of months ago put off having a small op because I had no one at home for my husband and was told I need to go back to the GP if I want it done. Since then I have had problems on 4 occasions.” “
- “Better response from Norfolk Mental Health Services. 3 years waiting for an appointment does not help me keep sane.”

Some respondents felt that more could be done at GP surgeries and suggested it would be useful for both carer and cared for to have access to the GP service without duplicating travel and having to factor in replacement care:

- “Doctors appointments with double time slots available for both parties.”
- “Not being able to pre-book appts at doctors. Help booking and taking wife to appointments.”

Again, there was an issue of finding some time away from caring:

- “Having time to take a regular exercise class each week, learning some yoga or meditation.”
- “Being able to attend groups, classes etc. with someone to stay with the person I care for 24/7.”

Money

For the most part, responses relating to finances were about the prohibitive cost of care services for when the carer wanted some time away:

- “The sitters service is too expensive - meetings and theatres are difficult to get to and have to pay £50 for a sitter makes it impossible to go anywhere because of the cost.”
- “Access to home sitters who are able to offer care at personal level without making the carers 2/3 hours respite beyond affordable.”

Other comments related to challenges between working and caring:

- “Not having worry of wages lost, even though on zero hours & flexibility of picking shifts... Haven’t got stamina to do both as have own long term health issue.”

Information/Advice/Training

Seven percent (7%) of all comments related to a desire for more information, advice and training:

- “More help and support firstly for my daughter and someone who I know is there who can give me good, up to date information both for my daughter and for myself. It is never clear what is available, feels like I am in a dystopian maze most of the time.”

Both general and specific training needs were expressed:

- “Some training in dressing an adult as it is not the same as dressing a child.”

- “Knowledge on how much it would cost if we had to increase carers visits.”

As reported earlier, the role of carers groups was seen as key:

- “More information and follow up in the role of the carer and group discussion on a regular basis.”

- “Continuing to receive information from organisations such as CCN.”

7. Next steps

The findings from this survey paint a diverse picture of the experiences of unpaid carers in Norfolk. It is clear that, for some carers, high quality information and advice, or simply some reassurance, can be immensely valuable. To that end, it is important to ensure that all carers have access to timely and appropriate information and advice. That being said, other carers felt they needed more tangible support or services. In particular, it was a recurring theme that carers wanted more support to help them have some time away from caring (respite) and it is important that Norfolk County Council continues to provide this support.

Recommendations for organisations across the health and social care system, including the newly commissioned service to support unpaid carers, Carers Matter Norfolk, are as follows:

1. **The importance of respite in supporting carers to manage their health and wellbeing needs to be better recognised through both cared for and carer's assessment and personal budget processes.**
    a. Carers to be involved in co-producing a review of the respite and social activity offer from Norfolk County Council, other statutory providers and the voluntary and community sector.
    b. A Norfolk County Council, Member led, Task and Finish Group to review the Council's role in enabling the voluntary and community sector to respond to the needs of carers for social inclusion and respite.
    c. Carers Matter Norfolk to co-produce and co-deliver awareness training sessions for Integrated Health and Social Care teams.

2. **All carers are supported to have plans for the future and emergencies.**
    a. Carers are involved in co-producing a revised Carers Emergency Card scheme with Norfolk County Council.
    b. Carers Matter Norfolk to co-produce a carers emergency plan toolkit and raise awareness with statutory, voluntary and community partners of the need to support carers to plan for emergencies.
    c. Carers Council for Norfolk and Carers Matter Norfolk to work with Acute and Community Hospitals to ensure that emergency planning is embedded within discharge processes.

3. **Working with home care providers to improve outcomes for unpaid carers**
    a. Establish a pathway for unpaid carers to be involved with co-producing and co-delivering training of home care providers.
    b. Norfolk and Suffolk Care Support (Carers Matter Norfolk) to undertake a programme of awareness raising with home care providers equipping them to identify hidden carers and signpost them to appropriate support.

4. **Supporting carers to manage their health and wellbeing.**
    a. Carers Matter Norfolk to work with statutory, voluntary and community providers and commissioners to improve the provision of information and advice and support to carers in navigating the health and social care system.
    b. Carers Council for Norfolk and Healthwatch Norfolk (subject to appropriate funding being made available) to co-develop a health and wellbeing strategy for carers with Norfolk Public Health to increase self-management and resilience.
    c. Carers Matter Norfolk in partnership with Public Health to devise and implement a public health campaign around caring and its impact on health and wellbeing.
    d. Carers Matter Norfolk in partnership with Norfolk Local Pharmaceutical Committee to develop a carer friendly pharmacy training programme, working with community pharmacies to pro-actively identify carers and signpost or refer them to appropriate support.
    e. Carers Council for Norfolk and Healthwatch Norfolk (subject to appropriate funding being made available) to work with Norfolk County Council and NHS CCG commissioners to ensure that carers are included and prioritised where appropriate within service/contract specifications for tenders such as those relating to Social Prescribing and Loneliness and Social Isolation projects and services.

5. **Monitoring and evaluation of outcomes**

    Carers Council for Norfolk and Healthwatch Norfolk (subject to appropriate funding being made available) to monitor and evaluate the progress towards achieving these outcomes through the Carers Council Countywide Strategic Partnership Group.

8. References

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9. Appendix

A full copy of the (postal) survey may be found overleaf.

Can you help us?

Are you providing unpaid care for a relative, partner or friend in Norfolk?

Carers Council for Norfolk and Healthwatch Norfolk would like to know more about what life is like for carers in Norfolk. By taking part in this survey, you can help us to improve information and support for local carers like you. The survey has 30 questions divided into four sections. Some questions may not be relevant to you. Most questions are multiple choice and should not take long to complete.

All responses will be anonymous. We will publish the feedback we collect on our public facing website and we will produce a written report that will be shared with Norfolk County Council and other local health and care organisations so that they can learn how you would like to receive information and support to help you in your caring role. You will not be named at any point and we will take great care to make sure that nobody will be able to find out who said what.

The closing date for this survey will be Monday 14st August. You can return the survey to Healthwatch Norfolk using the freepost envelope that was provided. Please note that by completing the survey you are giving your consent to take part. Once we receive your completed survey it may not be possible for it to be withdrawn.

If you have any questions or concerns, please contact Edward Fraser, Healthwatch Norfolk Project Officer, as follows:

Freephone: 0808 168 9669 **Email:** enquiries@healthwatchnorfolk.co.uk

About Carers Council for Norfolk

Carers Council for Norfolk (CCN) is the independent user-led charity representing unpaid carers in Norfolk. We believe carers should be involved from the beginning in the design and delivery of the services they receive.

About Healthwatch Norfolk

Healthwatch Norfolk is the consumer champion for health and social care in the county. We are here to help you have your say about the way that health and social care services are planned and delivered in Norfolk. For more information, please visit: www.healthwatchnorfolk.co.uk

About the person you care for

1. What is the age of the person you care for?

- ☐ Younger than 18
- ☐ 18-24
- ☐ 25-34
- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ 65-74
- ☐ 75-84
- ☐ 85-94
- ☐ 95+
- ☐ Prefer not to say

2. What is the nature of their condition? (Please tick all that apply)

- ☐ End of life
- ☐ Learning disability
- ☐ Mental health
- ☐ Physical disability
- ☐ Sensory impairment
- ☐ Substance misuse
- ☐ Prefer not to say
- ☐ Other (please describe):

3. On average, how many hours do you spend in your caring role per week?

- ☐ 1-9
- ☐ 10-19
- ☐ 20-29
- ☐ 30-39
- ☐ 40-49
- ☐ 50+ (this includes 24/7 carers)

4. Have you ever had a Carers Assessment?

☐ Yes	*Please continue to question 5.*
☐ No	*Please move onto question 16.*
☐ Don’t know	*Please move onto question 16.*

Please note that if you are providing unpaid care for a relative, partner or friend then you are entitled to a Carers Assessment, even if the person you are caring for is not currently receiving any support from the Council. Details about where you can go for more information can be found at the end of the survey.

About Carers Assessments

The questions in this section are all about your MOST RECENT Carers Assessment…

5. When did you have your (most recent) Carers Assessment?

☐ Don’t know
☐ Less than 6 months ago
☐ 6-11 months ago
☐ 1-2 years ago
☐ More than 2 years ago

6. How long did you wait for the assessment?

☐ Don’t know
☐ Less than 1 month
☐ 1-3 months
☐ 4-6 months
☐ More than 6 months (please state how long):

7. Where did you have the assessment?

☐ Face-to-face in my home
☐ Face-to-face outside of my home
☐ Over the internet
☐ Over the telephone
☐ Other (please describe):

About Carers Assessments

8. If you had the assessment over the Internet or telephone, were you offered a face-to-face assessment? *(If your assessment was face-to-face then please move onto question 9)*

☐ Yes
☐ No
☐ Don’t know

9. What did you hope to get out of the assessment?

10. Did the assessment help you achieve this?

☐ Yes completely
☐ Yes mostly
☐ Somewhat
☐ Not very much
☐ Not at all
☐ Don’t know / not relevant

About Carers Assessments

11. What was the outcome of the assessment? *(Please choose all that apply)*

☐ Services for cared for person
☐ Referral to Norfolk Carers
☐ Information and advice about what to do in an emergency
☐ Information and advice about support in community
☐ Carers Personal Budget
☐ Carers Learning Grant
☐ No information or support
☐ Other (please describe):

12. Has the assessment (and any subsequent support) helped you to continue in your caring role?

☐ Yes completely
☐ Yes mostly
☐ Somewhat
☐ Not very much
☐ Not at all
☐ Don't know / not relevant

13. How do you rate your overall experience of Norfolk County Council's assessment service on a scale of 1-5?

☐ 5 (very good)
☐ 4 (good)
☐ 3 (neither good nor poor)
☐ 2 (poor)
☐ 1 (very poor)

About Carers Assessments

14. Please can you explain why you have given this rating?

15. How could the assessment service be improved in the future?

Information and support for carers

16. Where do you access information for carers? *(Please choose all that apply)*

☐ I don’t know where to go for information
☐ Friends and family
☐ Hospital
☐ GP (Doctor)
☐ Norfolk Carers
☐ Social worker
☐ Voluntary organisation(s) (please state):
☐ Other (please describe):

17. Where else would you like to access information in the future?

Information and support for carers

18. Do you feel able to maintain your own health and wellbeing?

☐	☐	☐	☐	☐	☐
Yes completely	Yes mostly	Somewhat	Not very much	Not at all	Don’t know /not relevant

19. What would help you to better maintain your own health and wellbeing?

20. Do you feel confident continuing in your caring role?

☐	☐	☐	☐	☐	☐
Yes completely	Yes mostly	Somewhat	Not very much	Not at all	Don’t know /not relevant

21. What would help you feel more confident continuing in your caring role?

About you

Thank you for sharing your experiences with us. We would now like to ask some further questions about you. **You do NOT have to answer these questions if you do not want to** but any information you give us will help us to make sure that we are representing local carers effectively. Your personal information will remain confidential.

22. What is the first half of your postcode? *(e.g. NR18)*

23. What was your age on your last birthday?

- ☐ Younger than 18
- ☐ 18-24
- ☐ 25-34
- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ 65-74
- ☐ 75-84
- ☐ 85-94
- ☐ 95+
- ☐ Prefer not to say

24. What is your gender?

- ☐ Female
- ☐ Male
- ☐ Prefer not to say

25. Is your gender identity the same as the gender you were assigned at birth

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

26. What is your sexual orientation?

- ☐ Bisexual
- ☐ Gay or lesbian
- ☐ Heterosexual or straight
- ☐ Prefer not to say
- ☐ Other (please describe):

About you

27. Do you have any physical or mental health conditions or illnesses lasting, or expected to last for 12 months or more?

☐ Yes	*Please continue to question 28.*
☐ No	*Please move onto question 29.*
☐ Prefer not to say	*Please move onto question 29.*

28. What is the nature of your condition? *(Please choose all that apply)*

☐ End of life
☐ Learning disability
☐ Mental health
☐ Physical disability
☐ Sensory impairment
☐ Substance misuse
☐ Prefer not to say
☐ Other (please describe):

29. What is your religion?

☐ No religion
☐ Buddhist
☐ Christian (all denominations)
☐ Jewish
☐ Hindu
☐ Muslim
☐ Sikh
☐ Prefer not to say
☐ Any other religion (please describe):

About you

30. What is your ethnic group?

Choose one section from A to E, then tick one box which best describes your ethnic group or background…

A. White

- ☐ English/Welsh/Scottish/Northern Irish/British
- ☐ Irish
- ☐ Gypsy or Irish Traveller
- ☐ Any other white background

B. Mixed/Multiple

- ☐ White and Black Caribbean
- ☐ White and Black African
- ☐ White and Asian
- ☐ Any other Mixed/Multiple background

C. Asian/Asian British

- ☐ Indian
- ☐ Pakistani
- ☐ Bangladeshi
- ☐ Chinese
- ☐ Any other Asian/Asian British background

D. Black/African/Caribbean/Black British

- ☐ African
- ☐ Caribbean
- ☐ Any other Black/African/Caribbean/Black British background

E. Other ethnic group

- ☐ Arab
- ☐ Any other ethnic group
- ☐ Prefer not to say

If other, please describe:

Thank you

You have now completed this survey. Thank you very much for your time. Your feedback is important and will help us to make local services more responsive to your needs.

Please do not forget to send Healthwatch Norfolk your completed survey using the freepost envelope provided.

Tell us more

Carers Council for Norfolk (CCN) will be conducting further work to better understand the experience of carers in Norfolk. If you would be interested to hear more about our plans and share your experiences in more detail, please let us know how you would like us to get in touch with you below…

Name:	
Email:	
Telephone:	

Further information and support

If you would like to know more about support to help carers in Norfolk, including how to request a Carers Assessment, please contact Norfolk Carers:

Tel: 0808 808 9876 (Mon-Fri 9-5 & Sat 10-2)

Email: norfolkcarers.org.uk

Website: http://norfolkcarers.org.uk/

Norfolk County Council provides a 24-hour general helpline and you can ring this number for information about Adult Social Care and Children's Services, as well as in case of emergency: **0344 800 8020**