Carers FIRST
Case Profile & Carers' Star Utilisation Report

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CONTEXT

National Trends

Family caring is a key international issue and one amplified by the ageing profile of the world's population. In the UK, there are estimated to be 6.5 million family carers, a figure predicted to rise to 10 million by 2045 (Larkin and Milne, 2015). A third of carers are older (60 years and over) and as a proportion of the overall this proportion is growing. Family carers routinely experience a range of negative outcomes relating to caring including physical and mental ill health, reduced quality life, 'restrictedness' and poverty (Yeandle et al, 2017). The challenges of caring are especially pronounced for intensive carers - carers who provide support for their relative for many hours a week and offer personal care (Milne and Larkin, 2014, 2017). There are more carers supporting relatives with co-morbid complex needs in the community now than was the case twenty years ago and they are also doing more complex tasks such as monitoring medication drips.

The importance of supporting carers is increasingly recognised in policy and practice and there is growing emphasis on evaluating the effectiveness of interventions for carers (DH, 2014; HM Government, 2008). Evidence relating to service efficacy is mixed. Integrated programmes of support are effective in terms of delaying care home admission and psycho-educational groups for dementia carers enhance wellbeing (Milne et al, 2013). Information (e.g. advice about managing challenging behaviours) is highly rated and carers value practical help with physical aspects of care (e.g. incontinence). There is recent evidence that a manual-based therapy intervention to support dementia carers is highly effective: it reduces the risk of depression amongst carers in the short and medium term (Knapp et al., 2013). However, most research on interventions for carers is limited in scope and size, of variable quality, short term, & lacking in rigour. Good quality data on the impact of an intervention(s) over the longer term is rare (Milne & Larkin, 2014; Henwood et al, 2018).

Carers FIRST

Carers FIRSTis 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.

For many, caring is a rewarding and positive experience, but for others, without the right help and support caring can feel overwhelming. For some, caring can trigger feelings of loneliness and frustration and many find their physical and emotional health, work or finances is affected.

Carers FIRSTprovides information, advice, guidance, emotional support, training and activities, giving carers an opportunity to have a break from their caring role and help them to get the support they need.

Measuring Carer Outcomes – The Carers Star

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 'Carers' Star' collects information on 7 different domains: health; the caring role; managing at home; time for yourself; how the carer feels; finances; and work. A carer is 'scored' on a scale of 1-5 on each domain (1 = 'cause for concern' & 5 = 'as good as it can be'; see Figure 1). The data is entered into an agency wide database by carers' workers. The Carers' Star is not a validated measure but it is an evidence based tool that evaluates change; it was developed by a specialised agency in partnership with a national carers' charity (http://www.outcomesstar.org.uk/carers-star/). It is one of a family of 'outcomes stars' and suite of tools that are used in research (Killaspy et al, 2012).

The Carers FIRST service delivery model is a strengths based approach focusing on a carers strengths and community assets and the outcome they wish to achieve and incorporates the "3 conversations" model of support. Carers FIRST have developed a 'wellbeing summary' – a bespoke tool, using the Carers Outcome Star and guided conversations to inform and support a strength based approach to support planning with the carer. This "first conversation" covers the 7 different domains noted above, supports the carer to identify what support is available within their own family and community and help them utilise local resources to support positive outcomes in areas which they identify as needing improvement

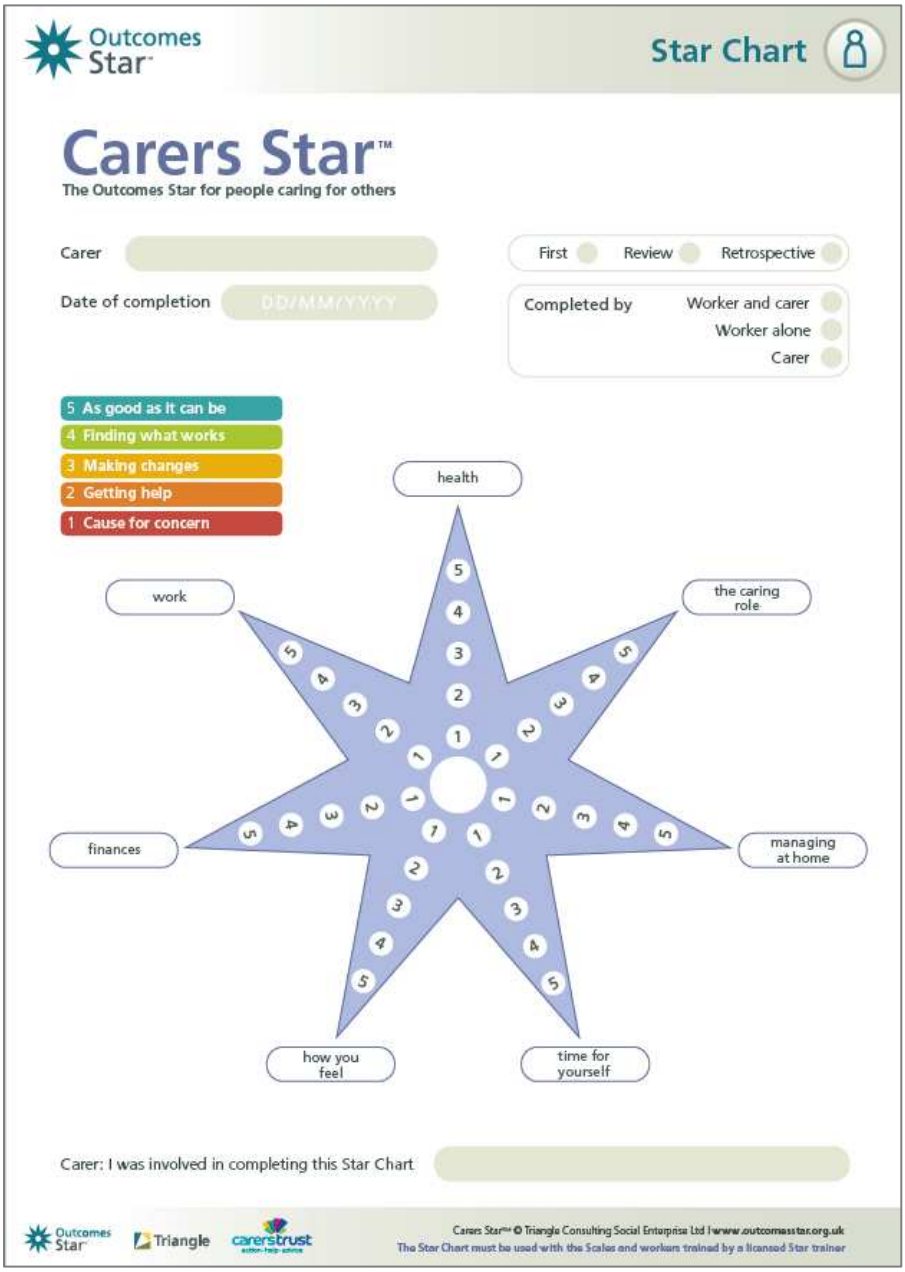
Conversation 2 takes place when a carer needs more support and is unable to acquire this from personal or community resources themselves. The Conversation may take place within the Carers Hub or with our community CSACs with carers who present more in crisis; it seeks to identify how best to help the carer in the short term. The CSACs us the Carers Star to identify risk thus enabling the worker and carer to concentrate on priority areas. A support plan is

devised with the carer to identify resources we can provide to promote a sense of safety and control.

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.

All Carers FIRST support staff are trained and licensed to use the (Triangle) Carers Outcome Star.

Figure 1. The Carers' Star



METHOD

Carers FIRST database was provided to the first author of the report including a list of pre-agreed variables. Variables of interest included:

- Carer ID
- Referral date
- Gender
- Area/Location
- Municipal ward
- Carer Age
- Carers Star scores for each of the 7 domains
- Carer level of need (hours of caring per week)
- Referrals out and signposting
- Relationship to the cared for person
- Cared-for person's age
- Primary vs secondary identification of the carer
- Cared-for person's main condition
- Cared-for person's secondary condition
- Number of conditions of the cared-for person
- Number of cared for individuals per carer
- Intensity of Carers FIRST involvement
- Cared-for person's age
- Primary vs secondary identification of the carer
- Cared-for person's main condition
- Cared-for person's secondary condition

Data cleaning and computing of composite variables was also performed; for example, see page 29 for formula used to quantify the 'intensity' of Carers FIRST involvement.

Demographic information was calculated producing Pivot Tables on Microsoft Excel Software. Area where the carers lived, their age and gender distribution, carer level of need / hours of caring, carer relationship to looked after person, looked-after person's number of conditions as well as type of main and secondary condition were investigated to see which groups were over- and under-represented in terms of carer numbers. Contingency tables were also produced to investigate if level of carer need differed in proportions depending on carer gender, age, relationship to the cared for person, and the cared for person's main condition.

To perform inferential statistical analysis the data was transferred onto IBM SPSS Statistics 24 software. Inferential statistics were predominantly performed to find out which demographic variables predicted carer scores on the Carers Star – and in what way.

Regression analyses were computed to see if the following factors predicted scores on Cares Star domains:

- Deprivation Indexes (IMD)
- Carer Age
- Cared-for person's age

Correlation analyses were computed to see if the following variables were related to scores on Cares Star domains:

- How many people the carer looked after
- How 'intensively' Carers FIRST worked with the carer

T-tests were computed to see if the scores on Cares Star domains depended on whether:

- The carer was male or female
- The carer was or was not signposted to other services
- The carer was a primary or a secondary carer

Analysis of Variance (ANOVA) were computed to see if the scores on Cares Star domains depended on whether:

- The carer looked after a partner, a child or a parent
- The carer looked after someone with dementia, a neurological condition, a physical disorder, a mental health difficulty or autism
- Carer Level of Need: low, medium or high

Finally a **Multiple Regression Analysis** was performed with the following variables to see if *together* they could better-predict scores on the Carers Star domains:

- Carer Age
- Carer Gender
- Cared-for-Person's Age
- Carer Level of Need
- Intensity of Carers FIRST involvement
- Deprivation (IMD) Score

FINDINGS

Demographic Information

3,602 carers were eligible for Phase 1 of the analysis, establishing a case mix of people making their first use of Carers FIRST services. For carers to meet eligibility criteria for the current analysis, a 'Carers Star' had to be completed at entry to the service.

The carers whose data was included in this analysis, come from 6 areas where Carers FIRST operates a service. A small proportion coming outside of these areas was also included as they were also provided a service (see Table 1).

Table 1. Carer numbers by area

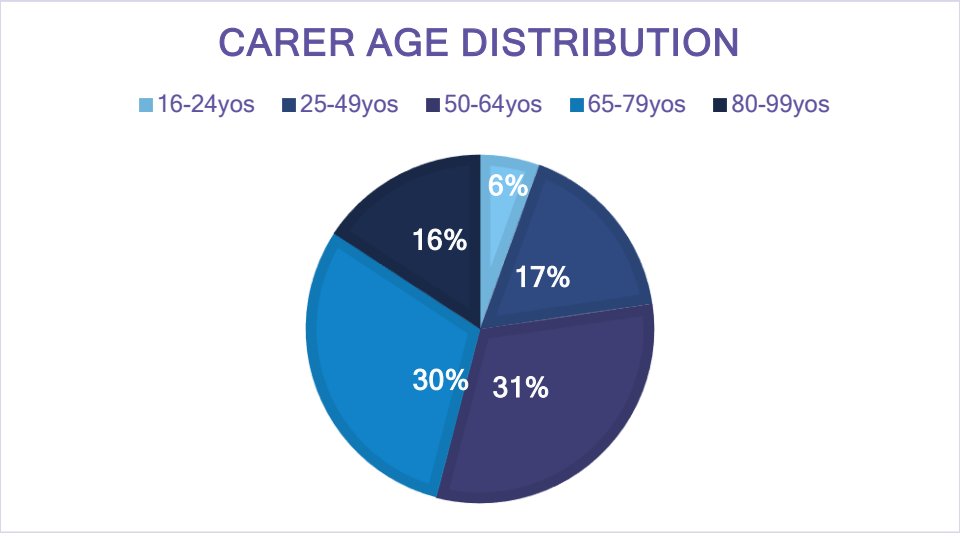
Area	No. of Carers
Dartford, Gravesham and Swanley	899
East Lincolnshire	371
Medway	816
South West Kent	1036
Waltham Forest	35
West Lincolnshire	405
Out of Area	40

N=3602

Municipal wards where the carers resided were also recorded in order to match these with the national multiple deprivation indexes (IMD). The average deprivation score for 332 wards in which Carers FIRST worked was 18.59, slightly lower than the 21.8 average for England. This shows that the population of carers that Carers FIRST works with - the ones included in this analysis - live in slightly less deprived areas than the national average. The ward with highest deprivation score was Princess Park in Medway (score = 59.6), while the least deprived ward was Sevenoaks Town and St John's (score = 3.6).

Carers were aged between 16 and 98; the mean age is 61.17 years (no age data available for 38 carers). As can be seen from Figure 2, nearly two thirds of carers were aged between 50 and 79. 70.18% of carers were female, and 29.76% were male.

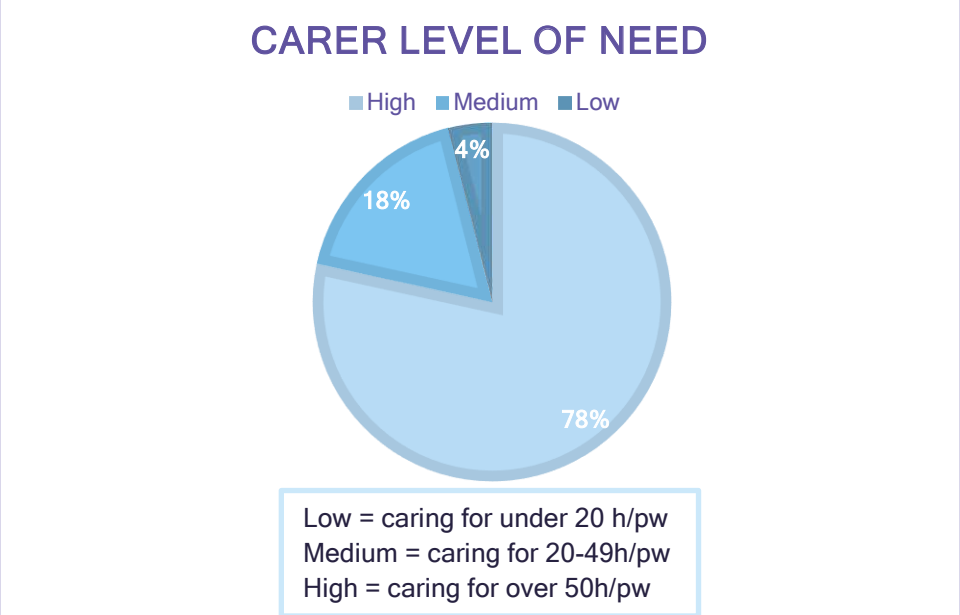
Figure 2. Carer age distribution



N=3561 (41 cases with missing age)

Figure 3 demonstrates that at entry to the service the majority (78%) of carers were recorded as having a 'high level of need'. Just under half (48%) of carers were 'signposted to other services'.

Figure 3. Carer level of need

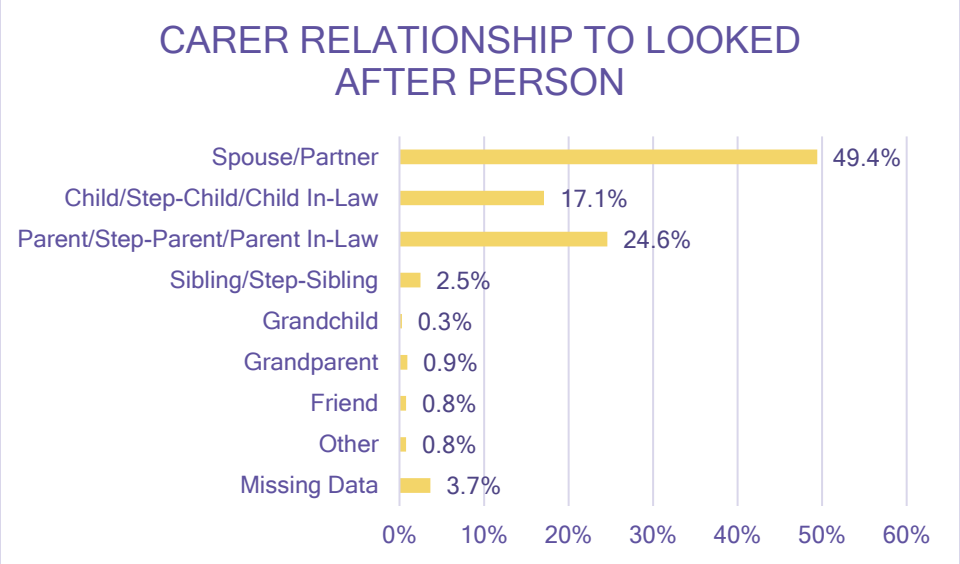


N=3602

96% of carers were the primary carer for their relative or friend. In terms of numbers of cared for people: 83% cared for one person, 14% for two and 3% provided care to three or more

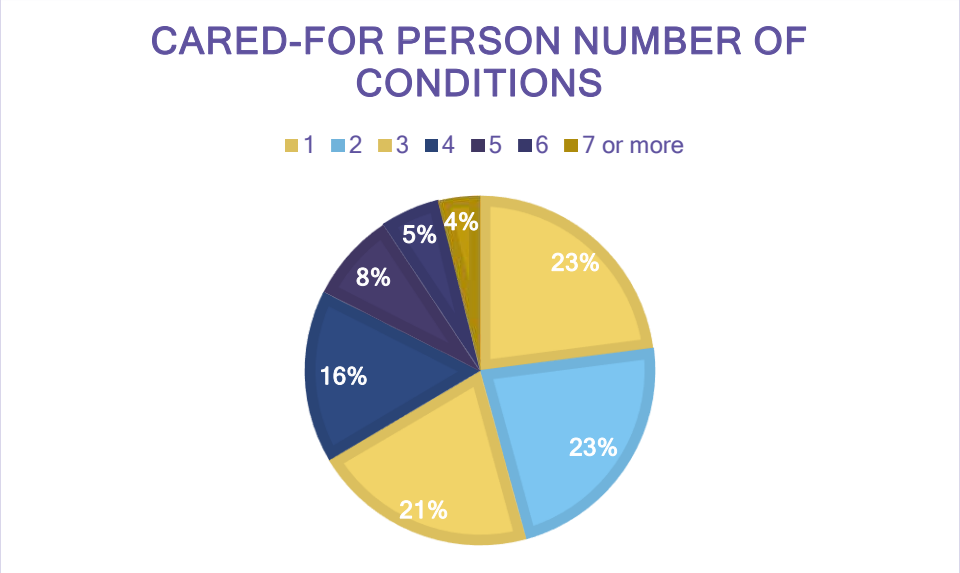
people at the same time. The maximum number of cared-for persons was six. Nearly half of carers (49.4%) looked after their spouse or partner, a quarter (24.6%) looked after a parent, step parent or parent-in-law and a sixth (17.1%) looked after their child/step child (often an adult son or daughter with disabilities or mental health problems) (See Figure 4). The average age of the cared-for person was 63.6 years.

Figure 4. Carer relationship to looked after person



N= 3556 (46 carers did not have a relationship recorded)

Figure 5. Number of Conditions

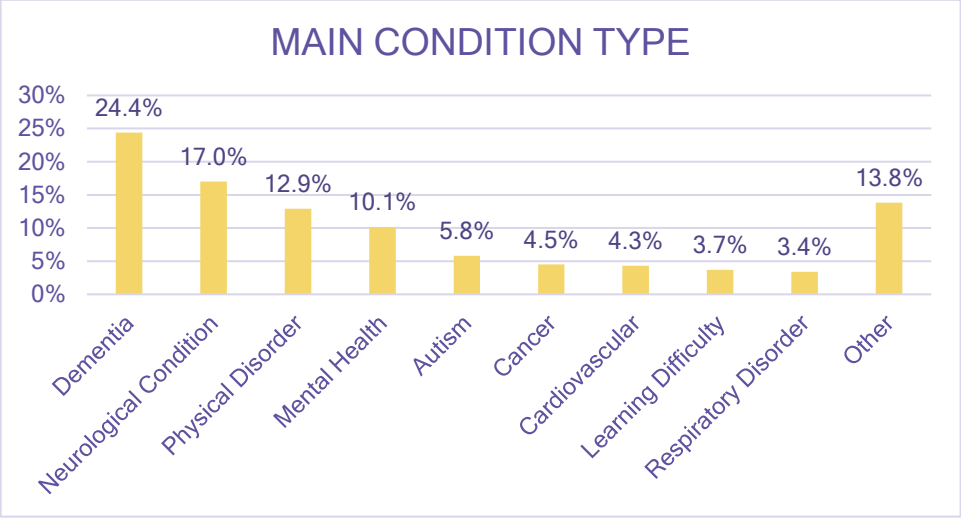


N= 3602

As can be seen from Figure 5, nearly a quarter of cared for individuals had two health conditions that required care support. A fifth (21%) had one condition and another fifth (23%) had three. The number of conditions ranged from one to twelve.

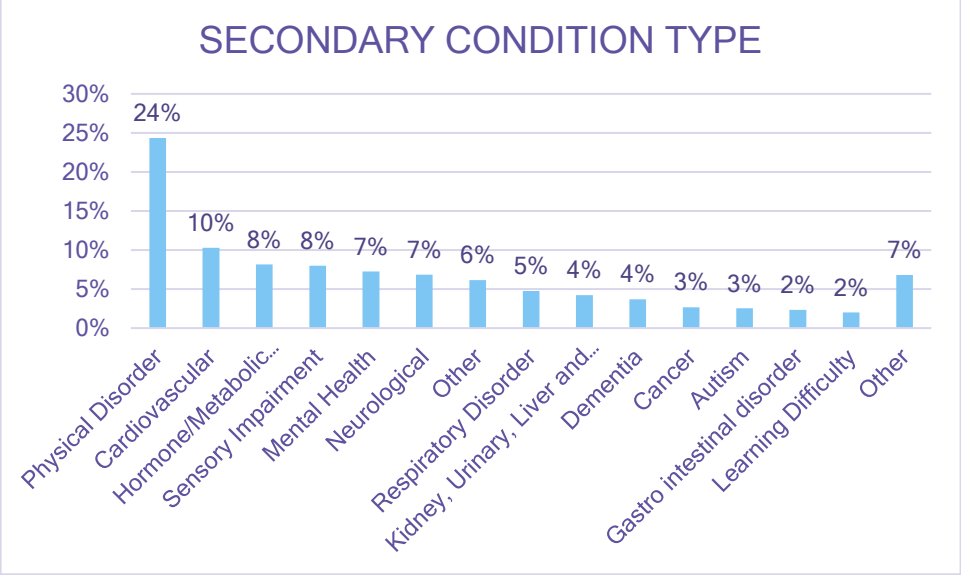
The carers were also asked to identify which primary (or main) condition 'impacted on the cared-for person's life the most'. Dementia was the most commonly cited condition affecting nearly a quarter of cared for individuals. Other dominant conditions included neurological conditions (17%), physical disorders (12.9%) and mental health problems (10.1%). As can be seen from Figure 6, a wide range of conditions were identified.

Figure 6. Main condition type



N = 3129 (information on main condition missing for 473 carers)

Figure 7. Secondary condition type



Secondary conditions were even more diverse, with physical disorders present in nearly a quarter of the cared for individuals (24%), and cardiovascular conditions affecting a 10th of the cases (See Figure 7).

Patterns: Carer Levels of Need

Demographic patters were cross-tabulated for some of carer characteristics. It was of particular interest whether carer level of need was different depending on carer characteristics. A carer was recorded as having a low level of need if they were caring for under 19 hours per week, medium need if they cared 20-49 hours per week and high need if they cared for 50 hours or more per week.

Table 2 demonstrate that male and female carers did not differ from by level of need.

Table 2. Level of Need by Gender

	Low Need	Medium Need	High Need
Female	**99** (4% of Females)	**453** (18% of Females)	**1976** (78% of Females)
Male	**43** (4% of Males)	**182** (17% of Males)	**847** (79% of Males)

N= 3600 (no gender recorded for 2 carers)

Age, however did show a relationship with level of need (see Table 3). 16 to 24 year olds were much less likely to provide over 50 hours of care per week, compared with older carers (i.e. carers aged 25 years and over).

Table 3. Level of Need by Age

	Low Need	Medium Need	High Need
16-24yrs	**44** (23% of 16-24yos)	**65** (33% of 16-24yos)	**86** (44% of 16-24yos)
25-49yrs	**16** (3% of 25-49yos)	**110** (18% of 25-49yos)	**484** (79% of 25-49yos)
50-64yrs	**36** (3% of 25-64yos)	**206** (18% of 25-64yos)	**876** (78% of 25-64yos)
65-79yrs	**30** (3% of 65-79yos)	**165** (15% of 65-79yos)	**882** (78% of 65-79yos)
80-99yrs	**13** (2% of 65-79yos)	**81** (14% of 65-79yos)	**467** (83% of 65-79yos)

N=3561 (41 cases with missing age)

The levels of need were also compared across cared for groups ie among the 91% of carers who looked after a spouse, an (often adult) child or a parent. As can be seen in Table 3, carers who provided support for their spouses showed the highest proportion of high need (85%), with a slightly lower proportion for carers looking after children (81%). Those carers who were looking after their parents, however, were considerably less likely to show a high level of need

(69%) with a quarter in the 'medium need' category (24%). It is likely that those who care for their parents are still working and unable to provide more than 49 hours of care and/or they share care responsibilities with siblings or other family members. They are less likely to be co-resident either ie to live with the cared for person.

Table 4. Level of Need by Caring Role

	Low Need	Medium Need	High Need
Spouse/Partner	**38** (2% of those caring for a spouse)	**234** (13% of those caring for a spouse)	**1508** (85% of those caring for a spouse)
Child/Step-Child/Child-in-Law	**18** (3% of those caring for their child)	**102** (17% of those caring for their child)	**496** (81% of those caring for their child)
Parent/Step-Parent/Parent-In-Law	**56** (6% of those caring for their child)	**215** (24% of those caring for their child)	**615** (69% of those caring for their parent)

N=3382 (46 carers did not have a relationship recorded, 228 carers' relationship did not fit the above categories)

Level of need was also cross-tabulated with the 5 most common 'main conditions' (i.e. conditions the carers noted as having the greatest impact on the cared-for person's life). There were no overwhelming differences in carers' level of need depending on the main condition although while 4/5ths of carers for people with dementia were in the 'high need' category, the same was true only for 3/4 of carers looking after someone with a physical disorder.

Table 5. Level of Need by Main Condition

	Low Need	Medium Need	High Need
Dementia	**19** (2% of those caring for someone with dementia)	**130** (15% of those caring for someone with dementia)	**708** (83% of those caring for someone with dementia)
Neurological Condition	**18** (4% of those caring for someone with a neurological condition)	**67** (14% of those caring for someone with a neurological condition)	**394** (82% of those caring for someone with a neurological condition)
Physical Disorder	**12** (3% of those caring for someone with a physical disorder)	**72** (18% of those caring for someone with a physical disorder)	**323** (79% of those caring for someone with a physical disorder)
Mental Health	**13** (4% of those caring for someone with a mental health condition)	**61** (20% of those caring for someone with a mental health condition)	**236** (76% of those caring for someone with a mental health condition)
Autism	**9** (6% of those caring for someone with autism)	**23** (15% of those caring for someone with autism)	**126** (80% of those caring for someone with autism)

N = 2211 (information on main condition missing for 473 main condition for 918 carers did not fit the above categories)

Initial Carers Star

Carers stars were completed for the carers discussed here between June 2014 and September 2017

Overall, at entry to the service carers were doing the best in areas of 'work' and 'finances', and worst in terms of 'having time for oneself' and 'the way they felt' (see Figure 8).

Figure 8. Initial Carer Star averages per domain

Health (N=3585), The Caring Role (N=3585), Managing at Home (N=3565), Time for Yourself (N=3566), How You Feel (N=3571), Finances (N=3567), Work (N=3576)

When divided by area (see Figure 9), however, carers scores across all domains were considerably lower in Medway than any other area, while West Lincolnshire carers were doing slightly better than other service areas. Carers from the relatively new Waltham Forest service and those living 'out of area' covered by Carers FIRST were removed due to comparatively small numbers of carers in these categories as well as Waltham Forest being a new service still familiarizing themselves with carer assessments.

Deprivation levels largely accounted for differences in area. A simple linear regression was calculated to investigate if multiple deprivation indexes for the municipal wards carer lived in were related to the scores on the carers star. Deprivation significantly predicted scores in ***all*** carers star domains, with higher deprivations indexes coinciding with lower scores on **all domains** of the carers star.

Health: *R^2 = .02, F(1, 3583) = 62.35, p < .001, the lower the deprivation indexes, the higher reported health, β = -.01, t = -7.90, < .001*

The Caring Role: *R^2 = .01, F(1, 3581) = 19.12, p < .001, the lower the deprivation indexes, the better the carer felt about the caring role, β = -.01, t = -4.37, < .001*

Managing at Home: *R^2 = .02, F(1, 3563) = 64.72, p < .001, the lower the deprivation indexes, the better the carer felt about managing at home, β = -.13, t = -8.05, < .001*

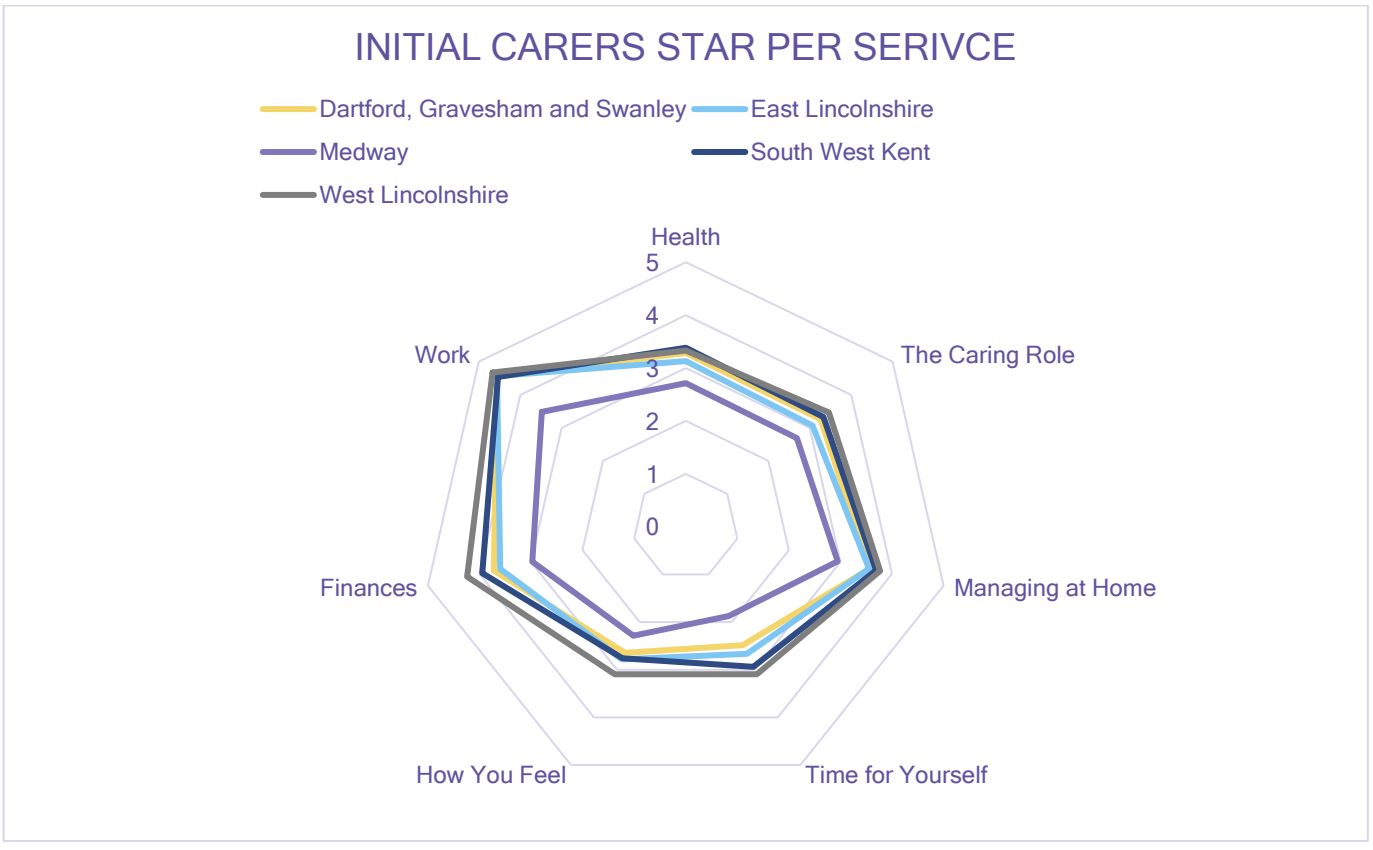
Time for Yourself: *R^2 = .02, F(1, 3564) = 57.98, p < .001, the lower the deprivation indexes, the better the carer felt about having time for themselves, β = -.13, t = -7.61, < .001*

How you Feel: *R^2 = .004, F(1, 3569) = 13.07, p < .001, the lower the deprivation indexes, the better the carer felt, β = -.06, t = -3.62, < .001*

Finances: *R^2 = .05, F(1, 3565) = 170.29, p < .001, the lower the deprivation indexes, the better the carer felt about their financial situation, β = -.21, t = -13.05, < .001*

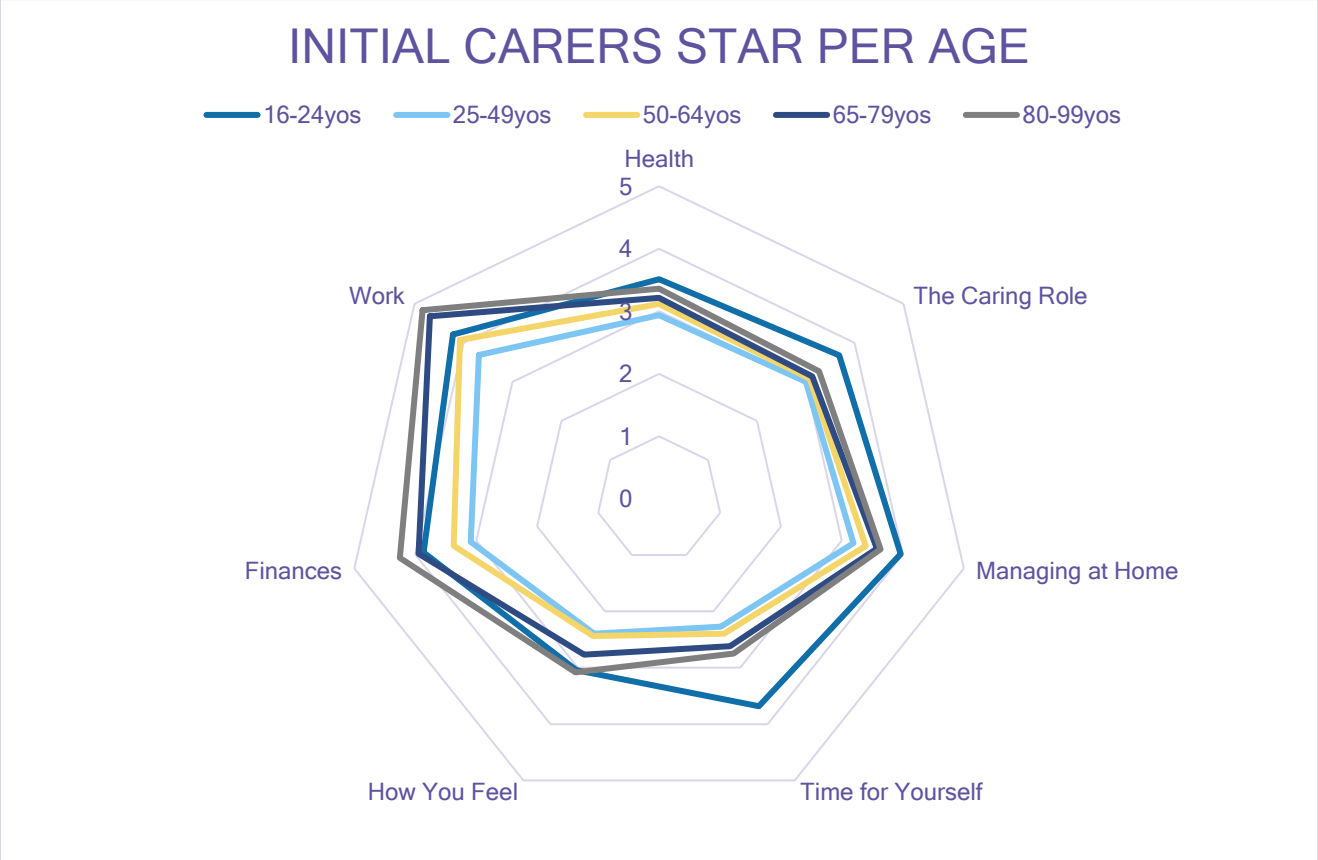
Work: *R^2 = .02, F(1, 3574) = 71.21, p < .001, the lower the deprivation indexes, the better the carer felt about work/managing their job, β = -.14, t = -8.44, < .001*

Figure 9. Initial Carer Star averages per domain for each Carers FIRST Service



Age also had an impact on the caring role (see Figure 10). As might be expected, carers of working age found work more problematic than other age groups and were also more concerned about their finances. Younger carers (16-24 year olds) struggled the least with having time for themselves, the caring role and managing at home. This is likely to be because, as can be seen in Table 3, younger carers were less likely to provide higher levels of care.

Figure 10. Initial Carer Star averages per domain by Carer Age Group



A single linear regression analysis was calculated to investigate if carers' age influenced their scores on the Carers Star domains. Age was a significant predictor of 'Health', 'Managing at Home', 'How You Feel', 'Finances' and 'Work' domains; the older the carer is, the better they were likely to do in these domains. How the carer scored on 'the Caring Roles' and 'Time for Yourself' domains, however, did not depend on age.

Health: *R^2 = .002, F(1, 3547) = 7.21, p < .01, the older the carer was, the higher reported health, β = .05, t = 2.69, < .01*

The Caring Role: *R^2 < .001, F(1, 3545) = .29, p = .59, age did not predict how the carer felt about the carer role*

Managing at Home: *R^2 = .002, F(1, 3527) = 7.92, p < .01, the older the carer was, the better the carer felt about managing at home, β = .05, t = 2.81, p < .01*

Time for Yourself: *R^2 < .001, F(1, 3528) = 1.37, p = .24, age did not predict how the carer felt about having time for themselves*

How you Feel: *R^2 = .01, F(1, 3533) = 46.30, p < .001, the older the carer was, the better they felt in themselves, β = .11, t = 6.81, p < .001*

Finances: *R^2 = .06, F(1, 3529) = 215.78, p < .001, the older the carer was, the better the carer felt about their financial situation, β = .24, t = 14.69, p < .001*

Work: *R^2 = .10, F(1, 3538) = 380.99, p < .001, the older the carer was, the better the carer felt about work/managing their job, β = .31, t = 19.52, p < .001*

A single linear regression analysis was also calculated to investigate if the age of the cared-for person influenced how well carers scored on any of the Carers Star domains. All domains apart from 'the Caring Role' significantly depended on the cared-for person's age. 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'.

Health: *R^2 = .02, F(1, 3200) = 52.75, p < .001, the older the cared-for person was, the higher the carer's reported health was, β = .13, t = 7.26, p < .001*

The Caring Role: *R^2 < .001, F(1, 3199) = 1.40, p = .24, the age of the cared-for person did not predict how well the carer felt about their caring role*

Managing at Home: *R^2 = .004, F(1, 3180) = 13.27, p < .001, the older the cared-for person was, the better the carer felt about managing at home, β = .06, t = 3.64, p < .001*

Time for Yourself: *R^2 = .001, F(1, 3185) = 4.31, p < .05, the older the cared-for person was, the better the carer felt about having time for themselves, β = .04, t = 2.08, p < .05*

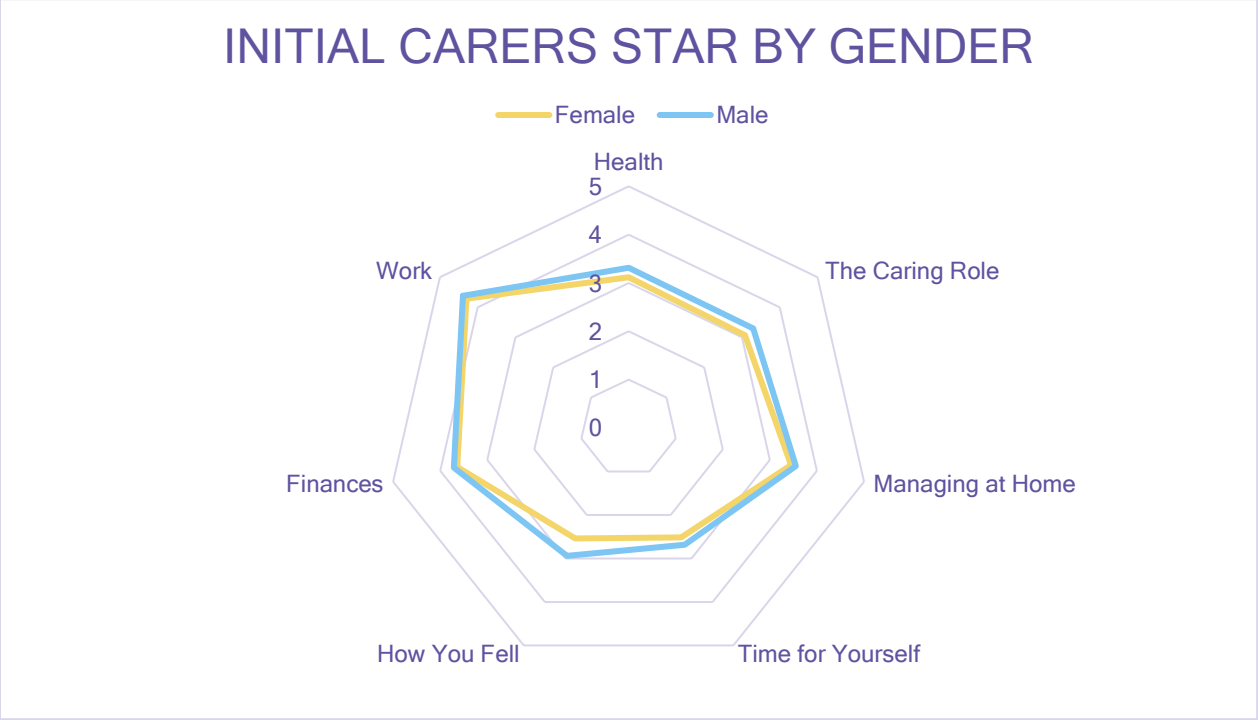
How you Feel: *R^2 = .01, F(1, 3187) = 37.45, p < .001, the older the cared-for person was, the better the carer felt, β = .11, t = 6.12, < .001*

Finances: *R^2 = .05, F(1, 3185) = 168.81, p < .001, the older the cared-for person was, the better the carer felt about their financial situation, β = .22, t = 12.99, < .001*

Work: *R^2 = .04, F(1, 3196) = 137.37, p < .001, the older the cared-for person was, the better the carer felt about work/managing their job, β = .20, t = 11.72, < .001*

Dividing the carers' scores on the initial Carers' Star by gender also demonstrated some differences. Men were doing slightly better in many domains, but particularly in reporting 'feeling better' than their female counterparts (see Figure 11).

Figure 11. Initial Carer Star averages per domain by Carer Gender



An independent sample's t-test was performed to see if there was a statistically significant difference between male and female Carers' Stars (results did not assume equal variances, as only 30% of carers were male). Male carers did statistically better than their female counterparts in all domains apart from finances. It is unclear, however, whether this was a difference in experience, or a difference in reporting (e.g. it is known that men are likely to under-report depressive feelings).

Health: *t(1897) = 4.82, p < .001; male carers (M = 3.31, SD = 1.13) report significantly better health than female carers (M = 3.12, SD = 1.07)*

The Caring Role: *t(2122) = 5.19, p < .001; male carers (M = 3.30, SD = 1.13) report feeling significantly better about their caring role than female carers (M = 3.08, SD = 1.20)*

Managing at Home: *t(2029) = 2.49, p < .05; male carers (M = 3.55, SD = 1.10) report managing at home significantly better than female carers (M = 3.45, SD = 1.12)*

Time for Yourself: *t(1938) = 3.53, p < .001; male carers (M = 2.68, SD = 1.31) report having significantly more time for themselves than female carers (M = 2.52, SD = 1.26)*

How you Feel: *t(1921) = 9.02, p < .001; male carers (M = 2.94, SD = 1.22) report feeling significantly better than female carers (M = 2.54, SD = 1.17)*

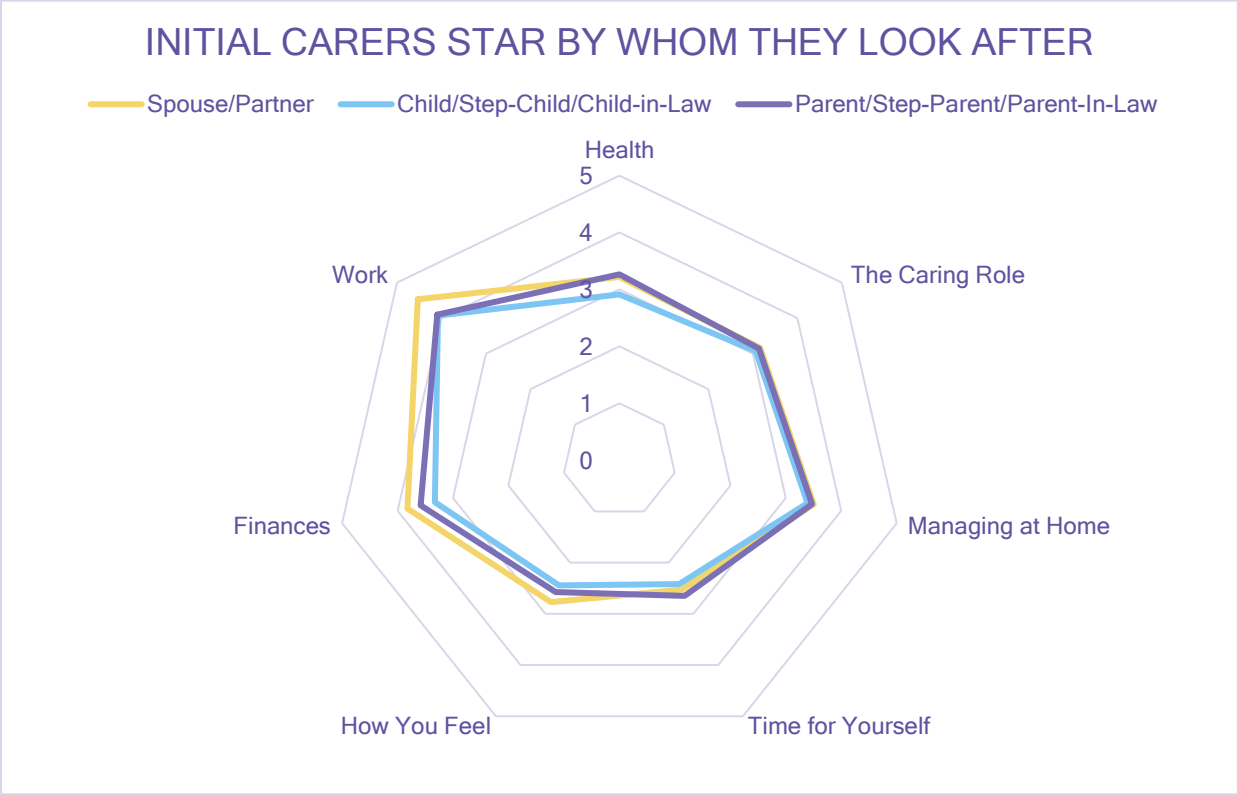
Finances: *t(2025) = 1.59, p = .11; male and female carers did not differ in their experiences of finances*

Work: *t(2055) = 2.28, p < .05; male carers (M =4.38, SD = 1.11) report significantly better about work than female carers (M = 4.29, SD = 1.14)*

Carer Star outcomes were also compared depending on who the carers looked after. Only the most prevalent categories broadly divided into partner, child and parent were compared. As can be seen from Figure 12, carers looking after a partner seemed to score better in terms of work, and finances than the other two groups of carers, while those caring after their (often adult) child scored less well in terms of heath.

Additionally, a one-way ANOVA was performed to see if carers looking after a partner (IV_1), those looking after a child (IV_2) and those looking after a parent (IV_3) significantly differed in terms of any of the Carers Star domains ($DV_{1\text{-}6}$). Who the carer looked after did not impact on the Caring Role and Managing at Home aspects of the Carer Star. In the majority of cases, carers looking after a child fared significantly worse than the other groups of carers, and in some cases (i.e. in terms of how they felt, finances, and work) those looking after a partner scored better than either of the other two carer groups (see shaded area on page 20 and Table 6 for precise breakdown).

Figure 12. Initial Carer Star averages per domain by whom the carer looked after



There was a statistically significant difference between carer groups as determined by one-way ANOVA in:

- **Health** ($F(2,3255) = 22.46$, $p < .001$). A Bonferroni post hoc test revealed that carer health was statistically significantly higher for those looking after a partner when compared to those looking after a child, but not those looking after a parent; and that carer health was statistically significantly lower for those looking after a child, than those looking after a partner or those looking after a carer;
- **Time for Yourself** ($F(2,3250) = 6.20$, $p < .01$). A Bonferroni post hoc test revealed that carers looking after their parent had statistically significantly more time to themselves than carers looking after a partner or those looking after a child.
- **How You Feel** ($F(2,3252) = 20.15$, $p < .001$). A Bonferroni post hoc test revealed that all three carer groups differed significantly from one another in terms of how they felt depending on who they looked after. Those who looked after a partner felt significantly better than those looking after a child or those looking after a parent, while those who looked after a child felt significantly worse than those looking after a parent.

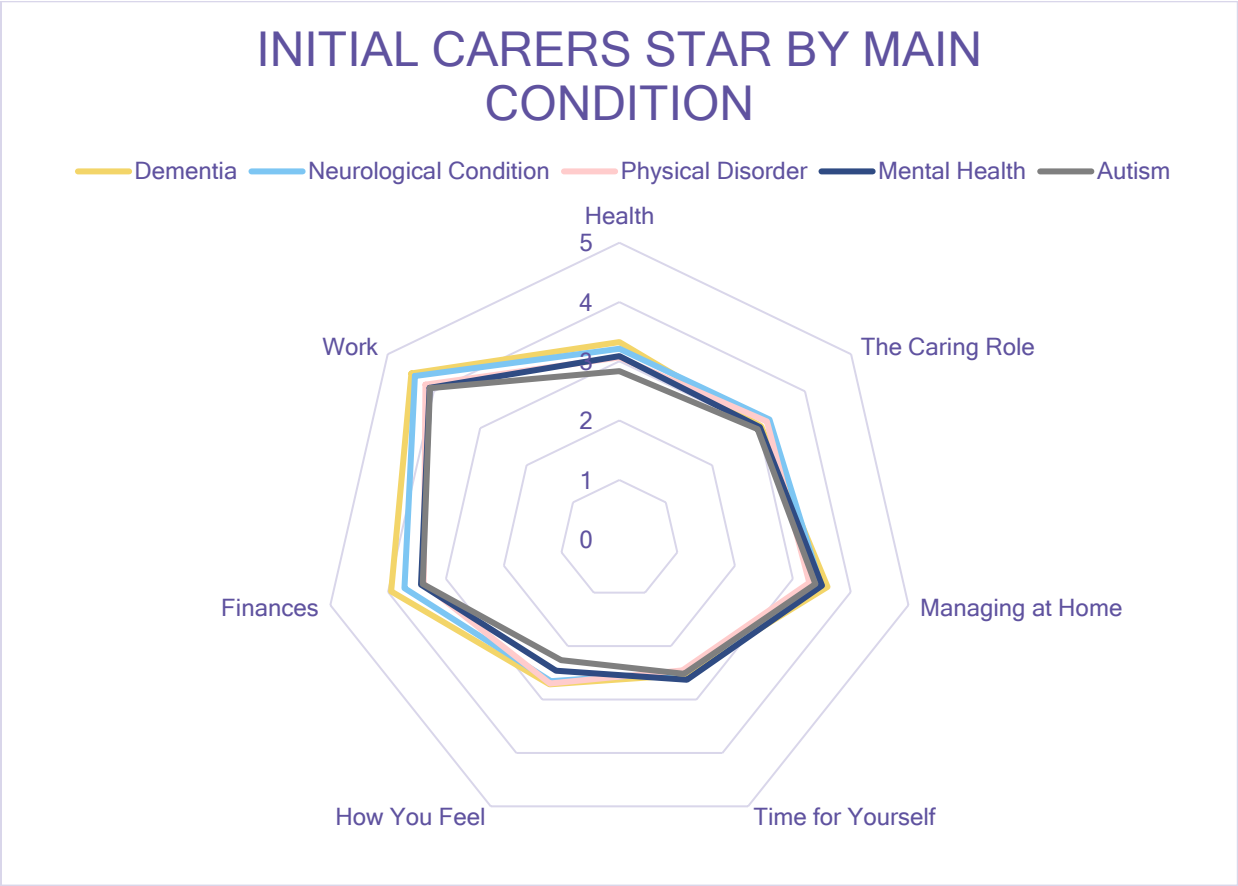
- **Finances** ($F(2,3250) = 39.77$, $p < .001$). A Bonferroni post hoc test revealed that all three carer groups differed significantly from one another in terms of how positive they felt about their finances. Those looking after a partner felt more positive than those looking after a child and those looking after a parent, while those looking after a parent felt significantly more positive about their finances than those looking after a child.
- **Work** ($F(2,3257) = 64.40$, $p < .001$). A Bonferroni post hoc test revealed that carers looking after a partner felt significantly more positive about work than those looking after a child or those looking after a parent. Carers looking after a child did not differ from those looking after a parent in terms of how they felt about work.

Table 6. One-Way ANOVA Results with Carer Star Domains as Dependent Variables.

	Spouse/Partner			Child/Step-Child/Child-in-Law			Parent/Step-Parent/Parent-in-Law				
	N	*M*	*SE*	*N*	*M*	*SE*	*N*	*M*	*SE*	*F*	*p*
Health	1770	3.22	1.08	614	2.91	1.09	882	3.26	1.09	22.46	<.001
The Caring Role	1767	3.17	1.09	615	3.07	1.27	884	3.14	1.19	1.55	.21
Managing at Home	1760	3.50	1.07	612	3.39	1.19	877	3.47	1.12	2.32	.10
Time for Yourself	1761	2.53	1.26	612	2.42	1.25	880	2.65	1.26	6.20	<.01
How You Feel	1761	2.77	1.19	613	2.45	1.20	881	2.57	1.20	20.15	<.001
Finances	1766	3.82	1.18	609	3.33	1.31	878	3.58	1.26	39.77	<.001
Work	1772	4.53	.97	610	4.08	1.29	878	4.10	1.23	64.40	<.001

Carer Star domains were also compared based on the main condition of the cared for person (see Figure 13). Carers looking after people with dementia and neurological coditions were less worried about work and finances than other carers; this may be because there are more older carers in these categories who are less likely to work. Also, carers looking after someone with autism experienced poorer health and felt worse than their counterparts.

Figure 13. Initial Carer Star averages per domain by the main condition of the cared-for person



Instead of comparing all Carer Star domains for the 5 main conditions, only the average Star Score (i.e. the average score per carer on all domains) was investigated statistically.

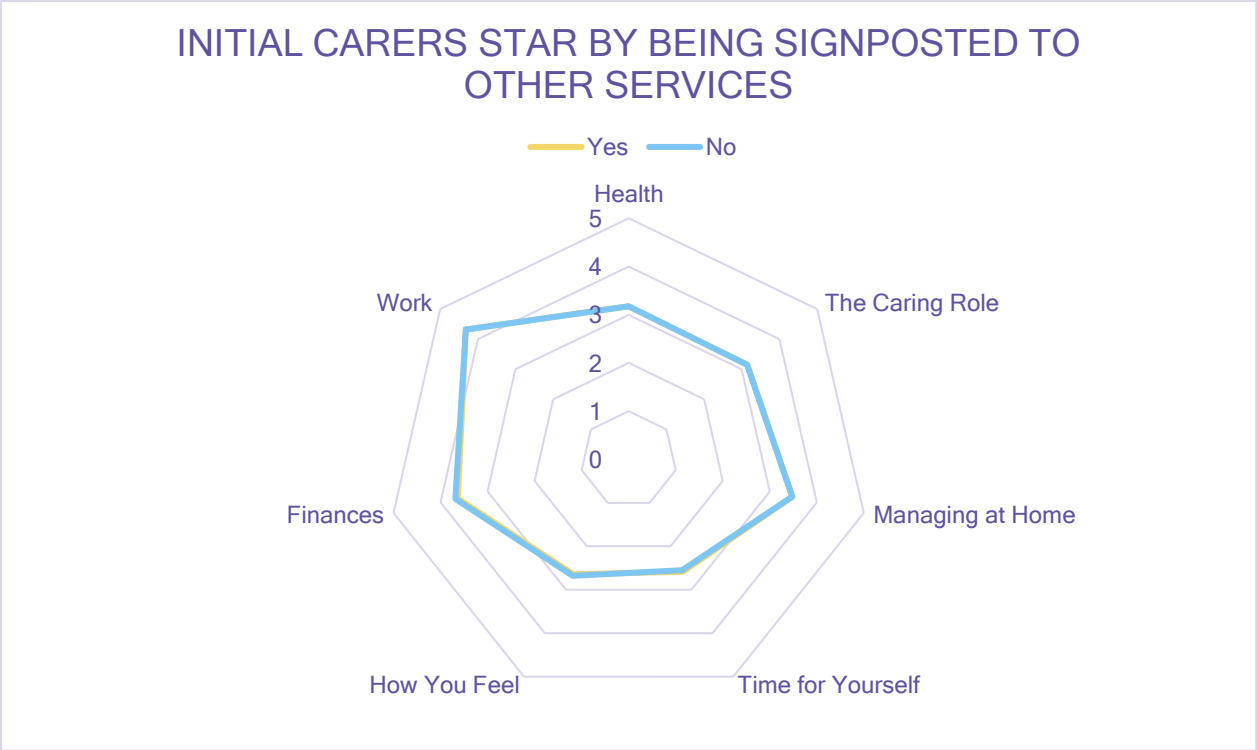
A one-way ANOVA was performed to see if carers looking after someone with dementia (IV_1), a neurological condition (IV_2), a physical disorder (IV_3), a mental health condition (IV_4) and autism (IV_5) significantly differed from one another in their overall Carers Star score (DV_1). The breakdown of findings is explained in the shaded area below.

There was a statistically significant difference between carer groups in the overall Carers Star score ($F(4,2202) = 10.24$, $p < .001$). A Bonferroni post hoc test revealed that:

- Carers looking after someone with **Dementia** were doing significantly better than those looking after someone with a physical disorder, a mental health condition or autism, but did not significantly differ from those looking after someone with a neurological disorder

- Carers looking after someone with **a Neurological Condition** were doing significantly better than those looking after someone with autism, but did not significantly differ from those looking after someone with dementia, a physical disorder, or a mental health condition.
- Carers looking after someone with **a Physical Disorder** were doing significantly worse than those looking after someone with dementia, but did not significantly differ from those looking after someone with a neurological condition, a mental health condition or autism.
- Carers looking after someone with **a Mental Health Condition** were doing significantly worse than those looking after someone with dementia, but did not significantly differ from those looking after someone with a neurological condition, a physiological disorder or autism.
- Carers looking after someone with **Autism** were doing significantly worse than those looking after someone with dementia, and those looking after someone with a neurological condition, but did not significantly differ from those looking after someone with a mental health condition or autism.

Figure 14. Initial Carer Star averages per domain by whether the carer was signposted to other services



Further comparisons were made between carers who were signposted to other services and those who were not. Visually (see Figure 14), the two groups did not appear to differ.

In addition to the visual plotting (Figure 15) an independent sample's t-test was performed to see if there was a statistically significant difference between Carers' Stars for those carers who were signposted to other services and those who were not. The two groups did not significantly differ from one another in any of the Carers Star Domains.

Health: *t(3582) = .05, p = .96*

The Caring Role: *t(3580) = .18, p = .86*

Managing at Home: *t(3562) = .06, p = .95*

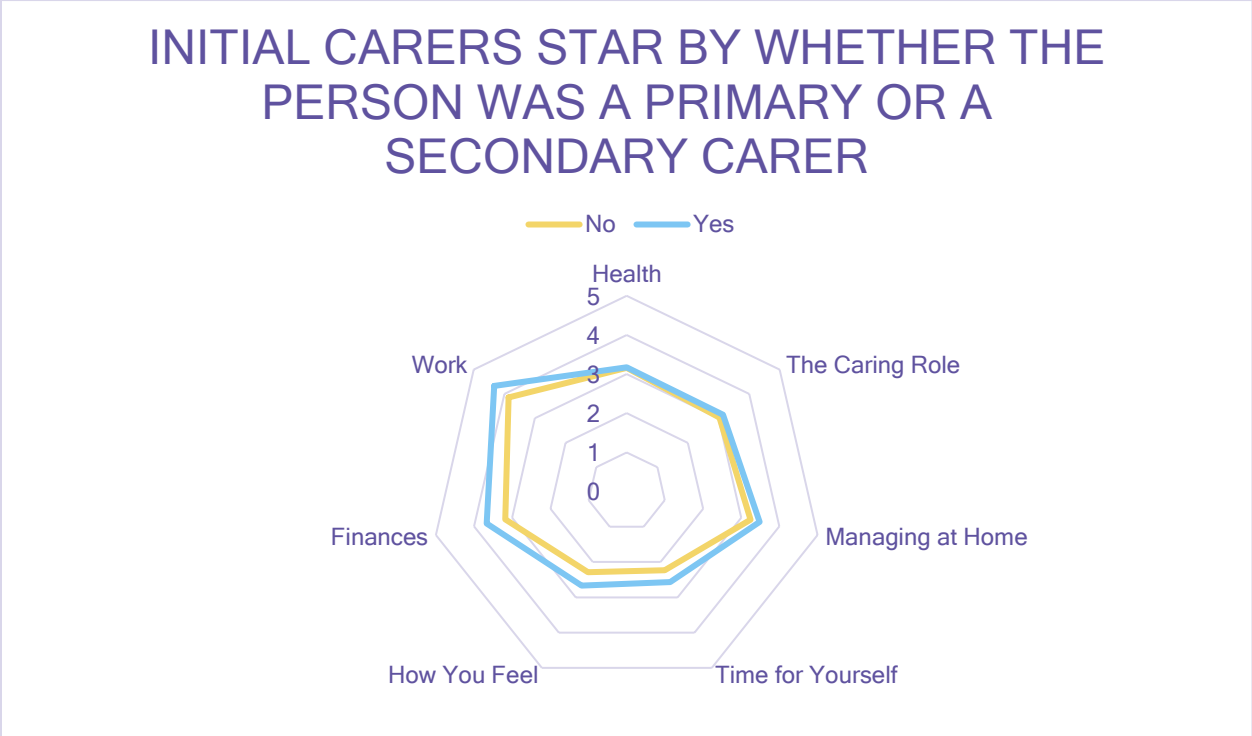
Time for Yourself: *t(3563) = .91, p = .37*

How you Feel: *t(3568) = -.90, p = .37*

Finances: *t(3564) = -1.28, p = .20*

Work: *t(3573) = .18, p = .86*

Figure 15. Initial Carer Star averages per domain by whether carers identified as a primary carer



Similarly, scores on Carers Star domains were compared among carers who self-identified as a primary carer and those who did not. It appeared that primary carers were doing better than secondary ones in the domains of Work, Finances, How they Felt and Time for Oneself.

An independent sample's t-test was performed to see if there was a statistically significant difference between Carers' Stars for those carers who identified as primary carers and those who did not (equal variances were not assumed as only 4% of carers identified as non-primary).

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.

Health: *t(99) = .14, p = .89; primary carers did not differ significantly from secondary carers in their experience of heath*

The Caring Role: *t(98) = .90, p = .37; primary carers did not differ significantly from secondary carers in their experience of the caring role*

Managing at Home: *t(99) = 2.11, p < .05; primary carers (M = 3.48, SD = 1.11) report managing at home significantly better than secondary carers (M = 3.24, SD = 1.07)*

Time for Yourself: *t(99) = 2.57, p < .05; primary carers (M = 2.56, SD = 1.27) report having significantly more time to themselves than secondary carers (M = 2.23, SD = 1.23)*

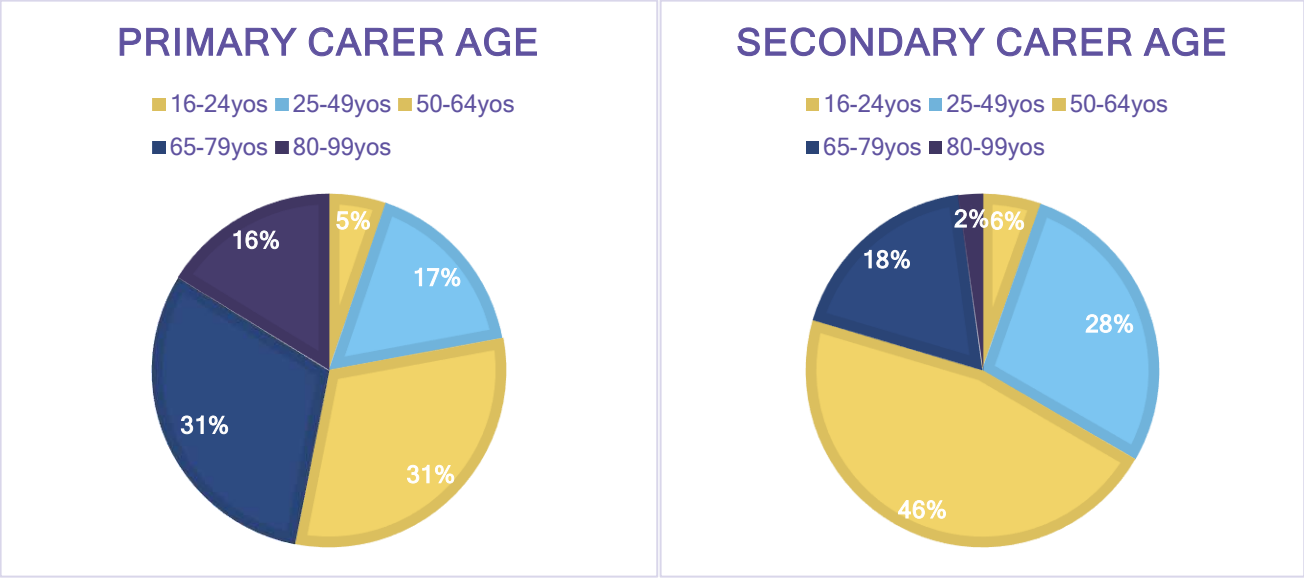
How you Feel: *t(99) = 3.20, p < .01; primary carers (M = 2.67, SD = 1.20) report feeling significantly better than secondary carers (M = 2.29, SD = 1.13)*

Finances: *t(97) = 3.63, p < .001; primary carers (M = 3.67, SD = 1.24) report managing finances significantly better than secondary carers (M = 3.18, SD = 1.28)*

Work: *t(94) = 3.31, p < .01; primary carers (M = 3.48, SD = 1.11) report managing work significantly better than secondary carers (M = 3.24, SD = 1.07)*

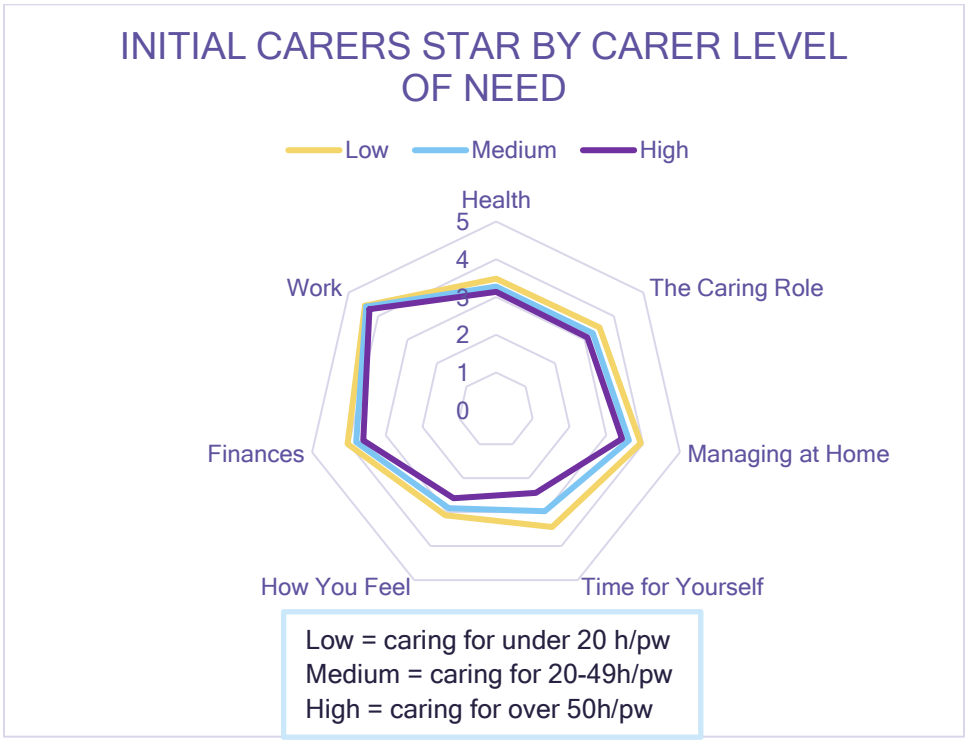
The reason why primary carers did better on four of the carer star domains may in part depend on age. As Figure 16 demonstrates, there were substantially more older carers in the primary carer group (47% carers aged 65 or over) than in the secondary carer group (20% of carers aged 65 or over).

Figure 16. Age breakdown for primary and secondary carers



Level of need was another characteristic investigated against the Carers' Star outcomes. As can be seen from Figure 17, carers providing fewer hours of care seemed to do better than those providing more care, especially in areas of time for oneself, managing at home, the caring role and how they felt.

Figure 17. Initial Carer Star averages per domain by carer level of need



To investigate if these differences were statistically different from one another, a one-way ANOVA was performed attempting to ascertain if carers with low level of need (IV_1), those with medium need (IV_2), and those with high level of need (IV_3) significantly differed from one another in their Carers Star score (DV_1) per each domain. The breakdown of findings is explained in the shaded area below and Table 7.

Overall, people with high level need scored better than those with low level need for all but one of the domains, whereas people with medium need at times did not differ from their counterparts. Carers did not differ on how they scored on work when compared by level of need.

There was a statistically significant difference between carer groups as determined by one-way ANOVA in:

- **Health** ($F(2,3582) = 10.35$, $p < .001$). A Bonferroni post hoc test revealed that carer health was statistically significantly higher for carers with low need level than carers with high need level, but not higher compared to carers with medium need level. Carers with medium level need scored significantly better on health than those with high level need.
- **The Caring Role** ($F(2,3580) = 12.94$, $p < .001$). A Bonferroni post hoc test revealed that carers with low need level felt significantly better about their caring role than carers with high need level, but did not differ from carers with medium need level. Carers with medium level need scored significantly better on health than those with high level need.
- **Managing at Home** ($F(2,3562) = 19.64$, $p < .001$). A Bonferroni post hoc test revealed that all three carer groups differed significantly from one another in terms of how they were managing at home. Carers with low level need scored higher than those with moderate or high level need, and people with moderate level need did significantly better than those with high level of need.
- **Time for Yourself** ($F(2,3563) = 84.85$, $p < .001$). A Bonferroni post hoc test revealed that all three carer groups differed significantly from one another in terms of how they felt about having time for themselves. Carers with low level need scored higher than those with moderate or high level need, and people with moderate level need did significantly better than those with high level of need.

- **How You Feel** (F(2,3568) = 24.85, p < .001). A Bonferroni post hoc test revealed that carers with low need level felt significantly better than carers with high need level, but did not differ from carers with medium need level. Carers with medium level need scored significantly better on how they felt than those with high level need.
- **Finances** (F(2,3564) = 12.99, p < .001). A Bonferroni post hoc test revealed that carers with low need level felt significantly better about their finances than carers with high need level, but did not differ from carers with medium need level. Carers with medium level need scored significantly better on how they felt about finances than those with high level need.

Table 7. One-Way ANOVA Results with Carer Star Domains as Dependent Variables.

	Low Need			Medium Need			High Need				
	N	*M*	*SE*	*N*	*M*	*SE*	*N*	*M*	*SE*	*F*	*p*
Health	142	3.49	.10	630	3.28	.04	2813	3.14	.02	10.35	<.001
The Caring Role	142	3.51	.10	625	3.28	.05	2816	3.10	.02	12.94	<.001
Managing at Home	140	3.94	.10	626	3.61	.04	2799	3.43	.02	19.64	<.001
Time for Yourself	142	3.44	.11	626	2.97	.05	2798	2.43	.02	84.85	<.001
How You Feel	140	3.09	.11	628	2.88	.05	2803	2.59	.02	24.85	<.001
Finances	142	4.04	.10	629	3.80	.05	2796	3.61	.02	12.99	<.001
Work	141	4.45	.09	629	4.40	.04	2806	4.30	.02	3.09	=.05

Further, a correlation analysis was performed to investigate whether there was a relationship between the number of people the carer looked after and their outcomes. On all Carers' Star domains, the more people the carer looked after, the lower the scores.

How many people the carer looked after at the same time was correlated with scores in the following Carer Star domains:

- **Health** (*r(3565) = -.07, p < .001*). The more people the carer looked after, the worse they felt about their health.
- **The Caring Role** (*r(3581) = -.06, p < .01*). The more people the carer looked after, the worse they felt about their caring role.

- **Managing at Home** (*r(3563) = -.07, p < .001*). The more people the carer looked after, the worse they reported managing at home.
- **Time for Yourself** (*r(3564) = -.10, p < .001*). The more people the carer looked after, the less time for themselves they reported having.
- **How You Feel** (*r(3569) = -.10, p < .001*). The more people the carer looked after, the worse they felt.
- **Finances** (*r(3565) = -.14, p < .001*). The more people the carer looked after, the worse they felt about their finances
- **Work** (*r(3574) = -.09, p < .001*). The more people the carer looked after, the worse they felt about work.

In addition to the above, it was felt important to ascertain if carer scores on the Carers Star related to the intensity of input from Carers FIRST.

Initially, intensity of Carer's FIRST input was calculated in the following manner:

$$Intensity\ (1) = \frac{\text{Sum of minutes of 'active' input}}{\text{Length of Carers FIRST Involvement in Weeks}}$$

Here, '*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). However, the database often lacked information on the length of time spent per contact; this meant that Intensity (1) could only be calculated for 735 (20%) of the cases included in the current analysis.

While contact times can vary significantly, due to low numbers on contact length Intensity of Carers FIRST involvement was re-calculated in the following way:

$$Intensity\ (2) = \frac{\text{Number of 'active' contacts}}{\text{Length of Carers FIRSTInvolvement in Weeks}}$$

Intensity (2) was available for 3547 (98%) of the cases and was therefore the indicator used in all analyses discussed below.

A correlation analysis was conducted to see if Initial Carers Star scores were related to intensity of Carers' FIRST involvement. Lower scores on the Caring Role, Managing at Home and How You Feel were related to more intensive subsequent input from Carers FIRST. Interestingly,

carers who felt more secure about their finances were also worked with more intensively. This may be because when it comes to finances, Carers FIRST can be effective and offer a 'quick fix' ie they can help with applications for benefits, PIP and/or direct payments. However, this is unlikely to account for the observed trend entirely and suggests a need for further investigation. Carers' scores on Heath, Time for Yourself, and Work were not statistically associated with intensity of Carers FIRST input. Lack of relationship with Health and Work are not surprising, giving the limited impact that the remit of Carers FIRST could have on these domains, but a lack of relationship with having time for oneself is somewhat surprising and warrants further investigation.

How intensively Carers FIRST worked with the carer was correlated with scores in the following Carer Star domains:

- **The Caring Role** (*r(3527) = -.07, p < .001*). The worse the carer felt about their caring role, the more intensively Carers FIRSTworked with the carer.
- **Managing at Home** (*r(3509) = -.04, p < .05*). The worse the carer felt about managing at home, the more intensively Carers FIRSTworked with the carer.
- **How You Feel** (*r(3516) = -.04, p < .05*). The worse the carer felt, the more intensively Carers FIRSTworked with the carer.
- **Finances** (*r(3511) = .05, p < .01*). The better the carer felt about their finances, the more intensively Carers FIRSTworked with the carer.

It is recognised that the above statistical analyses, where one characteristic is related to the Carers' Star domains at a time does not account for overlap between characteristics. For example, as can be seen in Table 3, carer age and level of need are related, where older carers are more likely to have higher levels of need. Therefore, it is important to investigate if these characteristics predicted carer scores on the Carers Star independently of one another. To do this, a multiple regression analyses were used to test if carer circumstances recorded on the Carers FIRST database *together* predicted carer scores on the Carer Star. **Carer Age, Carer Gender, Cared-for-Person's Age, Carer Level of Need, Intensity of Carer's FIRST Involvement** and **IMD (Index of Multiple Deprivation) score** were simultaneously entered into 7 regression analyses based on each of the Carers' Star domains as outcome variables.

The shaded area below summarises the findings per each analysis, whereas Tables 8-14 show the multiple regression outputs. Overall, the model with the 6 carer characteristics significantly predicted each of the Carers Star domains, but only explained between 2% and 15% of

variance in the scores, suggesting there may be other factors that can better predict Carers Star outcomes at entry to the service. Which of the 6 characteristics predicted Carers Star domains independently of one another did, however, vary considerably between Carers Star Domains.

- **Health.** The results of the regression indicated that the overall model significantly predicted carer experiences of health (*R^2=.04, F(6,3126)=20.51, p<.001*), but only accounted for 4% of the variance in health scores. As can be seen in Table 8, carer gender, cared-for person's age, carer level of need and deprivation score significantly predicted carer heath, while carer age and intensity of Carers FIRST involvement did not predict carer health independently of other factors in the regression model. **If the carer was male, the older the cared-for person, the lower the level of need, and the lower the deprivation level, the better their health score was likely to be.**

- **The Caring Role** The results of the regression indicated that the overall model significantly predicted carer experiences of the caring role (*R^2=.02, F(6,3125)=10.26, p<.001*), but only accounted for 2% of the variance in caring role scores. As can be seen in Table 9, carer gender, intensity of Carers FIRST involvement, carer level of need and deprivation score significantly predicted carer scores on the caring role, while carer age and cared-for person's age did not predict carer role independently of other factors in the regression model. **If the carer was male, the less intensive the involvement from Carers FIRST, the lower the level of need, and the lower the deprivation level, the better the carer was likely to feel about their caring role.**

- **Managing at Home** The results of the regression indicated that the overall model significantly predicted carer experiences of managing at home (*R^2=.03, F(6,3106)=17.38, p<.001*), but only accounted for 3% of the variance in managing at home scores. As can be seen in Table 10, intensity of Carers FIRS Tinvolvement, carer age, carer level of need and deprivation score significantly predicted carer scores on managing at home, while carer gender and cared-for person's age did not predict carers' experience of managing at home independently of other factors in the regression model. **The less intensive the involvement from Carers FIRST, the older the carer, the lower the level of need, and the lower the deprivation level, the better the carer was likely to feel about managing at home.**

- **Time for Yourself.** The results of the regression indicated that the overall model significantly predicted carer experiences of having time for themselves (*R^2=.06, F(6,3111)=34.84, p<.001*), but only accounted for 6% of the variance in time for

yourself scores. As can be seen in Table 11, carer gender, carer level of need and deprivation score significantly predicted carer scores on time for yourself, while intensity of Carers FIRST involvement, carer's age and cared-for person's age did not predict carers' experience of having time for themselves independently of other factors in the regression model. **If the carer was male, the lower the level of need, and the lower the deprivation level, the better the carer was likely to feel about having time for themselves.**

- **How You Feel.** The results of the regression indicated that the overall model significantly predicted how the carers felt (*R^2=.05, F(6,3114)=29.64, p<.001*), but only accounted for 5.4% of the variance in how you feel scores. As can be seen in Table 12, carer gender, intensity of Carers FIRST involvement, carer age, carer level of need and deprivation score significantly predicted carer scores on how the carer felt, while cared-for person's age did not predict how the carer felt independently of other factors in the regression model. **If the carer was male, the less intensive the involvement from Carers FIRST, the younger the carer, the lower the level of need, and the lower the deprivation level, the better the carer was likely to feel.**

- **Finances.** The results of the regression indicated that the overall model significantly predicted carer experiences of finances (*R^2=.12, F(6,3112)=72.80, p<.001*), but only accounted for 12% of the variance in finance scores. As can be seen in Table 13, intensity of Carers FIRSTinvolvement, carer age as well as that of the cared-for person, carer level of need and deprivation score significantly predicted carer scores on finances, while carer gender did not predict carers' experience of finance independently of other factors in the regression model. **The more intensive involvement from Carers FIRST, the older the carer and the cared-for person, the lower the level of need, and the lower the deprivation level, the better the carer was likely to feel about their finances.**

- **Work.** The results of the regression indicated that the overall model significantly predicted carer experiences of work (*R^2=.15, F(6,3129)=73.09, p<.001*), and accounted for 15% of the variance in work scores. As can be seen in Table 14, carer age, carer level of need and deprivation score significantly predicted carer scores on work, while intensity of Carers FIRSTinvolvement, carer's gender and cared-for person's age did not predict carers' experience of work independently of other factors in the regression model. **The older the carer, the lower the level of need, and the lower the deprivation level, the better the carer was likely to feel about work.**

Table 8. Summary of Multiple Regression Analysis for Carer Scores on **Health**

	B	*SE(B)*	*β*	*t*	*p*
Carer Age	<.001	.001	-.005	-.24	.81
Carer Gender	-.16	.04	-.07	-3.84	<.001
Cared-for-Person's Age	.004	.001	.10	4.69	<.001
Level of Need	-.15	.04	-.07	-3.97	<.001
Intensity of Carer's FIRST Involvement	-.01	.01	-.02	-.89	.37
IMD score	-.01	.002	-.12	-6.67	<.001

N = 3132, R^2 = .04

Table 9. Summary of Multiple Regression Analysis for Carer Scores on **The Caring Role**

	B	*SE(B)*	*β*	*t*	*p*
Carer Age	<.001	.001	.004	.17	.87
Carer Gender	-.20	.05	-.08	-4.37	<.001
Cared-for-Person's Age	<.001	.001	.001	.05	.96
Level of Need	-.16	.04	-.07	-3.80	<.001
Intensity of Carer's FIRST Involvement	-.04	.01	-.07	-4.16	<.001
IMD score	-.01	.002	-.06	-3.49	<.001

N = 3131, R^2 = .02

Table 10. Summary of Multiple Regression Analysis for Carer Scores on **Managing at Home**

	B	*SE(B)*	*β*	*t*	*p*
Carer Age	.01	.001	.07	3.32	<.01
Carer Gender	-.05	.04	-.02	-1.04	.30
Cared-for-Person's Age	<.001	.001	-.003	-.13	.90
Level of Need	-.21	.04	-.10	-5.29	<.001
Intensity of Carer's FIRST Involvement	-.02	.01	-.05	-2.71	<.01
IMD score	-.01	.002	-.13	-7.08	<001

N = 3112, R^2 = .03

Table 11. Summary of Multiple Regression Analysis for Carer Scores on **Time for Yourself**

	B	*SE(B)*	*β*	*t*	*p*
Carer Age	.002	.002	.03	1.20	.23
Carer Gender	-.14	.05	-.05	-2.92	<.01
Cared-for-Person's Age	<.001	.001	-.01	-.38	.70
Level of Need	-.52	.05	-.20	-11.58	<.001
Intensity of Carer's FIRST Involvement	-.02	.01	-.03	-1.93	.05
IMD score	-.02	.002	-.14	-7.91	<.001

N = 3117, R^2 = .06

Table 12. Summary of Multiple Regression Analysis for Carer Scores on **How You Feel**

	B	*SE(B)*	*β*	*t*	*p*
Carer Age	.01	.001	.13	5.90	<.001
Carer Gender	-.32	.05	-.12	-6.92	<.001
Cared-for-Person's Age	.001	.001	.02	1.02	.31
Level of Need	-.31	.04	-.13	-7.34	<.001
Intensity of Carer's FIRST Involvement	-.03	.01	-.05	-3.00	<.01
IMD score	-.004	.002	-.04	-2.25	<.05

N = 3120, R^2 = .05

Table 13. Summary of Multiple Regression Analysis for Carer Scores on **Finances**

	B	*SE(B)*	*β*	*t*	*p*
Carer Age	.02	.001	.22	10.66	<.001
Carer Gender	.02	.05	.01	.35	.73
Cared-for-Person's Age	.004	.001	.07	3.49	<.001
Level of Need	-.28	.04	-.11	-6.59	<.001
Intensity of Carer's FIRST Involvement	.02	.01	.04	2.44	<.001
IMD score	-.02	.002	-.18	-10.28	<.001

N = 3118, R^2 = .12

Table 14. Summary of Multiple Regression Analysis for Carer Scores on **Work**

	B	*SE(B)*	*β*	*t*	*p*
Carer Age	.02	.001	.32	15.87	<.001
Carer Gender	.02	.04	.01	.39	.70
Cared-for-Person's Age	<.001	.001	.01	.30	.77
Level of Need	-.19	.04	-.08	-4.92	<.001
Intensity of Carer's FIRST Involvement	.01	.01	.02	1.15	.25
IMD score	-.01	.002	-.09	-5.38	<.001

N = 3129, R^2 = .12

CONCLUSIONS

Demographic Profile of the Carers FIRST caseload:

- Carers FIRST work with a diverse population of carers in terms of age, gender, relationship to the looked-after person, and the number and types of conditions the look-up after person has
- Key trends include:
    - 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)

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 significantly predicted scores in all domains, with higher deprivation indexes correlating with lower scores on the carers star

- The older the carer was, the better they were likely to do in terms of Health, Managing at Home, How They Felt, Finances and Work
- 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.
- 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)
- The main condition of the cared for person had an impact on the average Carers Star score, but the patterns are complex (see pages 22-23 for detail)
- Carers who were signposted to other services and those who were not did not differ in their scores on the Carers Star
- 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
- Carers who felt more secure about their finances were also worked with more intensively
- Simultaneously accounting for Carer Age, Carer Gender, Cared-for-Person's Age, Carer Level of Need (i.e. hours of care provided per week), Intensity of Carer's FIRST Involvement and Indexes of Multiple Deprivation did predict carer scores on all of the Carer Star domains, but only accounted for 2-15% of variance in Carer Star codes. This model was able to predict carer stars on Finances and Work the most, suggesting that other – not yet recorded - aspects of the carer's life may better predict their

performance on the carers star at entry to the service or that demographic factors are not sufficiently related to the need profile in general.