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# Carers FIRST Summary Report

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FIRST Choice for Carers

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## NATIONAL CONTEXT

The 2011 population census recorded 6.5 million people in the UK as carers (Carers UK, 2015). People in mid-life (55-64) are the most likely to be carers, and this is the case for almost one in five of this cohort (18%) (Health and Social Care Information Centre, 2015). Some 40% of carers are aged 45-65, but a quarter of all carers are aged at least 65. Older carers are particularly likely to be caring for a spouse or partner, while middle aged carers are more likely to care for a parent or parent-in-law. It is noteworthy that as a consequence of the combined impact of the ageing population, reduced use of institutional care, and so-called 'welfare austerity' measures carers are now doing more complex tasks, for more hours per week and over a longer period than was the case 10 years ago. Fewer carers also get support from the public sector.

In terms of policy, any discussion of support for carers needs to be considered against the framework of the **2014 Care Act** (DH, 2014). This Act was intended to introduce parity of esteem between carers and the people they support, and to strengthen carers' rights including to an assessment of need and to have any 'eligible needs' met (by the local authority). The Carers Strategies are also a relevant part of the policy landscape; the first national strategy was introduced in 1999, since when there have been a number of updates and iterations, and a **Carers Action Plan** (Department of Health and Social Care, 2018). The role of health care is also relevant. **The NHS Five Year Forward View** published in 2014 focuses on prevention and better integration of primary and secondary care and health and social care (NHS England, 2014).

There is increasing policy emphasis on: recognising and identifying carers; providing effective support for carers; and ensuring that their wellbeing and health is protected and/or promoted. The majority of support for carers is provided by the third sector and there is a shift towards commissioning carers agencies to undertake carers' needs assessments (Larkin et al, 2018).

It is also crucial to note **that if carer needs remain unaddressed, they are likely to deteriorate over time** (especially when if the cared-for persons' functional status declines), leading to carer breakdown and inability to continue performing caring tasks (Grunfeld et al, 2004).

## CONTEXT

Carers FIRST is a not for profit organisation supporting people who look after a relative or friend who due to ill health, physical or mental illness, disability, frailty, or addiction cannot manage without their support.

Carers FIRST is leading the way in terms of routinely collecting data on outcomes related to its support to carers. Carers FIRST has been using a tool - the Carers Outcome Star - for over 3 years with a significant number of the carers that it serves.

The Outcome Star Tool allows Carers FIRST to record the impact of caring at the first point of contact and then again at a later stage - a review point - allowing us to measure the impact of the support that has been put in place.

Figure 1. The Carers' Star

**Outcomes Star** Star Chart

**Carers Star™**  
The Outcomes Star for people caring for others

Carer

Date of completion DD/MM/YYYY

First  Review  Retrospective

Completed by  
 Worker and carer   
 Worker alone   
 Carer

5 As good as it can be  
 4 Finding what works  
 3 Making changes  
 2 Getting help  
 1 Cause for concern

health  
 the caring role  
 managing at home  
 time for yourself  
 how you feel  
 finances  
 work

Carer: I was involved in completing this Star Chart

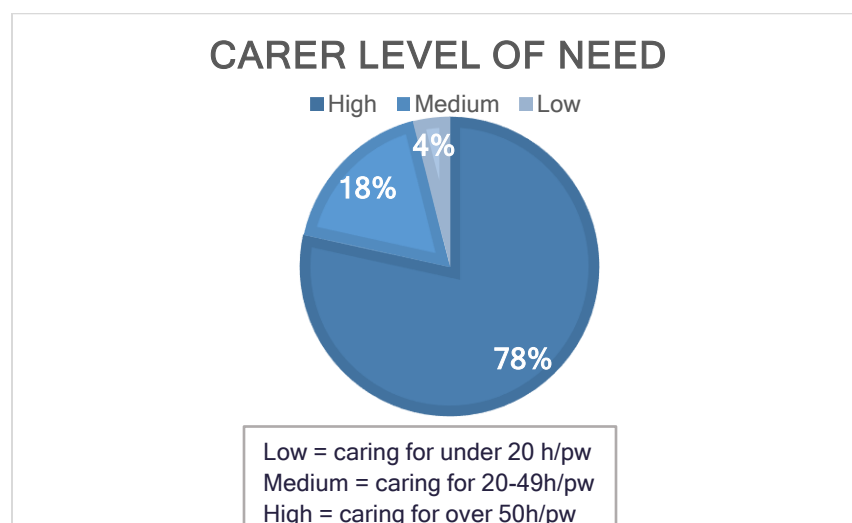
**Outcomes Star** **Triangle** **carers trust**  
 Carers Star™ © Triangle Consulting Social Enterprise Ltd | www.outcomesstar.org.uk  
 The Star Chart must be used with the Scales and workers trained by a licensed Star trainer

## CASE PROFILE

3,602 carers had a 'Carers Star' assessment completed at entry to the service.

Of these:

- Just under half of carers were older adults (65 years or older)
- 70% of carers were female
- Nearly 80% of carers were caring for 50 or more hours per week
- Nearly 50% of carers look after a spouse or partner
- More than two thirds of the cared for individuals have 3 healthcare conditions or less
- Nearly a quarter of cared for individuals experienced dementia as their 'main condition'
- Physical disorders were identified as a secondary condition in nearly a quarter of the cases
- The older the carer was, the more hours of care they were likely to provide
- Carers providing care for a spouse or partner were providing the most care (in terms of hours per week)
- Carers providing care for a person with dementia were providing the most care (in terms of hours per week)



**Key Message 1: Carers FIRST work with a highly diverse set of carers across a variety of complex situations.**

## CARERS STAR SCORES AT START OF RECEIPT OF CARERS FIRST SERVICE:

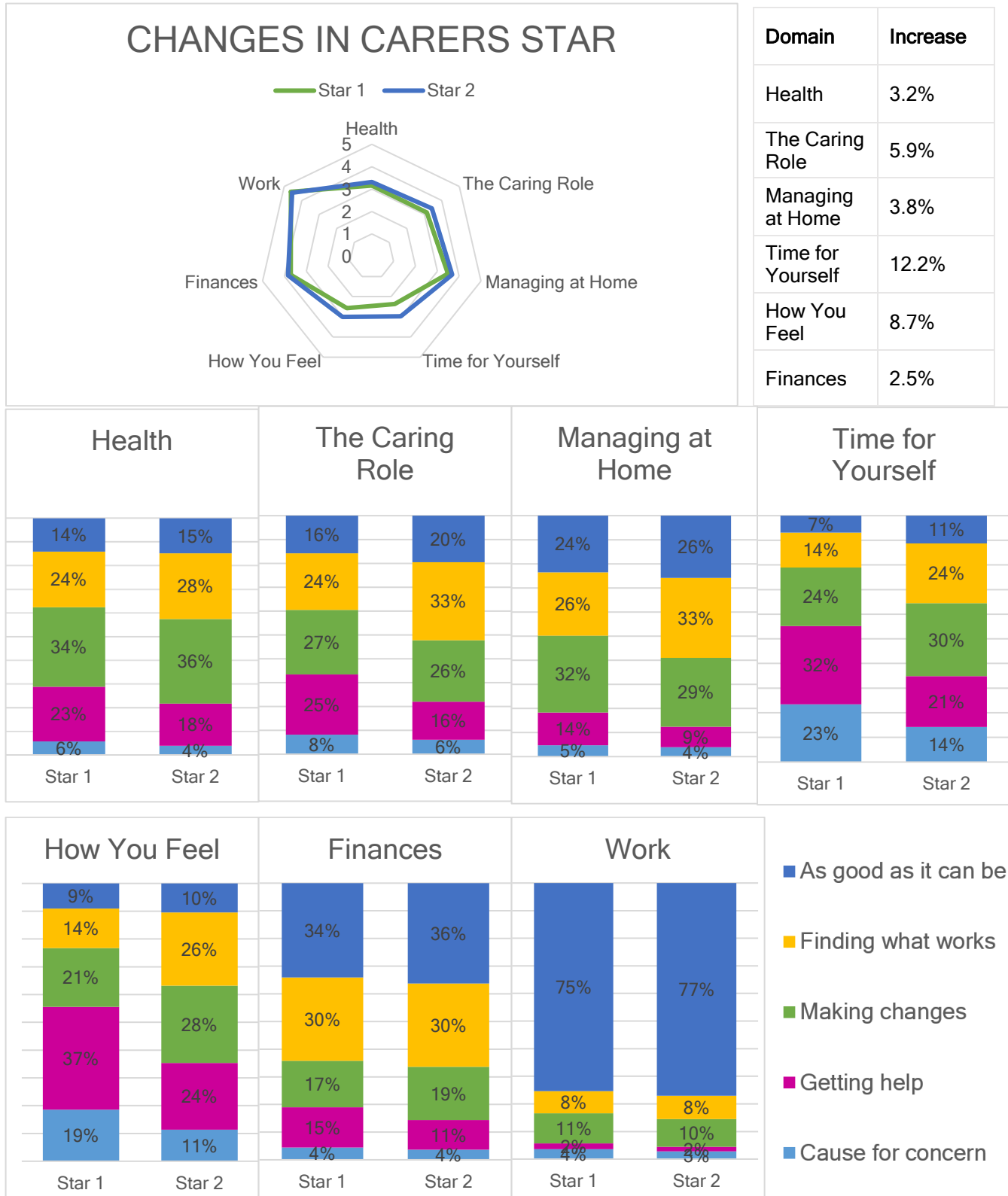
- Carers scored the highest on the work and finances domains and struggled the most with having time for themselves and the way they felt
- **Deprivation** predicted scores in all domains, with higher deprivation indexes correlating with lower scores on the carers star
- **Carer age** was an influential factor. The older the carer was, the better they were likely score in terms of Health, Managing at Home, How They Felt, Finances and Work
- **Age of the cared-for person** also played a role. The older the cared-for person was, the better the carer did in terms of their Health, Managing at Home, Time for Yourself, How You Feel, Finances and Work.
- **Gender** was influential. Male carers did statistically better than female carers in all Carers Star domains apart from finances.
- In the majority of cases, carers **looking after a child** fared significantly worse than other groups of carers and in some cases those **looking after a partner** scored better than either of the other two carer groups (child & parent)
- **Primary carers** fared better than secondary ones in terms of managing at home, having time for themselves, how they felt, finances and work than carers who identified as secondary
- People who provided **50+ hours of care per week** scored better than those providing under 20 of care on all Carer Star domains except for Work
- **The more people the carer looked after**, the worse they were likely to do on all Carer Star domains.
- Lower scores on the Caring Role, Managing at Home and How You Feel were related to **more intensive subsequent input from Carers FIRST**

*Key Message 2:* A number of demographic characteristics were related to how the carers scored on the initial Carers Star. It is possible to target carer groups who will need most support based on their demographic characteristics.

*Key Message 3:* Carers FIRST may need a separate strategy to work with carers looking after their (often adult) children, especially those living with autism. Carers in these groups are likely to score lower on the initial Carers Star than others.

## CARERS FIRST IMPACT BETWEEN INITIAL AND FOLLOW-UP CARERS STAR

723 carers had both the initial and the second Carers Star completed within 6 months.





Carers FIRST had a statistically significant positive impact on all areas of the Carers Star apart from Work. Significant improvement happened in carer health, their caring role, managing at home, time for yourself, how the carer felt, and finances. On average, scores in these domains improved from 3% to 12%.

*Key Message 4: While unmet carer needs are likely to deteriorate over time, Carers FIRST not only maintained carer performance on the Carers Star, but also significantly improved their scores on all domains apart from Work.*

- **Demographic factors** had very little influence on how much impact Carers FIRST had on carer outcomes:
  - Gender, relationship to the cared for person, main condition of the cared-for person, identification as a primary or secondary carer, number of individuals the carer looked after
  - **Carer age** only influenced carer scores on health and work domains; the older the carer was, the less impact Carers FIRST had on these domains; likely because ageing related ill health is difficult to improve and older carers are more likely to be retired.
  - **Deprivation levels** influenced Carers FIRST impact on health only; less deprivation was associated with more positive impact from Carers FIRST on Health.
  - **Number of hours the carer spent caring per week** influenced Health, Managing at Home and Time for Yourself
    - Carers in the moderate need group (20-49 caring hrs/pw) experienced a more positive CF impact than those in a high need group (50+ hrs/pw) when it came to health and managing a home,
    - In terms of time for yourself, carers in the low need group (<20 hrs/pw) experienced poorer CF impact than those in both the moderate and high need groups. This is not surprising as people in the 'low need' category may not feel in need of more time for themselves.



- **Carer FIRST input**, however, had a marked influence on how much impact Carers FIRST had on carer outcomes:
  - **Number of referrals** CF made influenced CF impact on Health, The Caring Role, Managing at Home, How the Carer Felt, and Finances (the more referrals, the less positive the CF impact in these domains), but not Time for Yourself
    - *This suggest CF staff were able to identify the limits of CF input and proactively sought other services likely to meet carer needs.*

**Key Message 5: If Cares FIRST were not able to improve carer outcomes, they were more likely to refer the carers to other services.**

- **Intensity of CF involvement** predicted CF impact in The Carinig Role, Managing at Home, How the Carer Felt (the higher the intensity, the more positive CF impact in these domains), but not Health, Time for Yourself, Finances, or Work
  - Intensity was calculated as a ration of number of ‘active’ contacts with the carer per length of time of CF involvement. ‘Active’ input counted as anything apart from sending out newsletters and included Carers FIRST staff spending time liaising with other professionals about the carer’s case and needs (i.e. making inquiries or referrals).

**Key Message 6: Carers FIRST impact on carer outcomes depended on their input, rather than carer characteristics. CF could delivered the same degree of change regardless of the group the carer belonged to.**

**Key Message 7: To ensure equality of outcomes, Carer FIRST require resources to work more intensely with carers who score lower on the initial Carers Star**

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