Carer's experiences and issues

In 2016 and 2017, Healthwatch North Tyneside spoke to carers about their experiences of the Carers Wellbeing Assessments. During this research a number of other issues emerged.

This short paper highlights the key suggested actions we have identified based on the feedback and research we conducted during this period. We hope this will help shape the joint action plan for carers currently being developed by North Tyneside's Carers Partnership Board.

Many of the actions below respond directly to the feedback received from carers, others are based on our review of good practice and other evidence from across the country. North Tyneside Carers Centre and North Tyneside Council have supported us in developing these suggested actions. The detailed feedback and analysis behind this report is available on request.

Background

In 2016 and 2017 we heard from 139 carers about their experiences of the Carer's Wellbeing Assessments. Carers took the opportunity to share other issues that mattered to them. We used a variety of methods to engage with carers from different backgrounds and experiences including:

A survey (on and offline) – 52 responses

Discussions at established carers meetings & support groups – 29 responses

General feedback activity – 58 responses

We could not have conducted this research without the support of North Tyneside Carers Centre, Action for Blind People, Alzheimer's Society, Age UK, Headway, Learning disability Reference Group, NTDF and PROPS. The Carers Centre and North Tyneside Council have supported us in developing these suggested actions.

Most of all we would like to thank all of the carers who shared their experiences with us.

Identification of Carers

The issue: Many carers told us they were unsure whether health & social care services knew they were a carer. 29% said their GP was aware and 39% said social services were aware of their caring role. The Carers Partnership Board is aware that early identification of carers is a key issue.

Recommended actions:

1. Review training and support to ensure that all front line health and social care staff are trained in: how identify carers, understand the impact of the caring role on the carer, provide information to the carer to get the support they need and can easily make referrals.

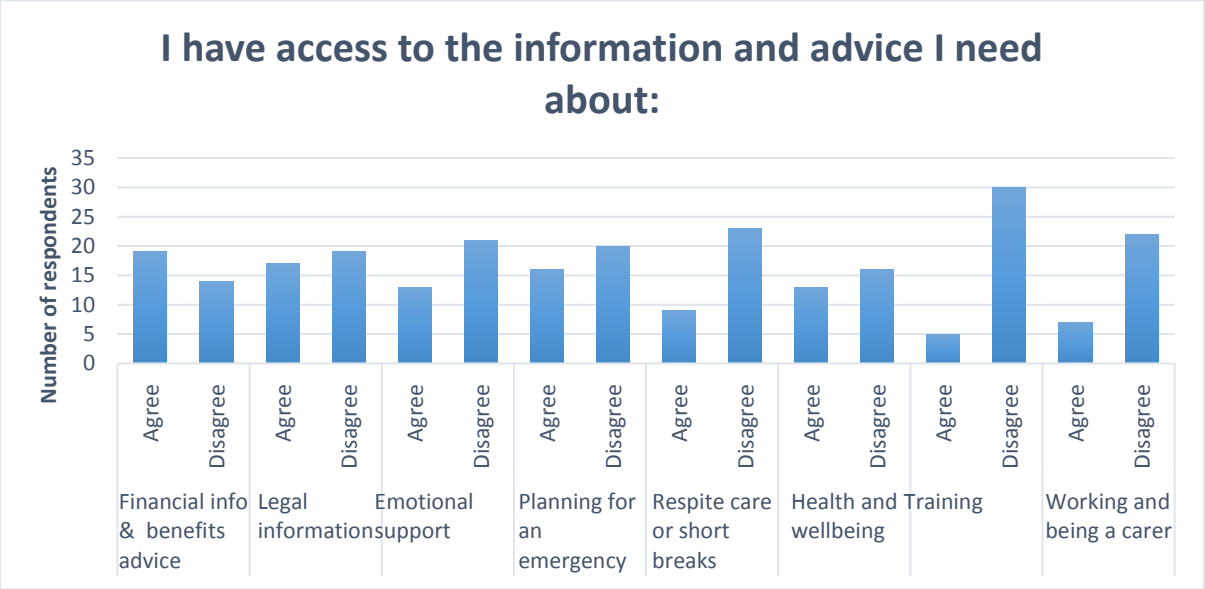
2. Investigate how GP practice carer registers can be best used to improve early identification and support for carers.

3. Include carer identification, information and referrals in all health and social care provider contracts so all services are aware of their obligations and performance can be monitored as part of the contract management.

4. Consider adopting the framework created by NHS England and others for an 'Integrated approach to identifying and assessing carer health and wellbeing' https://www.england.nhs.uk/wp-content/uploads/2016/05/identifying-assessing-carer-hlth-wellbeing.pdf

Information, advice and support for carers

The issues: The carers we heard from told us they get their information from a number of different sources (family members, Support Groups, GPs and work being key) and in different formats. They said information and services can be disjointed and confusing and there are gaps. Some carers said that they found it hard to understand the roles of different people within the different services and would find a guide to basic services helpful in navigating the systems themselves and with the person they care for. The graph below shows how carers thought their information and advice needs were being met.



Recommended actions:

5. Review existing sources of information about what support is available. Identify and fill any gaps.

6. Consider a joint initiative across health and social care and/or focus point of information to give access to high quality information to carers at the right time across the system.

7. Given GPs are recognised as a critical contact for carers, develop an initiative to specifically work with GP practices to ensure they make good quality information available to carers & utilise referral pathways.

8. Produce a guide to the roles and responsibilities in different services that carers are likely to come into contact with so that they can better navigate systems.

9. Involve carers as well as the person needing care in decisions about what is happening - practically about planning for crisis and also in relation to admittance/discharge.

Carer's Wellbeing Assessment

The issues: The feedback from the carers we spoke to indicates there are gaps in people's understanding about their right to and the purpose of a Carer's Wellbeing Assessment. Some people confused the Carer's Wellbeing Assessment with personal budgets, assessments that the person they cared for needs and many didn't understand the process. Some carers were concerned that their ability to care was being assessed.

Recommended Actions:

10. Develop a joint initiative between health and social care to promote the right to, and purpose of, a Carer's Wellbeing Assessment, the right to an individual rather than joint assessment and what carers can expect. Alongside this, highlight the other support that is available across the borough.

11. Continue to gather feedback from carers about their experience of the carers wellbeing assessment and develop an understanding of why some carers decide not to have an assessment.

12. Involve carers when reviewing the Carers Wellbeing Assessment approach as carers were involved in its development and should continue to be involved as it evolves.

13. North Tyneside Council should continue to review the quality of the Carers Wellbeing Assessments being carried out – particularly when these are completed as part of a joint assessment of the cared for person – so carers needs are captured.

The impact of the caring role

The issues: Whilst telling us about their experiences, carers explained that time, money and a sense of responsibility all impacted on their wellbeing. Carers ability to work or study were highlighted as key issues, around 38% of carers responding to the survey told us that they were in work and many described the impact of caring on their working life. This including, leaving work/study, retiring early, using most of their leave for caring responsibilities and having difficult conversations with employers about needing flexibility. Carers also described this creating significant pressures on family finances.

Carers also told us about how difficult they have found adjusting to a change in their role and what is expected of them when the needs of the person they care for changes – either when their support needs become greater, they go into hospital or move into a care home.

Recommended Actions:

14. Continue to raise awareness of carer's issues with local employers so they better understand carers' needs and encourage flexibility.

15. Develop a better understanding of how best carers can be supported to gain employment, continue in work or access opportunities to study.

16. Ensure work/study opportunities are fully explored as part of a Carer's Wellbeing Assessment.

17. Provide training for front line staff across health and social care to understand and support carers to adapt when their caring role changes, either when the person they care for is in hospital or goes into a care home.