

Caring Together: Enabling carers in North Tyneside

A report by
Healthwatch North Tyneside
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Acknowledgement and thanks

With thanks to:

Action for Blind People, Alzheimer's Society, Age UK, Headways, Learning Disability Reference Group, North Tyneside Disability Forum and North Tyneside PROPS.

Healthwatch North Tyneside staff and board.

Most importantly, to all the carers who took part.

Introducing Healthwatch North Tyneside (HWNT)

Healthwatch is the independent champion for people using local health and social care services. We listen to what people like about services and what could be improved. We share their views with those with the power to make change happen. We also share them with Healthwatch England, the national body, to help improve the quality of services across the country. People can also speak to us to find information about health and social care services available locally. Our sole purpose is to help make care better for people.

In summary - Local Healthwatch is here to:

- help people find out about local health and social care services
- listen to what people think of services
- help improve the quality of services by letting those running services and the government know what people want from care
- encourage people running services to involve people in changes to care

Local Healthwatch organisations have been set up in each local authority area in England creating a national network to make sure the voices of the people who use health and social care services are heard at the highest level.

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1. Summary and key findings

During 2016-2017 we engaged with carers through a variety of methods to understand carers' experiences of assessment of their needs, information and support. Carers' experiences were collected through both a paper and online survey, engagement with carers' groups and discussions with local service providers.

Experience of Carer's Wellbeing Assessments

Overall, we highlighted a number of issues with the current Carer's Wellbeing Assessment¹ (implemented under the Care Act (2014)). The most significant issue was the lack of carers who had received an assessment. Only 10 of the carers we talked to stated that they had received such an assessment. We identified several reasons why uptake may be low such as; failure to identify carers, lack of clarity about the assessment and issues regarding the efficacy of the assessment in clearly addressing carers needs.

Impact of caring on wellbeing

We found that carers' wellbeing was significantly impacted by maintaining the carer role. This was evidenced when exploring several factors such as:

- Participation in work
- Participation in education and training
- Economic wellbeing
- Participation in recreation activities
- Physical and emotional wellbeing

Carers struggled to balance caring and participation in work or education, leaving many unable to maintain employment and placing additional barriers to engaging in education. This linked directly to carers' economic wellbeing, which was often negatively impacted by carers being unable to work enough to support themselves financially while maintaining their caring role.

42% of carers responding to the survey question stated that they were 'able to continue to take part in leisure activities or hobbies' although this was not without its constraints. Therefore, participation in recreation activities was largely

¹ "A carer's assessment is an opportunity to discuss with the local council what support or services you need. The assessment will look at how caring affects your life, including for example, physical, mental and emotional needs, and whether you are able or willing to carry on caring" (www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment)

described as limited, with carers facing many barriers such as lack of time and worries about leaving the person they cared for alone. This consequently impacted carers' emotional and physical wellbeing, as often they felt unable to maintain their own wellbeing alongside that of the person they cared for.

Information, advice and support for carers

Carers described a range of experiences relating to the access, quality and effectiveness of the information and support available to them. We found that the majority of carers maintained their wellbeing through family networks and support groups, with a minority also using other services and their GPs for support. This was often to do with GPs and care services not being aware of the carer's role. Carers also highlighted gaps in the information available to them especially with regards to training needs and planning for emergency.

A number of carers told us about the good experiences that they have had when accessing information and support from a range of local organisations and support groups. However, access to this support remained inconsistent and should be promoted to engage more carers who currently have minimal support available to maintain their wellbeing.

We have developed recommendations in order to further investigate and address the issues that carers voiced around these three themes. Our recommendations highlight four key areas for improvement:

Early identification of carers - Ensuring GPs and care navigators are sufficiently trained in how to identify carers and North Tyneside Council work with providers to ensure identification and referral of carers is incorporated into their contract specifications, reviewing procedures and monitoring systems.

Awareness of the Carer's Wellbeing Assessment - Implementing a joint initiative between health and social care to promote the right to a carer's assessment across the borough and inclusion of a measurable target on awareness levels within the Commitment to Carers Action Plan.

Strengthening of the Carer's Wellbeing Assessment - Including carers involvement in the co-production of the Carer's Wellbeing Assessment and addressing significant gaps in the existing assessment.

Improving information, advice and support for carers - Including strong, time bound, measurable actions in the Commitment to Carers Action Plan and an update on the existing goals.

For our full list of recommendations, see Section 5.

2. Background

North Tyneside Commitment to Carers (2015) states that:

“Adult carers provide, or intend to provide, ‘necessary’ care for another adult who has care and support needs. ‘Necessary’ care means activities that the person requiring support should be able to carry out as part of normal daily life but is unable to do so because of their care and support needs.”

There are around 22,000 adult carers in North Tyneside² offering care and support at a range of levels and for a wide range of different reasons.

Healthwatch North Tyneside has a history of engaging with carers to understand their experiences of accessing services. In 2014, we talked to carers to find out if the joint NHS and local authority North Tyneside Carers’ Strategy (2012-14) had achieved its aims and made a difference to the lives of carers and, if not, how services could improve in the future.

We published our report in April 2015 and the recommendations contributed to the Joint North Tyneside Carers’ Strategy ‘Commitment to Carers’³. This local strategy identifies priorities and actions to meet the needs of carers in North Tyneside as well as fulfilling the key policy aims of the Care Act (2014) which came into force in April 2015.

As a result of listening to carers’ continued feedback and concerns during 2015-16 Healthwatch North Tyneside recognised that there was a need for focused engagement with carers about Carer’s Wellbeing Assessments and the information available to support carers.

Consequently, in 2017 we gathered feedback from adult carers of adults in North Tyneside about their experiences of accessing information, advice and support and, undertaking Carer’s Wellbeing Assessments to maintain their wellbeing.

We have listened to carers about the challenges and good practice that they have experienced with health and care services while undertaking their caring roles. This report has been prepared to assist carers’ voices to be heard by commissioners and providers so that they can continue to improve the ways in which they meet carers’ needs and to highlight good practice.

This report was not focused on the views of parent carers or young carers in line with eligibility for adult carers of adults’ wellbeing assessments.

² 2011 Census cited in North Tyneside’s Commitment to Carers, page 14

³ North Tyneside’s Commitment to Carers <http://my.northtyneside.gov.uk/sites/default/files/web-page-related-files/North%20Tyneside%20commitment%20to%20carers.pdf>

3. Our approach

Recognising that carers' time is limited, we listened and gathered their feedback⁴ through a variety of different approaches including:

Method	Number of participants
A survey (online and offline)	52
Discussions at carers' meetings and support groups	29 (within 5 carers' groups)
General engagement activity and HWNT feedback centre (from April 2016 to March 2017)	58
Total 139	

We also talked to a range of care providers and voluntary and community groups in the area to build a picture of how Carer's Wellbeing Assessments are approached and maintained and to discuss some of the issues that carers face.

When analysing carers' responses we benchmarked their experiences against three key documents throughout this report:

The Care Act 2014 (including guidance and amendments)⁵

The Care Act 2014 acknowledges and describes the need to promote carers' wellbeing as well as the wellbeing of people who require care and support. It places additional duties and responsibilities on local authorities regarding the provision of information and advice, the assessment and the prevention of carers' needs for support.

The Care Act, along with amendments and guidance, details the need to consider and assess carers' own needs for support in their caring role, and whether there is, or is likely to be an impact on carers' wellbeing and their ability, for example, to take part in everyday activities, maintaining key relationships including work, education, training and recreation.

The Care Act Eligibility Regulations describe when the local authority must carry out carer's assessments, what an assessment must include and what the local authority must consider.

⁴ For demographic information about the participants, see Appendix A.

⁵ www.legislation.gov.uk/ukpga/2014/23/contents/enacted

North Tyneside Commitment to Carers 2015⁶

North Tyneside Commitment to Carers 2015 embeds the aims of the Care Act within six priority areas that it aims to achieve locally. We have structured carer comments throughout around the Care Act as well as the priority areas agreed locally to highlight whether carers feel they are receiving the services they are entitled to.

North Tyneside Carers' Charter 2014⁷

The Carers' Charter 2014 is a set of principles agreed by carers in North Tyneside to promote better recognition and support for them. We have used this to highlight where principles have been met or fall short.

For more information on our approach, see Appendix B.

⁶ <http://my.northtyneside.gov.uk/sites/default/files/web-page-related-files/North%20Tyneside%20commitment%20to%20carers.pdf>

⁷ http://my.northtyneside.gov.uk/sites/default/files/web-page-related-files/Carers_Charter._Oct_14.pdf

4. What people told us

Healthwatch North Tyneside have analysed the views expressed by carers and set out the main trends under 3 key areas:

- Experience of carer's wellbeing assessments
- Impact of caring on wellbeing
- Experience of information, advice and support for carers

4.1 Experience of Carer's Wellbeing Assessments

To understand levels of awareness of the Carer's Wellbeing Assessment, the experience of being assessed and the outcomes for wellbeing we explored the following:

- If carers knew about Carer's Wellbeing Assessments
- If carers had been offered an assessment and how easy it was to access
- Carers' experience of being assessed and how it could be improved
- If carers' wellbeing was maintained or improved as a result of the assessment

Lack of awareness of Carer's Wellbeing Assessments

The Carers Trust (2016) report 'The Care Act, One Year On'⁸ highlighted a large number of carers who had not received support or assessment under the Care Act and "who were not even aware that these rights existed". Therefore, stressing that:

"Local authorities and carers groups need to keep reaching out to make carers aware of their rights and how they can realise them; this will include helping them to understand that they are carers in the first instance".

This seems to be similarly true for North Tyneside. Of those who took part in our survey just 38% of carers said that they had heard of Carer's Wellbeing Assessments. Whereas 53% of carers said that they had not heard of them and 9% were unsure if they had heard of them.

However, of those aware of the Carers Wellbeing Assessments, only 10 reported to us that they had undertaken an assessment within the last year.

⁸ https://carers.org/sites/files/carerstrust/care_act_one_year_on.pdf

One carer who had an assessment described the need for increased information and awareness about the assessment:

“More info being made available to carers to tell them about the benefits of having a Carer’s Wellbeing Assessment as most carers do not know about this”.

Prior to our research we recognised the number of carers that Healthwatch met in general engagement who did not appear to know about Carer’s Wellbeing Assessments. In 2016 Healthwatch North Tyneside partnered with North Tyneside CAB to raise awareness of the assessment with leaflets and posters distributed across the borough. This attempt to boost the efforts of the council and North Tyneside Carers’ Centre to reach carers, does not appear to have reached far enough as awareness continues to be low and requires further action.

Barriers to the uptake of Carer’s Wellbeing Assessments

2 of the 10 carers⁹ who reported that they had experienced a Carer’s Wellbeing Assessment described accessing the assessment as difficult:

“[heard of assessment] only through family member. Adult Services North Tyneside haven't, only one person knew. Being stressed and trying to find and receive help. I didn't know what to expect. Sorting out the appointment wasn't easy; family member did that for me”.

“Everything seems too hard to get. In an uphill struggle”.

Whilst it is very possible that the small proportion of respondents identified who have completed assessments does not reflect the uptake in the wider population, it can be assumed that there continue to be significant barriers to accessing carers assessment.

Failure to identify carers

The North Tyneside Commitment to Carers Priority Area 1 stresses the need for earlier identification of carers and states that the identification and recognition of carers is the responsibility of all services whether NHS or local authority.

However, only 29% of carers said that their GP was aware of their status as a carer, whilst 43% said that their GP did not know they were a carer and 28% were not sure if their GP knew they were a carer.

⁹ This includes carers responses from both the survey and general engagement period

These findings are reflective of the findings of the NHS Commitment to Carers (2014) which identified the low level of identification of carers specifically by GPs:

“70% of carers come into contact with health professionals yet health professionals only identify one in ten carers with GPs”.

Both the NHS Commitment to Carers (2014) and the subsequent NHS Commissioning: Commissioning for Carers¹⁰ recognize the potentially negative impact of caring on a carer’s physical and mental wellbeing when they fail to receive adequate support. As highlighted in the NHS Commitment to Carers (2014):

“Caring responsibilities can have an adverse impact on physical and mental health, education and employment potential of those who care, which can result in significantly poorer health and quality of life outcomes”.

When considering other services; 39% of carers taking part in the survey suggested that care services were aware of their status as a carer, 45% said that care services were not aware and 16% were not sure. Even though these figures are slightly higher than the levels of GP awareness, this still highlights the continued low levels of carer identification within the borough.

If this trend is borne out in the broader population of carers in North Tyneside, it would be entirely reliant on the carer’s awareness of their right to an assessment and self-referral to increase the uptake of carers’ assessments.

The ‘Integrated approach to identifying and assessing carer health and wellbeing’ toolkit (2016)¹¹ provides a valuable framework to assist local authorities and health services identify and effectively address carers’ needs. Therefore, this should be utilised to promote the identification of carers within North Tyneside.

Lack of understanding about how to access an assessment

71% of carers responding to the question said they do not know where to get more information about Carer’s Wellbeing Assessments. 29% of respondents stated that they are aware of where to access this information.

In addition to raising awareness amongst carers about how to access an assessment, there is a need to raise awareness about carers’ entitlement to an assessment, the routes to follow, who is eligible for additional support and how carers can benefit from an assessment.

¹⁰ www.england.nhs.uk/commissioning/comm-carers/principles/

¹¹ www.england.nhs.uk/wp-content/uploads/2016/05/identifying-assessing-carer-hlth-wellbeing.pdf

Lack of clarity about whether an assessment had been carried out

A number of carers described having had a carer's assessment 'years previously' but nothing recently. At the same time carers appeared to be unclear about the purpose or benefits of the new Carer's Wellbeing Assessments.

12 carers said they had not or were unsure as to whether they had taken part in a Carer's Wellbeing Assessment. Another carer said that a social worker carried out an assessment but the carer was not sure if they did a carer's assessment at the same time. A similar lack of clarity about assessments was reflected by carers approached in general engagement¹².

One carer described having a carer's assessment and being told the decision over the telephone, not being given 'anything in writing'. Supplying carers with a written record of an assessment would assist carers to be clear about the assessment they have undertaken and the level of support they can expect, in accordance with the Care Act regulations¹³.

Quality of the Carer's Wellbeing Assessment

The relatively small number (10) of carers who had experienced Carer's Wellbeing Assessments reported a mixed view of the quality of the assessment.

Seven carers felt that the assessment enabled them to fully or partly explain their needs. 6 of the 7 felt that the assessment was useful overall and in particular in the provision of information about respite and signposting. Four carers felt they had a positive outcome with new information or support being offered as a result of the assessment:

"Able to get things off my chest which had given me cause for concern - problem solved."

"It was great to have someone listen to how my role as a carer has affected my quality of life. I was offered a breathing and relaxation short course and a further course to help understand Alzheimer's. These were really useful to me."

However, four carers said that the assessment was unhelpful. This was due to lack of clarity around the assessment process or not being offered any new information as they didn't feel that they were listened to:

"[the assessment] wasn't clear enough, they mentioned a points system I didn't understand and was confused about the outcome."

¹² It is important to note that the assessment is proportionate, and will be filled out proportionately to the carer's needs.

¹³ The Care Act Part 1 12(4) states that: "The local authority must give a written record of a carer's assessment to (a) the carer to whom the assessment relates (b) any carer that the adult has, if the adult asks the authority to do so, and (c) any other person to whom the carer asks the authority to give a copy"

Due to the small numbers of carers who participated who had experience of carer's assessments, it is difficult to draw solid conclusions about the quality of the assessments or the processes on the basis of this alone.

However it is important to note, based on a discussion with staff delivering assessments, it appears that whilst there is regular audit of the quality of assessments from the point of view of services, there appears to be no opportunity for carers to feedback about the process, if they feel their needs have been identified, listened to, and met.

Waiting times and lack of response from services

A limited number of carers who had received an assessment described waiting times of between days to 4 to 6 weeks for an assessment.

In addition, carers described that they had applied for or undertaken assessments but had heard nothing back:

"...offered a carer assessment twice by Social Services but it never materialised. I should go to the Carers' Centre but can't face it alone. I try not to be overwhelmed and take each day as it comes but it's very difficult."

"It was easy to get [an assessment form]. I filled it in, sent it in but don't think I heard anything back."

"I undertook an assessment by phone from social services nothing came of it."

One carer reported having to wait until the new financial year to get the decision about additional support resulting from an assessment:

"I was told about the Carer's Personal Budget but unfortunately as this is the end of the financial year I have to wait to find out if this bid is successful."

Another carer expressed frustration in waiting a long time to get a decision and ultimately not getting anything as a result:

"...Social worker terrible at communicating, not getting back to you or keeping you informed about the outcome."

Although a relatively small number of people reported concern about a lack of response on the outcome of an assessment, this may indicate that there is an area of the process which is not working as it should.

Lack of confidence in the assessment process

In the survey, 21 carers said they were not sure whether having an assessment would be helpful, 6 suggested that they didn't think having an assessment would help and 10 carers said they felt having an assessment would be beneficial. This not only reflects a lack of confidence in the assessment but could indicate further issues around the clarity of the assessment's purpose.

Some groups of carers described feeling that undergoing a Carer's Wellbeing Assessment would not be worthwhile for them in improving their wellbeing. In particular, this was mentioned by some carers of people with lifelong complex needs, who offered 24/7 care and had been in contact with care services and NHS services for a number of years. However, this could be reflective of carers prioritising the needs of the person they care for, rather than considering how their own needs as a carer are being met.

Carers of people with life-long complex needs described the stresses that they faced in offering care and support. One carer described not being bothered about a Carer's Wellbeing Assessment as they felt that as long as the person receiving care was ok, that was enough.

Another carer described Carer's Wellbeing Assessment personal budgets (up to £500) as a 'token gesture' for carers who care for people with life-long or complex 24/7 care needs. They also added:

"Most carers regard any support budget for them as being automatically scavenged by the council from the young person's budget. In other words, what's the point in applying for a carer assessment?"

One carer who had an assessment described how the care services rearranged the care given to the person they care for in response to the assessment so the carer could go out, meaning the carer still had to deliver the same number of hours caring:

"Listen to what help the carer needs instead of going to bother of filling it in to get nothing at the end".

In discussion, another carer described having an assessment and losing a third of the paid care given to the person they care for after their joint assessment. The carer described now feeling under increased pressure to offer more unpaid care to ensure the health and wellbeing of the person they care for. The carer feels that the person they care for will deteriorate quickly without the paid care that is in place.

Conclusion - experience of carer's wellbeing assessments

It would be easy to discount the findings due to the limited experience of carers who have undertaken carer's wellbeing assessments. However, since Healthwatch North Tyneside has reached out to carers already networked through support groups and care services, and numbers are still low it is clear that there continues to be low levels of awareness and uptake of carer's wellbeing assessments. It could be presumed that this awareness will be even lower amongst 'seldom heard from' carers.

Feedback from carers identifies significant barriers to accessing assessments and issues within the process which need further investigation and plans to address.

4.2 Impact of caring on wellbeing

In order to understand what is fully meant by the term 'wellbeing', the Social Care Institute for Excellence (SCIE, 2017) guidance relating to the Care Act, offers a useful definition.

Wellbeing is defined as “a broad concept...relating to a range of areas, in particular:

- personal dignity (including treatment of the individual with respect)
- physical and mental health and emotional wellbeing
- protection from abuse and neglect
- control by the individual over day-to-day life (including over care and support provided and the way it is provided)
- participation in work, education, training or recreation
- social and economic wellbeing
- domestic, family and personal
- suitability of living accommodation
- the individual's contribution to society”

SCIE, 2017

The SCIE (2017) further describe:

“the individual aspects of wellbeing or outcomes above are those which are set out in the Care Act, and are most relevant to people with care and support needs **and** carers. There is no hierarchy, and all should be considered of equal importance when considering 'wellbeing' in the round.”

Promoting and maintaining carers' wellbeing and ensuring that information and advice is available to all carers, whatever the level of support they offer are key elements in the Care Act.

The Care Act (2014) Chapter 23 states that the local authority must have regard to:

“the importance of enabling adults with needs for care and support, and carers with needs for support, who wish to do so participate in work, education or training”

North Tyneside Carers' Charter (2014) 'Recognising Carers' asks services to:

"take my [carer's] needs into consideration" and emphasises the importance of recognising that "I have my own life outside of caring and may have other commitments".

To fully understand the impact of caring on carers' wellbeing we explored the following themes:

- Participation in work
- Participation in education and training
- Economic wellbeing
- Participation in recreation activities
- Physical and emotional wellbeing

In addition to these themes people also told us about the continued role they play when the person they care for is moved into a care home:

"There is an assumption that once someone lives in 24 hour care that family carers no longer have a responsibility for their relative. This may be true legally but emotionally, morally and socially this is not the case."

A minority of carers described assisting with 'sorting out' medical, personal and financial concerns as well as assisting the person to continue to take part in interests or daily activities.

The impact of caring on participation in work

The Care Act and its related guidance¹⁴ itemises 'engaging in work, training, education or volunteering. Local authorities should consider whether the carer can continue in their job, and contribute to society, apply themselves in education, volunteer to support civil society or have the opportunity to get a job, if they are not in employment'.

In addition, North Tyneside Commitment to Carers Priority Area 4d states it will explore 'options to support carers to remain in employment' with a specific focus to 'raise awareness of support available to return to employment'. However, the main area of support in the action plan is targeted at young carers and parent carers which therefore fails to include adult carers caring for another adult.

Around 38% of carers responding to the survey told us that they were in work and many described the impact of caring on their work, work arrangements and the pressure they were under to combine both responsibilities as well as maintain their own wellbeing.

¹⁴ www.gov.uk/government/publications/care-act-statutory-guidance/list-of-changes-made-to-the-care-act-guidance#chapter-2-preventing-reducing-or-delaying-needs

Carers explained that they are unable to work or had to leave work as a result of their caring responsibilities:

“Not able to work as only me to look after mam and take to appointments”

“Had to retire early to care for husband”

“Caring necessitated cessation of work”

Carers also described having to use annual leave in order to carry out their caring responsibilities, limiting their opportunity to take a break which impacted on their wellbeing:

“On my days off work I spend all day caring for my parents.”

“I use most of my holidays on hospital appointments etc. Hence I often don't get the breaks I should.”

“Frequently need to go to meetings in work time which are to do with the person I care for. Have to use annual leave to do.”

Working carers explained the additional pressures of fulfilling their caring role while achieving the expectations of their employer, which arguably has the potential to put their employment at risk:

“My employer is very understanding, but this is still a problem as I am late for work every morning. Although I try to make the time up it is not always possible”

“...constantly leave work early unpaid to care for my wife”

The impact of caring on participation in education and training

Only four carers responding to the survey described taking part in studies or training whilst fulfilling their caring role. Each described the challenges that they face combining their roles, both in achieving their studies as well managing competing responsibilities, worries and distractions.

“Studying is hard to complete in the evenings as this is the time where most care is required”

The limited number of respondents may be reflective of the difficulties carers face when entering and maintaining education. However, this may also be related to the age range of respondents taking part (See Appendix A).

Impact of caring on economic wellbeing

The financial impact of caring is closely related to the impact of caring on participation in work. Some carers reported becoming financially worse off due to the need to reduce hours or stop work altogether:

“Unable to work full time due to having to be around to care for relatives, which affects my financial circumstances.”

“I can only do a few hours a week when I really need to work more for the money to keep us going.”

“Caring necessitated cessation of work. Leisure activities can only be enjoyed occasionally due to both financial constraints and caring role.”

As this quote highlights, the financial impact of being unable to participate in work can often have a knock-on effect on carers' engagement with recreational activities and therefore their level of wellbeing.

The impact of caring on participation in recreation

In preventing or reducing carer needs for care and support, the Care Act¹⁵ offers guidance to the regulations. These state that local authorities should consider whether the carer has an opportunity to make use of local community services and facilities and, for example, consider whether the carer has time to use recreational facilities such as gyms or swimming pools or engage in a hobby.

42% of carers responding to the survey question stated that they were 'able to continue to take part in leisure activities or hobbies' although this was not without its barriers and constraints. This was evidenced when carers said that they had very limited or no time left to participate in recreation activities due to their caring responsibilities:

“I have no time left and I'm exhausted.”

“Unfortunately, I have to be available at any time day or night in case I am needed. That leaves very little time for me although I would really enjoy an occasional visit to the gym for de-stress.”

Others were more explicit about the limitations or pressures they face when they are unable to leave the person they care for alone:

“I can't do anything alone, because I can't leave... but I have made a lot of friends through support groups.”

“I don't feel happy leaving my husband for any length of time due to his inability to walk even though we have rails all over the house, he has still had a few falls.”

¹⁵ www.legislation.gov.uk/ukpga/2014/23/contents/enacted

Impact of caring on physical and emotional wellbeing

For those carers who described the emotional or physical impact of caring, this was often closely linked to their opportunity to participate in recreation activities. A number also felt that their own physical and emotional wellbeing is not always taken into consideration:

“It's not always the physical effects of caring. The emotional side of it has a great effect on my own health and wellbeing.”

“Tiredness due to disrupted sleep or worry. I like to go on holiday, even for short breaks quite local, but feel I can't get away because of caring duties.”

“No one thinks about the impact on carer only the cared for one.”

As noted, there was often a link between emotional wellbeing and recreation. This was evidenced when carers described the emotional impact of their taking time out to undertake recreation activities acting as a barrier to them taking them up. One carer also highlighted that enjoyment of recreation activity is also limited by the potential to become socially isolated.

“I also participate alone as we no longer are able to do things together.”

However, over a quarter of those carers talked to describe being offered a range of local information, the opportunity to take part in activities, relaxation sessions and advice on managing stress to support health and wellbeing:

“Was offered 'relaxation' and breathing course at Carers Centre - fantastic but only 3 sessions... was also offered a 'Carers Budget' and hoped to pay for gym membership but this has been put on hold due to financial year end.”

“I was given info on relaxation and aromatherapy sessions and a list of support groups etc. The leaflet Carers Voice has comprehensive advice on everything from activities, to training to help with caring role.”

“Where to turn when isolated, unable to function at 100mph (i.e. stressed out) and suggested ways of trying to relax and find 'me time.'”

Conclusion - impact of caring on wellbeing

Together these narratives begin to highlight the way caring responsibilities limit the time carers have to spend on their own wellbeing, as well as limit their opportunities to follow their interests and interact with, retain and develop a range of different community networks, potentially increasing the risk of social isolation. Carers often had an understanding of the support that they would benefit from (see next section 'Where do carers get information advice and support') and a carer's assessment could explore how this impact may be reduced through being offered tailored support.

4.3 Where do carers get information, advice and support?

The Care Act gives local authorities a responsibility to provide carers with information and advice relating to care and support for adults and support for carers themselves.

The Care Act guidance additionally suggests that:

“Information and advice is fundamental to enabling people, carers and families to take control of, and make well-informed choices about, their care and support and how they fund it. Not only does information and advice help to promote people’s wellbeing by increasing their ability to exercise choice and control, it is also a vital component of preventing or delaying people’s need for care and support.”

North Tyneside Commitment to Carers sets out priorities to:

- Increase opportunities for carers to find out what is available to support them and how to access it.
- Ensure good quality information is available at key points of access.

Additionally, the North Tyneside Carers Charter states:

- “Give me information in a timely manner;
- Check that I have fully understood and been able to take on board what you have told me;
- Make me aware of my rights and what I am entitled to;
- Advise me how to access support and services.”

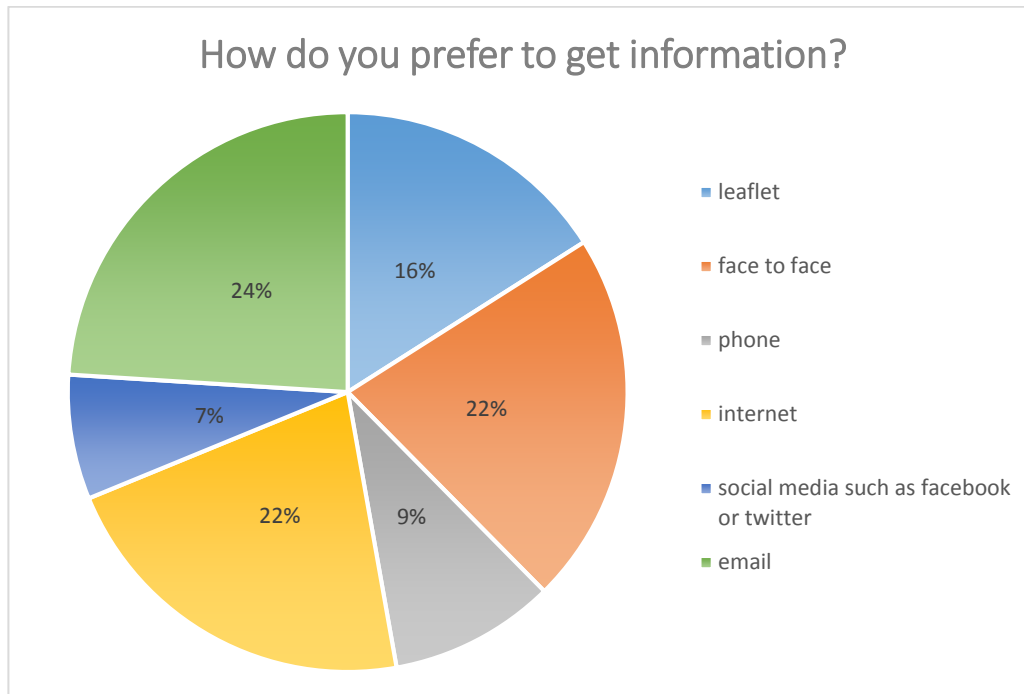
We wanted to understand carers’ experiences and access needs for information, advice and support. In order to address this, we focused on the following areas:

- Sources of information, advice and support for carers
- Where and how carers would prefer to access information, advice and support.

Sources of information, advice and support

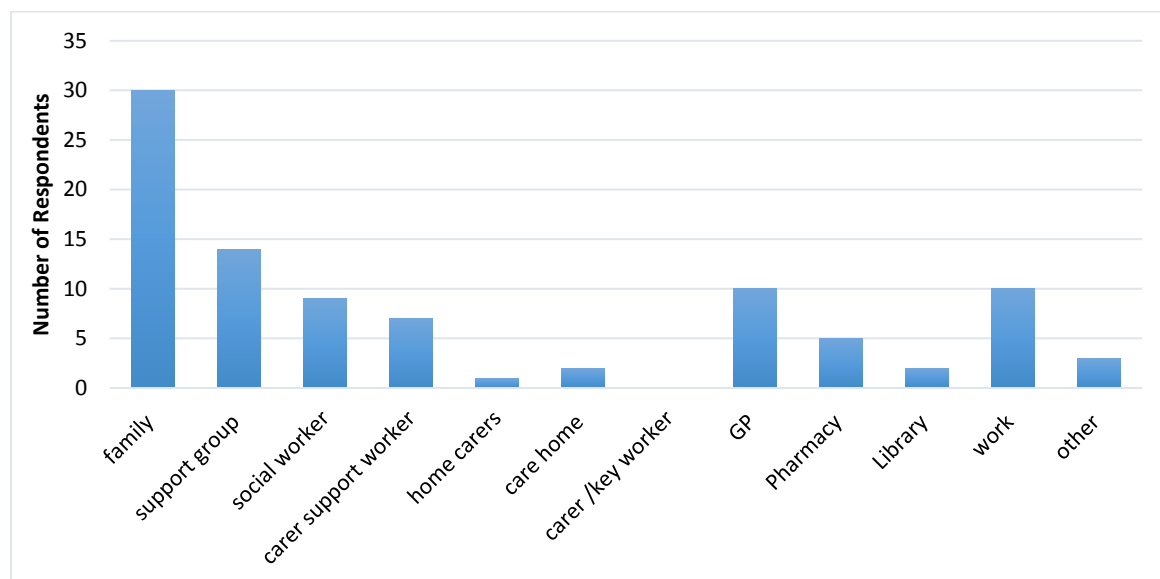
In order to establish carers’ information needs and how they are currently being addressed, we asked carers how they would prefer to access information. The following data relates to responses from the survey.

The majority of carers felt comfortable accessing information through digital methods. However, 28% of the carers explained that they would like to receive information only through face-to-face means. For the most part, people were happy to receive information through multiple means, that is written, verbal and digital methods.



When asked if carers felt they knew where to access information from, only 19% were confident they knew where to find this help. Whereas 31% of carers felt that they did not know where to access information and half described just sometimes knowing where to access this.

Following this, we asked where carers were currently accessing information, advice and support:



The four key areas of support highlighted by carers across the survey and general engagement related to support from **family, support groups, GPs and work.**

Family

Family support was cited as the most common way carers maintained their own wellbeing. With 61% of carers who responded stating that they got support in their role from family and just over 20% stating that family was their only source of support:

“My husband helps me. My two children will visit when I go on holiday.”

“By telling me if I look stressed or am behaving differently.”

Support groups

18% of carers responding to the survey stated that they access information, advice and support from support groups.

Carers described how much they enjoyed attending support groups and the benefits they experienced through discussing and sharing experiences with others facing similar situations.

“Support groups are very helpful - you can share info.”

“Great relief from carers’ [support] group, knowing someone who is going through the same thing, this is the most helpful, they are the only people who understand.”

While some carers felt supported by being able to attend groups with the person they care for, others described the challenges they faced trying to attend and discuss their needs individually.

“Very challenging to find opportunities for carers to get together by themselves to talk about their particular difficulties.”

GPs

Less than half of carers who said their GP knows that they are a carer, said they access information, advice or support from them. Only 20% of carers who responded to the survey said they had accessed information and support from their GP. Where carers accessed this form of assistance, some praised their GP and described various types of support and consideration that they received from their GP including advice, ‘CBT... to manage stress’ and supportive personal approaches that helped the carers feel valued.

“GP very helpful - offered to bring prescription to work.”

“It said on medical notes I was a carer and same on wife's it relieved me - as if phoning GP they know what the circumstances were.”

“GP knows their patients, very proactive, you don't have to repeat yourself, receptionist very sympathetic, District Nurse tremendous.”

Another two carers praised the attentiveness of their GP practices and one described being given information about Carer's Wellbeing Assessments. However, this was not always the case, as two carers described contact with their GP and practice staff as unhelpful.

While the majority of comments made about GPs were positive, the number of carers that access information advice and support from their GPs is low. This is the case especially as many carers are likely to be in contact with their GP, if not for themselves then, in relation to the person they care for. Lack of recognition of carers by health professionals and GPs is acknowledged as a key area for development within the NHS as described earlier in this report (see page 9).

Work

Similarly, only 20% of the carers stated that they currently received information, advice and support from their employer. However, positive experiences of support from work was often described by carers who already worked within the sector:

"Work provides practical information about the health and social care sector."

"I work part time for a local disability charity and they have really helped pointing me in the right direction."

Care services

It is important to note that carers were also largely accessing information through several care services, including social workers, carer support workers, home carers and care homes. With 19 carers overall stating that they currently get advice from one or a range of these care services.

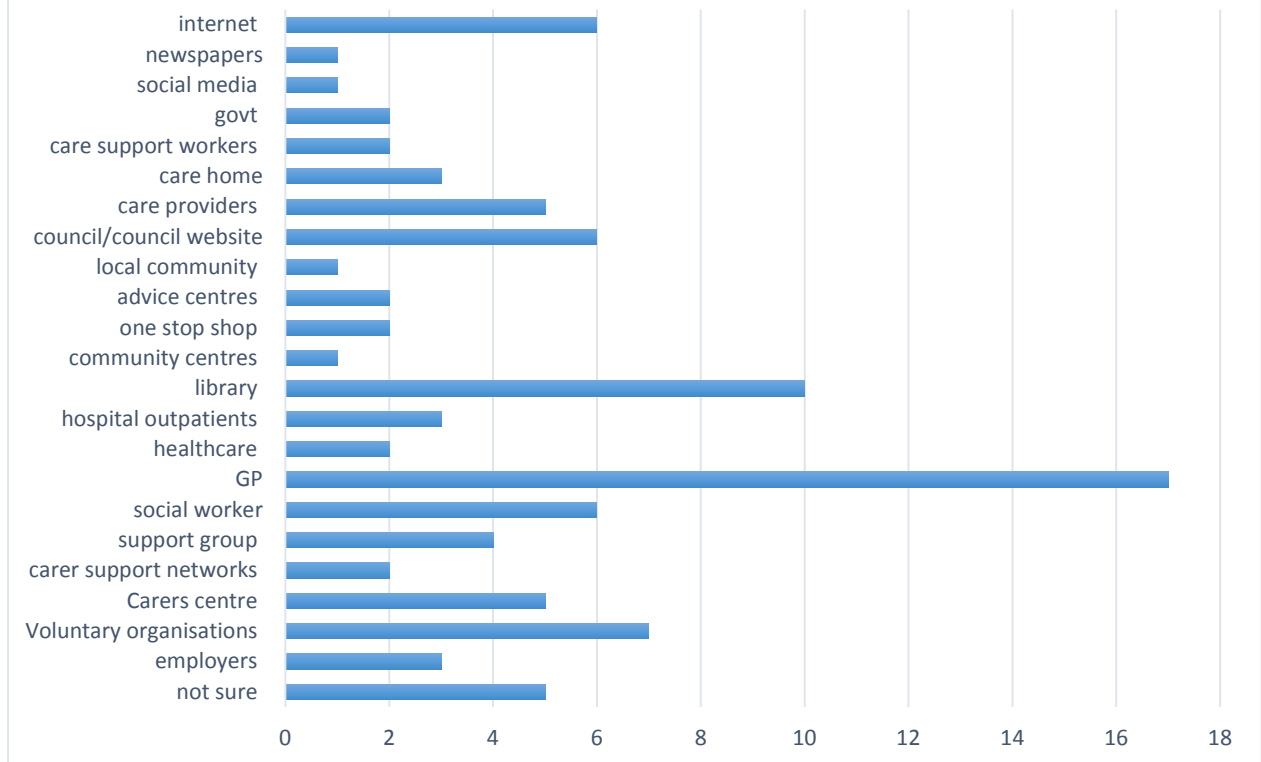
Carers with limited support

43% of carers said they access information advice and support from only one source. This indicates that there is a large group of carers who are caring in isolation and would benefit from greater access to sources of information, advice and support.

A small number of the carers we talked to stated that they had no access to information, advice or support from any source:

"No one gives me advice I have to do it myself if I need it."

Where carers feel they should be able to get information from



42 carers suggested a wide range of places they should be able to get information from. The most frequently identified was GP surgeries (17) followed by libraries (10). Carers additionally identified a range of voluntary organisations within North Tyneside. Carers suggested further examples such as:

“A short booklet would help from the social workers - an internal list of people [Adult Social Care] about their roles and names - could bring the info to the meeting because they [staff] keep changing.”

“Should be one-stop-shop. When the person you are caring for first becomes ill, advice should be on hand, the unpaid carers shouldn't have to move around various departments and feel let down by the system, passed on from one department to another. Adult services need to get their act together - be more helpful.”

Conclusion - getting information, support and advice

Carers described a wide range of positive experiences when sourcing information and support from a number of services, most notably from their family, support groups, GPs and work. However, only a minority of carers felt confident in how and where they could source information, advice and support to maintain their wellbeing.

It was largely recognised that carers would prefer to access information through their GP. North Tyneside CCG and the NHS acknowledge carers wish to have more information available through GP and health services. This is reflective of carers' suggestions around the distribution of the information and support they need.

4.4 Are carers information, advice and support needs met?

We followed up where carers said they accessed their information, advice and support needs, by enquiring about what sort of information was available to them. We asked carers taking part in the survey to let us know if they felt they had the information and advice they needed to support their wellbeing in a range of areas which are explored below:

- Financial
- Training
- Respite care
- Working and being a carer
- Emotional support
- Planning for an emergency
- Legal
- Health and wellbeing

In addition to this, on review of the experiences shared with us, we identified another theme of carers' experiences when acting in a 'care co-ordinator role'. We feel this theme needs to be highlighted and is likely to warrant further investigation. Therefore, we have also begun to outline carers' experiences of acting in a care co-ordinator role.

Experiences of accessing information, advice and support

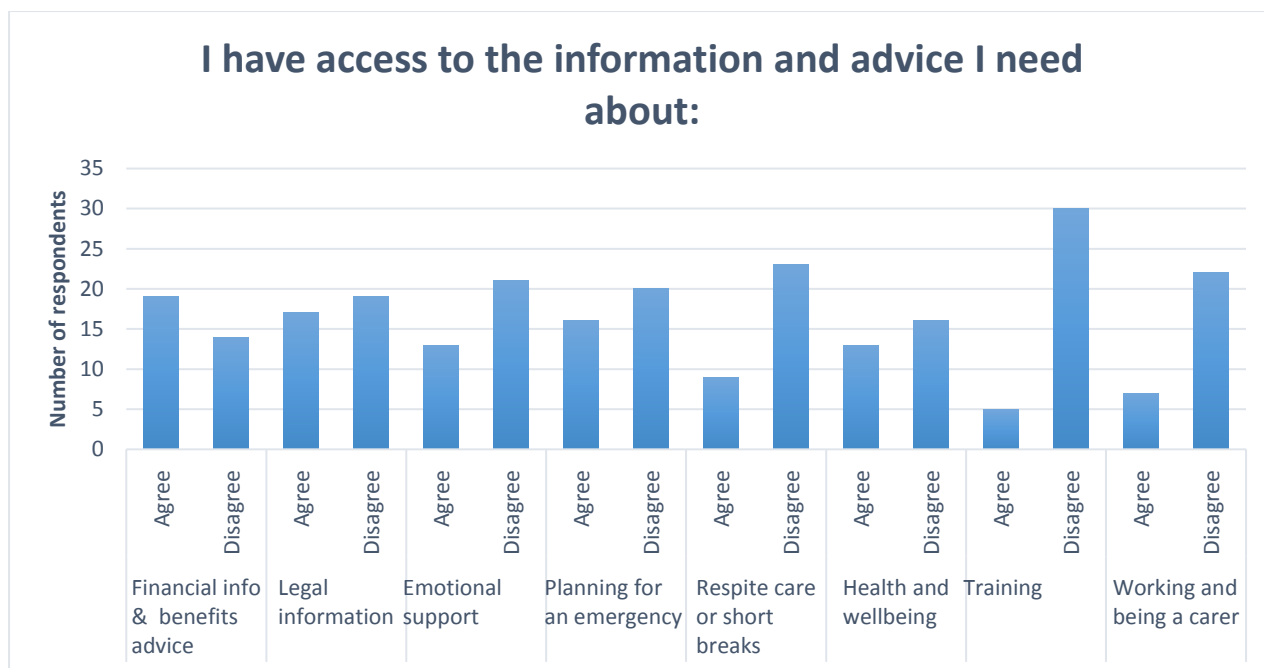
Carers mentioned a wide range of different services and support groups that they had experienced good practice from when receiving information, advice or support:

"Far exceeded all the help I needed."

"This is a nice place to come to at a time that can be quite distressing for individuals and their families or carers. Brilliant service!"

"This person gave me great, solid advice in the early days [before diagnosis] and helped me understand some behaviours. It normalised things to discuss them with someone else."

While 40% carers described good experiences, half of the carers also described the struggle they continue to encounter when trying to access information, advice and support to maintain their wellbeing and to enable them in their caring role.



We asked carers what sort of information, support and advice was available to them, the majority suggested that their information and advice needs remain unmet, with the exception of information relating to the financial aspect of caring.

- **Training** - 54% of carers felt that their needs for information and support around training are unmet. With only 11% feeling that they have received adequate assistance in this area.
- **Respite care** - Though 18% of carers feel their needs are met, almost half of the carers identified respite care and short breaks as an unmet need and feel that they need more access to information, advice and support in this area.
- **Working and being a carer** - 45% of carers felt they didn't have access to information about working and being a carer, with around half of this 45% of carers currently in some form of employment. Only 14% of carers agreed that they had the information, advice and support needed in this area, with several carers struggling to access the support they need to balance their work and caring role.
- **Emotional support** - Only around a quarter of carers responding to the survey felt they have adequate emotional support. Whereas, 42% of carers feel their needs for emotional support remain unmet.
- **Planning for an emergency** - 41% of carers felt that training when planning for an emergency was an unmet need. Only 33% of carers felt that their needs were met in this area.
- **Legal** - 35% of carers felt they do not have access to information about legal matters, for example Power of Attorney, while 39% of carers feel that their needs have been adequately met in this area.

- **Health and wellbeing** - 33% of carers felt that their needs for information, advice and support to maintain their own health and wellbeing are unmet.

Overall, these results demonstrate that there are a range of areas that carers need further information, advice and support by indicating a consistent lack of information available in several key areas.

Experiences of co-ordination of care



Definitions of what it means to be a carer and the roles in which a carer takes on largely fail to recognise and support the role of co-ordinating a myriad of services for the person requiring care.

One example of this is reflected in the Carers Week definition¹⁶ which portrays the multiple responsibilities a carer does such as providing practical, emotional and financial support, but does not recognise the function of care co-ordination.

Based on the feedback, we feel that the important role of co-ordination of health and social care services that carers undertake is not adequately captured by current definitions. Carers mentioned challenges they face when accessing and managing services for the person receiving care and support, specifically the complexity and changing nature of service provision and staffing.

“It’s about all services working together, you’re juggling a lot of balls, if one drops it creates lots of difficulties.”

¹⁶ Image available at: <http://www.carersweek.org/about-us>

Carers described key challenges in the following areas:

- Staffing
- Ensuring quality of care
- Involving carers in decision making.

Staffing

The Health and Social Care Act (2008) Regulation 18¹⁷ states that:

“Providers must provide sufficient numbers of suitably qualified, competent, skilled and experienced staff to meet the needs of the people using the service at all times.”

In addition, The Care Act Guidance¹⁸ states that:

“The ambition is for local authorities to influence and drive the pace of change for their whole market, leading to a sustainable and diverse range of care and support providers, continuously improving quality and choice, and delivering better, innovative and cost-effective outcomes that promote the wellbeing of people who need care and support”.

When considering carers’ feedback on staffing, issues fell into three key areas - staff attitudes, continuity of staff and lack of staff.

Carers’ experiences of staff attitudes were often mixed. However, carers described experiences of poor communication such as staff being unhelpful and general lack of customer service:

“Don’t want to speak to social worker, seems impersonal as though reading from a script, no flexibility, just felt not interested too busy thinking about council’s funding.”

“Being signposted to incorrect departments, customer service has gone out of the window, upon picking up the phone, no 'good morning' or 'afternoon', no names are given, you have to repeat and repeat your story and when they say they will call you back they never do. I felt I was on a treadmill getting nowhere.”

Carers encountering these difficulties often described avoiding using these services in future thus limiting their access to the support networks and services they are entitled to as carers.

¹⁷ www.cqc.org.uk/guidance-providers/regulations-enforcement/regulation-18-staffing#guidance-links

¹⁸ www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#chapter-4

“They sounded not interested and were very, very cold and unhelpful... that was difficult for a person in my position, asking for support... I didn’t get it, I would not want to call them again.”

Issues around continuity of care were also prevalent. Carers described their concerns related to how staff changes can impact on the carer’s wellbeing as well as the wellbeing of the person receiving care:

“Can’t guarantee the same support worker day-to-day... due to the relative’s autism consistency is extremely important, so the support on offer is not fit for purpose.”

In addition, some carers described not having access to staff at all. This was often due to staff being withdrawn, which had a significant impact on the carer and person they cared for:

“When I am really at my wits end it helps to have someone to contact. I was for a short period of time able to talk to a CPN but mum’s case was closed so that ended.”

“Tend to use Internet as a source for this as got no named person to contact for information or advice since we lost our carer support worker.”

Ensuring quality of care

The Care Act states that:

“A local authority must promote the efficient and effective operation of a market in services for meeting care and support needs” (c.23, 1.5).

Carers have discussed the difficulties and additional stress that they face when working with services that they feel are not delivering the expected standard of care for the people that they care for. They also identified issues around services effectively working together to meet carers needs.

Working together

Carers noted the importance of services working together to ensure that their needs were being met:

“So many organisations working to help but if they could combine a bit together that would help. If I could call someone in the evening to calm me down that would have helped - listening to what they would advise, someone to talk to”.

Care standards

Carers described worries around ensuring providers met their standards of care and guaranteeing that care plans were followed accordingly. This was particularly evident with carers of people requiring high levels of support due to cognitive or communication difficulties. They often described their concerns with levels of staff training, understanding and resources of staff to offer appropriate support and supervision to appropriately meet their needs.

“Not sure how much GPs know about dementia.”

“Social workers are very caring but can't help. One of the main issues is that the care agency are so poor. The standards are shocking and they regularly make mistakes which result in issues with medication errors and missed calls. They deliver the basics and don't do what they can and should in the time they have...”

“The service and support my husband and I have received since his stroke has been diabolical. The discharge team just left us to get on with it after the initial 12 week review. We have asked for various help and just keep getting told we are on a waiting list. It is now two years since it happened and he receives no support apart from myself.”

In discussions carers described their concerns about what would happen if they fell ill:

“Not sure what to do in an emergency.”

Another carer stated that they had asked for information ‘years ago’ which was not received and was worried what would happen if they were taken ill. Carers also described their concerns over the lack of emergency respite beds. One carer said:

“What could they say to keep me going? One thing, ‘we have emergency respite’ just knowing it's there would help.”

Involving carers in decision making

The North Tyneside Carers Charter (2014) states that carers should be involved in the care and treatment of the person they care for and specifically states to:

“involve me [carers] in the planning of discharge” and “involve me [carers] in the decisions being made about the person for whom they care.”

It also states that services should:

“listen to what I [carer] have to say” and “respect my [carers] views.”

The NHS Carers' Charter states that we must:

"Listen to carers without bias or prejudice and take what they say seriously" and "Ensure carers are valued by all professionals".

However, carers' responses evidenced that this was often not enacted in practice:

"Carers for those who live in a care home need to be able to share their experiences, have their voices heard and be part of improving the service that their loved ones receive and (by default) they receive."

When engaging with services, carers often noted the struggle to be listened to. A prominent example was given by one of the carers whereby they described being in hospital and nothing being put in place for the person they give 24/7 care for. This was despite the carer informing every member of staff that they were a carer. The carer described being very ill and in pain and there being no hospital discussion about how they (the carer) would be supported on return to their home or how they would be supported to care for the person at home even though the carer frequently stated their needs as a carer.

Conclusion - meeting needs for information, advice and support

Although there are some positive experiences of carers' access to information, advice and support, the majority of their information needs remain unmet and therefore need to be addressed further.

In particular, when carers are accessing information needs around training, respite and emergency planning (carer and person requiring care), working and being a carer and emotional support.

Furthermore, the carer's role as a coordinator of health and social care services needs to be acknowledged and improvements are required through; training of staff, improved continuity of care, integration of services and proactive engagement of carers in care planning and evaluation.

5. Recommendations

As a result of this survey and engagement with carers, HWNT has identified the following four key actions we feel are needed to enable carers more effectively within North Tyneside. These are:

- Early identification of carers
- Awareness of the Carer's Wellbeing Assessment
- Strengthening of the Carer's Wellbeing Assessment
- Improving information, advice and support for carers

5.1 Early identification of carers

Though we are encouraged to see that the North Tyneside Commitment to Carers (2015) acknowledges the need to train agencies to recognise carers, based on our findings we are concerned that more proactive action is required to ensure the early identification and entrance of carers on to the pathway towards assessment and assistance.

Therefore, Healthwatch North Tyneside recommends that:

- 5.1.a **North Tyneside Clinical Commissioning Group (CCG)** work with the local GP consortium to ensure that GPs are trained in how to identify carers and that their registration processes, health checks and general record keeping includes prompt questions and alerts for identification and assessment of carers. Compliance with this should be monitored as part of performance systems.
- 5.1.b **North Tyneside Council** work with home care and other care providers to ensure that identification and referral of carers is incorporated into their contract specifications, reviewing procedures, monitoring systems and core training of all staff.
- 5.1.c The new **GP based Care Navigators** should have sufficient training in identifying and working with carers. Systems should be in place to record carers issues as they arise and report these back to the CCG.

5.2 Awareness of the Carer's Wellbeing Assessment

North Tyneside Commitment to Carers (2015) identifies the need to "increase opportunities for carers to find out what is available to support them and how to access it". It aims to ensure that "carers know how and where to access an assessment of needs and support with clear information on eligibility".

On the basis of the low numbers of participants self-identifying as having undergone assessment and confusion about the outcome of the assessment, Healthwatch North Tyneside makes the following recommendations to **North Tyneside Council** and **North Tyneside Clinical Commissioning Group**:

- 5.2.a A joint initiative is undertaken to promote the right to a carer's assessment across the borough on an ongoing basis. This should focus on all carer groups including hard to reach carers.
- 5.2.b The Commitment to Carers Action Plan should include a measurable target on awareness levels and uptake of carers' assessments to improve accountability for reaching the target.
- 5.2.b The carers' assessment process should be reviewed to ensure that carers are made aware that they are being assessed as part of their rights under the Care Act and ensure that there is timely and clear communication on the outcome of the assessment.

5.3 Strengthening of the carer's wellbeing assessment

- 5.3.a The Commitment to Carers Action Plan sets out the intention to develop a system to evaluate carers' experience of the Carer's Wellbeing Assessment.

Healthwatch North Tyneside request an update from the council on progress towards this goal.

Healthwatch North Tyneside has also reviewed the form used to guide and record the Carer's Wellbeing Assessment in North Tyneside. In particular, we looked at how the form addresses the areas identified in the definition of wellbeing contained within Care Act (2014) guidance. The form addressed physical and mental health well but other impacts are only covered in a generic table which may mean some support needs are not identified.

- 5.3.b We therefore recommend that **North Tyneside Council** strengthen the Carer's Wellbeing Assessment form as follows:
 - Clarify how wellbeing is defined in order to assess the impact of caring against a clear mutual understanding of wellbeing.
 - Review the balance within the assessment form between the focus on understanding the needs of the person who is cared for with the impact of caring.
 - When discussing 'my employment' include a focus on the impact of caring on their employment as well a discussion of any resultant risk of loss of employment or future aspirations.
 - Include a question about current or aspired to education and training and the impact of caring on these.

- Identify any impact of caring on financial wellbeing within the assessment.
- Identify the impact of caring on domestic and family circumstances within the assessment.
- Identify if the person is, or is at risk of, social isolation as a result of caring.
- Identify the current support and information accessed by the carer and identify further information and advice needs.
- Provide an opportunity for carers to deliver feedback, following an assessment, about how effective the assessment has been in fully addressing their needs.

5.3.c The strengthening of the assessment should encompass the needs carers identified to ensure their voices are clear from the offset. Therefore, we recommend that carers should be involved in the further co-production and development of the revised Carer's Wellbeing Assessment in order to address their needs fully. HWNT would be happy to be part of the facilitation of this process.

5.4 Improving information, advice and support for carers

5.4 a Healthwatch North Tyneside request that **North Tyneside Council** provide an update on the progress on the following goals of the North Tyneside Commitment to Carers Action Plan:

- Information about the number of working carers who have undertaken a carer's assessment.
- The commitment sets out the intention to "explore options to support carers to remain in employment" through a pilot project 'Carers in Employment' which is now underway. The learning from this will inform future services.
We request further details on the expected end date for this pilot and date of publication of the report and action plan for improving provision in this area.
- The commitment sets out the intention to increase opportunities for carers to access breaks and we are glad to see that a review is underway of access arrangements for carers' respite, however a current progress update of this review is required.
We request further details on this review and when findings are likely to be published.

5.4.b Whilst we welcome the development of an action plan to implement the Commitment to Carers in North Tyneside, we are concerned that the action plan is now out of date (ending in 2016) and does not appear to have strong time bound and measurable actions for each priority goal and objectives.

Therefore, Healthwatch North Tyneside recommend the following changes to the action plan:

1. **North Tyneside Council and North Tyneside Clinical Commissioning Group** should review the action plan to implement the Commitment to Carers both in light of the findings of this report and in recognition of the plan to include time-bound and measurable targets and actions to which they can be held to account for implementing.
2. **North Tyneside Council** should set out actions to work towards ensuring employers have carer friendly policies and fully understand the needs of working carers.
3. The Commitment to Carers Action Plan sets out intentions to support parent carers to access training. However, it fails to include carers of adults.
This needs be clearly addressed within the Commitment to Carers Action Plan with steps to ensure this group are not excluded from equal access to training opportunities.
4. The Commitment to Carers Action Plan sets out the intention to explore options for crisis management for all carers to reduce the number of carers who reach 'breaking point' or encounter a health crisis of their own. However based on the feedback from carers in this report, we recommend that the action plan is altered to prevent and respond to different types of crisis:
 - Develop a model for advanced planning during 'good times' on how to respond to or avoid various types of crisis.
 - Improve ways that carers can access help if they are suddenly incapacitated, to enable rapid response support to be put in place for the person requiring care.
5. Carers reported concerns about the role they are expected to take when the person requiring care is admitted or discharged from hospital and the impact on the carer's wellbeing. The action plan should be changed to include actions to:
 - Review and adapt the pathway for admission of a person requiring care into hospital to ensure that adequate care provision is in place for the duration of their hospital care, the continuity of care is considered and that funding arrangements for this care are clear.

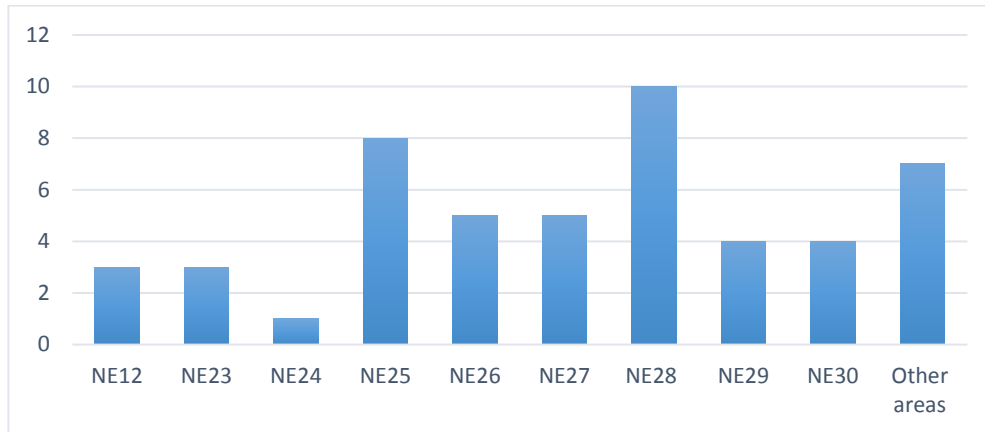
- To review the current discharge process from hospitals and A & E services by sufficiently identifying and assessing carers needs. Improvements should be made and reviewed to ensure this process is robust and supportive for carers.
6. There are many actions within the North Tyneside Commitment to Carers Action Plan which relate to improving access to information for carers. However, whilst this does refer to 'quality' information, there are no actions which directly relate to how this quality will be measured and improved. This should be addressed in the action plan.

HWNT are not in a position to make a recommendation on improving support for carers in their care coordination role as this area requires further investigation. However, we encourage statutory services to consider adding this to their action plans and feedback systems to ensure this role is considered.

Appendices

Appendix A - Who took part

Locality

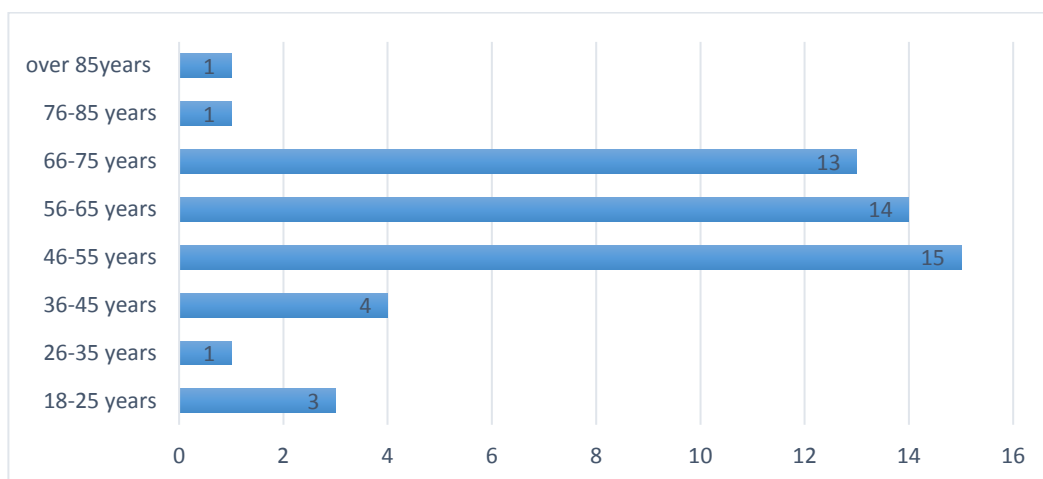


Carers engaged with this study were located across the borough and involved with a range of services including those based in Howdon, Longbenton, North Shields, Shiremoor and Whitley Bay.

Carers' comments were gathered through general and targeted engagement throughout 2016-17 in Battle Hill, Howdon, Killingworth, Longbenton, North Shields, Shiremoor, Wallsend and Whitley Bay.

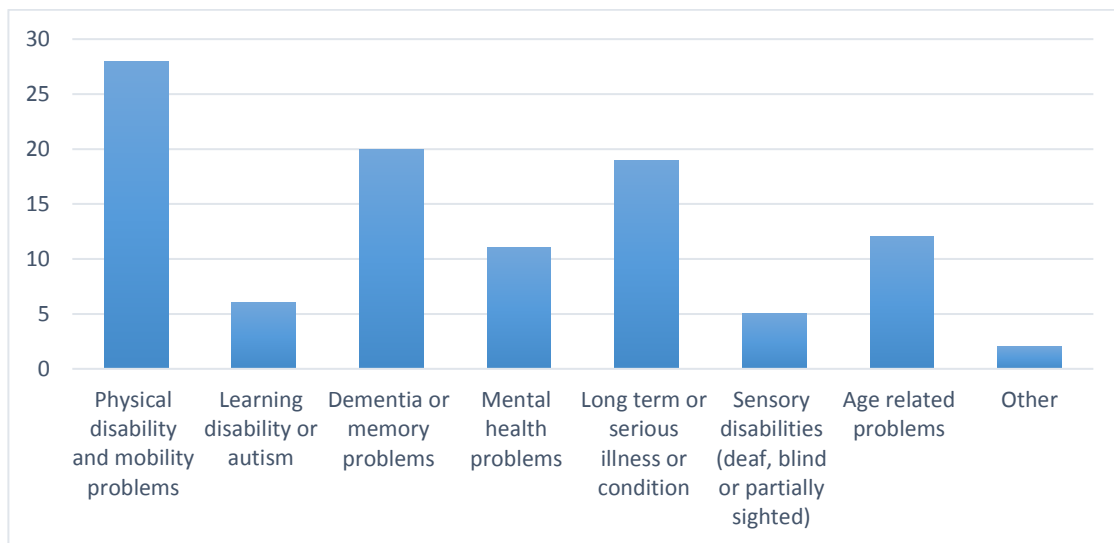
Carers were also engaged through support groups in North Shields, Shiremoor, Whitley Bay and Wallsend.

Age range



The majority of carers who participated were aged between 46-75 years old. As this study was considering adults caring for adults responses were not collected from young carers. The age range collected reflects the aging population within North Tyneside.

Needs of the person requiring care

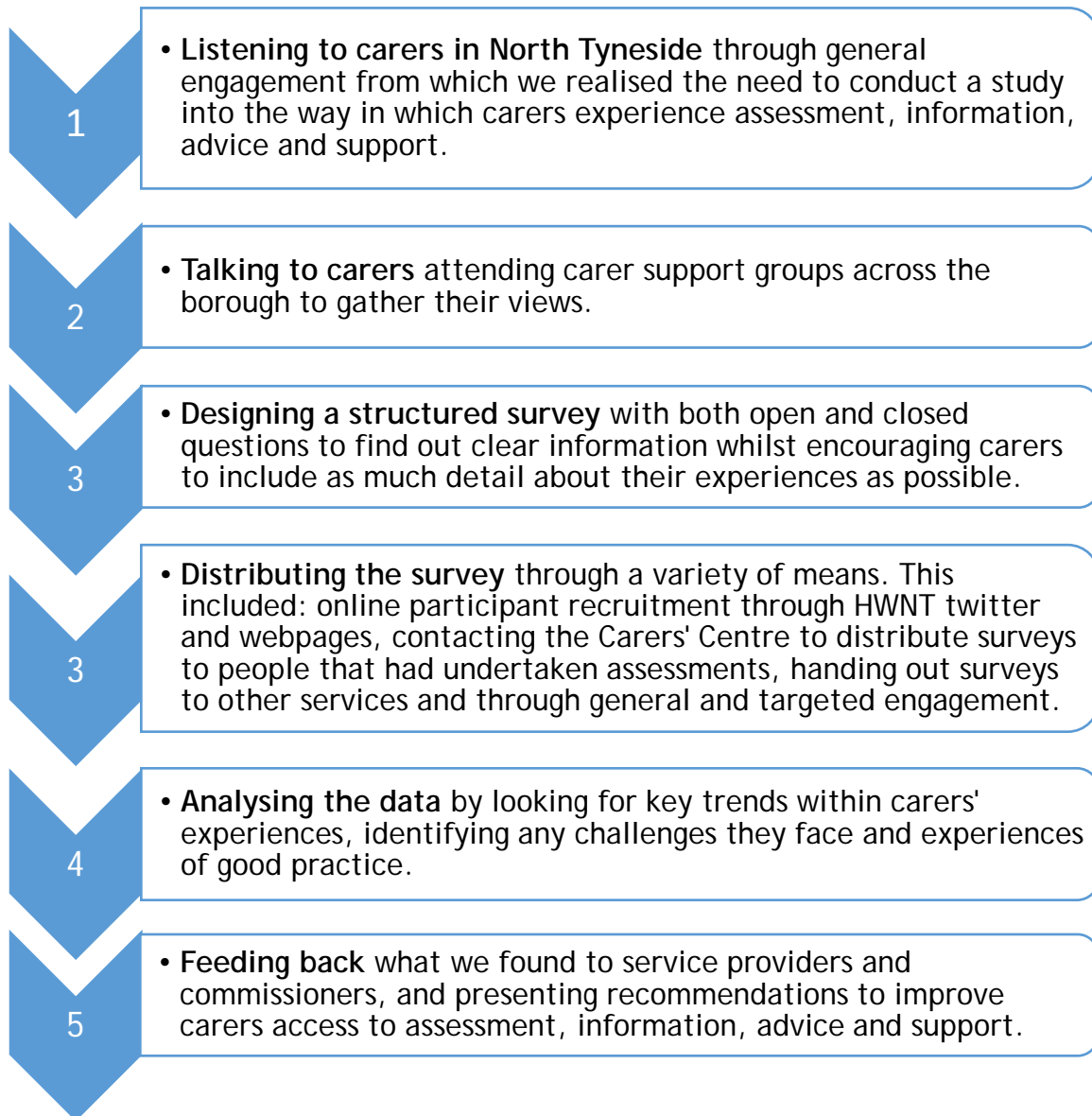


Carers cared for people with a range of different support needs. 19 carers identified one reason they offer care, 12 carers identified 2 reasons they offered care whereas 17 carers identified 3 or more reasons they offer care and support. Therefore, a number of carers that took part in this survey cared for people with multiple and complex needs.

Additionally, whilst the majority of carers cared for one person, 14 of those who took part stated that they cared for two or three people.

Appendix B - What we did

In order to capture carers' experiences effectively we primarily used qualitative methods of data collection, the data collection process included:



Appendix C - Our survey

Many people who look after a family member or friend do not realise that they are carers and are entitled to information and advice and possibly additional support.

You are probably a carer if you help a relative or friend:

- Do things that they should be able to carry out as part of normal daily life but can't because they have care and support needs.
- Wash, dress, eat, take them to appointments, do their shopping, or support them emotionally.
- You are not paid. (Carers who get Carer's Allowance are not paid carers)

Healthwatch North Tyneside want to hear from unpaid carers about:

Healthwatch want to find out whether unpaid carers know about and have access to information and support to maintain their wellbeing so that they can continue to do the things that are important to them and their families.

Let us know your views

We will gather people's comments and record them anonymously. We will then feed people's comments to service commissioners to help services improve. We can also signpost people to organisations to discuss their comments further.

To discuss the survey or give your answers over the telephone, call 0191 263 5321.

You can also fill in the survey online at www.healthwatchnorthtyneside.co.uk

You can return this survey by **April 3 2017** using the freepost envelope attached.

You do not need to give your name or address unless you want Healthwatch to contact you and discuss your situation further.

To find out more about the work Healthwatch are doing with carers in North Tyneside or for useful contacts for carers call Healthwatch or visit our website.

Many thanks

Yes / No answers - please circle or mark with a cross

About you

Some information about you to help us understand your situation.

1. Are you:

Working? Yes / No

Studying or in training? Yes / No

Able to continue to take part in leisure activities or hobbies? Yes / No

2. Tell us how caring affects your ability to work, continue studying or take part in leisure activities or hobbies

3. Does your GP know you are an unpaid carer? Yes / No / Not sure

4. Do any care services know you are an unpaid carer? Yes / No / Not sure

5. To help us know we are reaching different carers across the borough can you tell us the following?

Your age

The first part of your postcode

6. How do you prefer to get information?

leaflet

talking to someone face to face

talking to someone over the phone

internet / email

Social media such as Facebook or twitter

Information and advice

7. Do you know where to get information and advice to maintain your wellbeing? Yes / No / Sometimes

8. Do any of the following offer you information, advice or support to maintain your own wellbeing?

- | | |
|-------------------------|----------|
| Family | Yes / No |
| Support groups | Yes / No |
| Social Worker | Yes / No |
| Carer support worker | Yes / No |
| Home carers | Yes / No |
| Care home staff | Yes / No |
| GP | Yes / No |
| Pharmacy | Yes / No |
| Library | Yes / No |
| Your work | Yes / No |
| Other - please describe | |

9. Use this space to tell us about the information they have offered you

10. Which statement best describes you:

I have access to information and advice for me relating to the following:

	Strongly disagree	Disagree	Neither disagree nor agree	Agree	Strongly agree	Not applicable
Financial support and benefits advice, for example: Carer's Allowance						
Legal matters for example: Power of Attorney						
Emotional support						
Planning for an emergency						
Respite care or short breaks						
Health and Wellbeing						
Training						
Working and caring						

11. Have you had any difficulties getting information and advice when you need it over the past year?

12. Have you had any good experiences getting information and advice when you need it over the past year?

13. Where do you think unpaid carers should be able to get information and advice?

About the person or people you give care and support to:

14. Who do you care for?

- Adult son or daughter
- Parent
- Grandparent
- Husband, wife or partner
- Brother or sister

Other - please describe

15. What are the main reasons you offer care to the person or people?

- Physical disability and mobility problems
- Learning disability or autism
- Dementia or memory problems
- Mental health problems
- Drug or alcohol dependency
- Long term or serious illness or condition
- Sensory disabilities (deaf, blind or partially sighted)
- Age related problems
- Other - please specify

16. If you offer care and support to more than one person please describe here:

Carers' wellbeing assessments

A new type of assessment for adults caring for adults was introduced in April 2015. The assessment is called a Carers' Wellbeing Assessment.

Carers' Wellbeing Assessments aim to identify carers' support needs and whether carers are eligible for additional support.

17. Have you heard of the new Carers' Wellbeing Assessments?
Yes / No / Not sure

18. Have you had a Carers' Wellbeing Assessment in the last year?
Yes / No / Not sure -

If you answered no or not sure go to question 24

19. **If you have had a Carer's Wellbeing Assessment - tell us about the assessment:**

Was it easy to get a Carers' Wellbeing Assessment? Yes / No

How long did you wait before you had an assessment?

Were you offered support to complete the form? Yes / No

20. Did you feel you were able to describe your needs through the assessment process? Yes / partly / No

Tell us what happened

21. Where you offered any new information or support following the assessment?

22. Do you feel having the Carers' Wellbeing Assessment was helpful?
Yes / No / Not sure
Can you tell us more?

23. Could the assessment be improved? Yes / No

Tell us how:

If you haven't had or aren't sure if you have had a Carers' Wellbeing Assessment:

24. Do you think it would help you as a carer if you had an assessment?

Yes / No / Not sure

25. Do you know where to get more information about getting a Carers

Wellbeing Assessment if you want one? Yes / No / Not Sure

26. Anything else you want to tell us?

Appendix D - References and reading list

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http://my.northtyneside.gov.uk/sites/default/files/web-page-related-files/Carers_Charter._Oct_14.pdf (Accessed on: 18/05/2017)

North Tyneside Commitment to Carers. Available at:

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www.legislation.gov.uk/ukpga/2014/23/contents/enacted (Accessed on: 18/05/2017)



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