
Evaluation of Carers Matter Norfolk

Norfolk County Council

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1. Executive summary

In 2020 the Institute of Public Care at Oxford Brookes University was commissioned by Norfolk County Council (the Council) to evaluate in real time the implementation of a model of support for carers, commissioned under the umbrella of Carers Matter Norfolk (the Service). An interim report was produced in October 2021, and this is the final report of the evaluation.

The contract with the provider – a partnership of voluntary organisations - was established using a social impact bond mechanism. The central assumption and expectation of the Council was that the new carers service would be successful in sustaining carers over time, and in preventing the 'breakdown' of caring relationships. As such, it was further anticipated that this would significantly reduce costs falling on adult social care.

In this report we present findings drawn from a mixed-methods approach combining both quantitative and qualitative analysis including; a longitudinal survey of carers in contact with the service; analysis of a sample of case files held by the service and the Council; and interviews with carers and professional stakeholders.

We report on the positive value of the service, as well as indicating scope for improvements. However, we did not find evidence that the service is able to offer savings to social care by preventing or delaying carer breakdown. Indeed, we challenge the assumptions that underpinned these expectations, both in terms of the scale of carer breakdown (significantly less than projected), and in the capacity of the nature, duration and intensity of the offer to reduce the likelihood of carer breakdown.

The provision has continued to evolve throughout the evaluation, in part responding to the findings of the interim report and developing a more streamlined and personalised offer to carers.

The Service was established to provide universal access that would be a gateway to information and advice, and to the support required to improve carer wellbeing. There were two key objectives for the service:

- Increase the identification and understanding of needs of carers in the county.
- Improve the wellbeing of carers and support them in sustaining their caring relationship.

There has certainly been improved identification of carers (starting from a low base where relatively few carers were known to the Council). Between September 2020 and April 2023 the Service recorded almost 8,000 carers who had been referred (or had self-referred) to the service. The profile of carers in Norfolk is similar to that which exists in national data, with carers tending to be older people, typically caring for someone aged over 65 (most likely to be either their partner or a parent). Carers referred to the Service are those who are more heavily involved in a spectrum of caring, often committing more than 50 hours per week to caring demands.

The wellbeing of carers has been measured by the Service through the use of the validated instrument of the Carers Star, applied at assessment and at subsequent review. Improvements in wellbeing on this measure have been achieved. However, the scores are a poor predictor of risk of carer breakdown, and where caring situations did breakdown, carers had similar Star scores to other carers.

Breakdown of caring relationships occur relatively rarely, and where they do happen these are typically the result of unavoidable circumstances. This challenges the central assumption made by the Council that reducing carer breakdown is the key to supporting carers and delivering cost savings to adult social care. Our findings indicate that this is a flawed assumption; most carers will continue to care as long as they possibly can.

There are tensions in the breadth and depth of the Service; providing a universal information and advice service to carers can be helpful in meeting straightforward needs. However, targeting carers who require a more nuanced and tailored service necessitates the ability both to identify this higher need group, and to deliver appropriate support of sufficient intensity and duration to sustain them in their caring and improve their wellbeing.

Support from the Service is generally highly valued by carers and is contrasted with their experience of other services which often fail to address carers' needs. However, carers also point to the frustrations of accessing appropriate support rather than simply being signposted to information and of receiving short-term interventions (such as carer breaks) when their underlying needs are unchanging, or indeed intensifying.

The Service is likely to be able to make the greatest difference to carers with lower-level needs.

Support for carers, and the people they support, between the Service and the Council is poorly coordinated; the lack of transparency and communication between respective file systems is a significant limitation in achieving joined up and coherent care and referral pathways for both carers and cared for people.

Higher risk carers identified by the Council were more likely to benefit from contingency support (such as respite), which appeared to be effective in sustaining caring. This points to the importance of support for carers being integrated across the Council and the Service. Opportunities for enhancing carer wellbeing offer the greatest prospects for positive outcomes and continuing to invest in contingency and respite support for carers facing more intensive demands, alongside a service able to offer low level and flexible support to an increasing number of carers is likely to be the most positive way forward.

2. Introduction

This report presents the findings from the evaluation of, an innovative strategic partnership between a local authority – Norfolk County Council – and voluntary sector providers using a social impact bond mechanism to improve the service offering for (unpaid) carers in the county (the Service). The key objectives of the service redesign were to:

- Identify more carers in the county and better identify carers that need the services the most.
- Connect up Council commissioned services to create a single, simplified pathway for carers and reduce duplication. The front door of the service remains universal, with additional support offered to those that need it most.
- Create a set of services that are person-centred and asset-based, focus on building carer resilience and wellbeing for those that most need it, with the longer-term impact of reducing breakdowns of the caring relationship.
- Focus on data collection to evaluate what works, with the ambition to grow the service if the desired impact is demonstrated.

In 2020 Norfolk County Council appointed the Institute of Public Care (IPC) at Oxford Brookes University as an independent research organisation to evaluate the implementation and impact of the Service. A formative, interim report was produced in 2021, and this is the final evaluation report.

2.1. Evaluation methods

The evaluation was mixed-methods study, drawing on primary and secondary collection and analysis of qualitative and quantitative data. The methods can be summarised as

- Preparation and set up, including a theory of change workshop and a [rapid research review](#) on the well-being needs and characteristics of adult carers, and what successful support looks like for them, as well as the evidence for effective social impact bonds to support adult carer wellbeing.
- Secondary analysis of outcome data (Carers Star) and sustainment checks collected by the Service up to May 2023.
- A longitudinal survey of carers in contact with the Service, to explore satisfaction and changes in wellbeing (n=1,180).
- Analysis of a sample of case files for people with care and support needs held by the Council (n=61).
- Analysis of a stratified random sample of carers' case files held by the Service (66 in year 1) and re-analysis of those case files along with an additional stratified random sample held by the Service in year 3 (100 in year 3).
- Semi-structured interviews with carers (n=15 in 2021 and n=8 in 2023), sector leaders (n=5 in 2021), local authority managers and Service partner leaders (n=8 in 2023).
- A survey of professional stakeholders and practitioners in 2022 (n=38), repeated in 2023 (n=62).

2.2. Background and context

2.2.1. Outcomes framework and baseline

The Service is implemented via a delivery partnership using a social impact bond mechanism. The service is designed around two key outcomes:

- Increasing the identification and understanding of needs of carers in Norfolk.
- Improving the wellbeing of carers and support them in sustaining their caring relationship.

Payment triggers, measurement, value and expected number of carers achieving particular outcomes were set out at the start of the programme. Table 1 presents the programme's outcomes framework.

Table 1 Outcomes framework of the Service

Risk	Outcome	Evidence
All	Increase information available on carers	Data recorded on known carer
All	Increase number of carers known	Data recorded on unknown carer
Low	Support carers at a lower level of risk by co-producing a low-level support plan	Completions of low-level support plan and risk score
High	Support high risk carers	Wellbeing assessments and action plan completed
High	Preventing carer breakdown for 6 months since support plan agreed	<ol style="list-style-type: none"> 1. Confirmation that caring role is being maintained 2. Improvement in wellbeing score after successful completion of action plan
High	Preventing carer breakdown for 12 months since support plan agreed	<ol style="list-style-type: none"> 1. Confirmation that caring role being maintained 2. Improvement in wellbeing score after successful completion of action plan

Risk	Outcome	Evidence
High	Support high risk and high need carers	Wellbeing assessments and action plan completed
High	Preventing carer breakdown for 6 months since support plan agreed	<ol style="list-style-type: none"> 1. Confirmation that caring role being maintained 2. Improvement in wellbeing score after successful completion of action plan
High	Preventing carer breakdown for 12 months since support plan agreed	<ol style="list-style-type: none"> 1. Confirmation that caring role being maintained 2. Improvement in wellbeing score after successful completion of action plan

Source: NCP Project Summary, NCC

The Carers Star¹ was identified as the main wellbeing outcome measure and a 2-point improvement in wellbeing was identified as a successful outcome (triggering full payment).

For carers identified as at risk of “breaking down” (i.e. high risk or initially defined as Cohort 3 and 4), the outcome measure is whether the carer is able to sustain their role:

- Carer is still a carer, 6 months after being identified as high risk.
- Carer is still a carer, 12 months after being identified as high risk.

The Council commissioned an independent analysis of the estimated value to government that will be created by the implementation of the social impact bond. It was projected that improvement of carer wellbeing will have benefits across all parts of government, including:

- Value to the Council: Sustainment of the caring role will avoid costs to the council of residential care and care visits.
- Value to the NHS: Improving the wellbeing of the carer will require lower need for primary care and secondary care of the carer. Sustaining the caring role, and therefore preventing unplanned breakdown, will also prevent emergency hospital admissions.

¹ Carers Star | Triangle. (n.d.). Triangle. <https://www.outcomesstar.org.uk/using-the-star/see-the-stars/carers-star/>

- Value to the Department for Work and Pensions (DWP): Improving the carers wellbeing will improve their ability to sustain their employment and therefore, reduce their likelihood to receive benefits from DWP.

Potential savings for LA adult social care were calculated at baseline (not part of this evaluation) as follows:

- 13% of 250 carer assessments where carer breakdown was indicated resulted in an increase of £170 per week – for the 32 cases in this cohort an annual increase in costs to LA of £283k.
- 26% of 250 reassessments where carer breakdown was indicated resulted in an increase of £250 per week – for the 65 cases in this cohort an annual increase in costs to LA of £845k.

It was predicted that reducing and delaying carer breakdown had “potential value for adult social care of up to £50m taking into account full scope, service transformation and assumptions that outcomes to delay breakdown were achievable for all people reviewed for up to 12 months. However, based on the High scenario cohort savings and assumptions regarding outcomes, potential savings to Adult Social Services are expected to be £8m over the life of the SIB” (NCP Project Summary).

2.2.2. Interim report

A formative, interim report completed by IPC in October 2021 explored the first year of implementation of the Service, particularly:

- The process of implementation: whether the programme has delivered a simple, accessible and equitable pathway for carers to access support in Norfolk.
- Carers’ experiences and short-term impacts: whether carers can access good quality, timely and person-centred support, focused on developing resilience and wellbeing.
- Early impact and outcomes: whether carers experience improved wellbeing and are better supported to continue caring.

In June 2022, the [formative report](#) was updated to incorporate additional findings from an online survey of professionals and community organisations, and from telephone interviews with sector leaders about the implementation of the Service, gaps in carer support, and learning so far from the social impact bond.

The findings in the formative report resonated with the management of the Service, who recognised the opportunity to make major changes rather than incremental adjustments. The transformation reflected the Service responding to the direct experiences of carers using the service and the issues identified in the formative report. It focused on the following key areas:

- Reducing backlogs and delays in carers getting support.
- Introducing more proportionate carer assessments based on level of need.
- Streamlining the experience for carers, particularly ensuring that carers do not have to repeat their stories at different stages of the process.

- Introducing a new IT data system.
- Creating a more bespoke offer that allows more person-centred support for carers.

Alongside a simplified process for assessments, a major change was the introduction of on-line self-assessment for carers using the 'You Matter' form and enabling carers to identify how they feel and what's important to them.

In addition to enabling carers to identify what matters to them, the self-assessment process generates a weighted score which determines the course of their onward journey. If someone scores highly on various domains, it effectively fast-tracks them to the Community Team. More straightforward needs for information or advice can be dealt with promptly.

2.2.3. Evaluation approach

This, final, report explores the third year of implementation and draws together evidence of the emerging impact of the Service. It seeks to build insights around the implementation of the Service, the needs and characteristics of carers, and the commissioning approach. We address the following main areas:

- Identifying the needs and characteristics of carers in contact with the Service and their experiences of support.
- Understanding the pathways that carers take through the Service and the quality of support provided, including the identification of any gaps in support.
- Examining the impact of the service against the original outcomes framework – carer wellbeing and breakdown – and assumptions about potential savings.
- Exploring stakeholders' awareness and perceptions of the Service.

In approaching year three of the evaluation, we were mindful of the substantial changes that had taken place, or were in progress, in how the Service operates. We also acknowledge that it is too soon to assess the impact of these changes, but they seem positive and constructive developments which have potential to improve the operation of the service, and the experience and outcomes delivered for carers. We explored the nature of the changes and the rationale for their introduction in some interviews with the managers of the Service and with senior members of partner organisations. These provide context for reporting of findings.

Managers thought that the improvements would be beneficial both to those working to deliver the service, and importantly for carers themselves:

The system's going to make a difference for us; it's going to take out a lot of our admin, and all of those time-consuming tasks, but it is all about improving the carer journey. And I think it's been really lovely with the recent chaos of the system change to know that actually this is all being done to improve the service for the carer.

Interviewees from partner organisations involved in the delivery of the service also commented on the opportunities offered by the new IT system and approach:

They've been really good at taking on lots of feedback from carers about the processes that they were following and worked really hard to try and streamline everything and make it more carer friendly and proportionate to what the carer needs at the time.

3. Findings from the carers' survey

We conducted a longitudinal survey of carers who have been in contact with the Service. Shortly after their first contact with the Advice Line, carers who consented to take part in the evaluation were invited to complete a survey (Wave 1). Depending on their preferences, they either received a link to complete the survey online, a postal survey, or were contacted by a member of the research team to complete the questionnaire over the phone. Those who responded to Wave 1, were invited to complete Wave 2 six months later. The survey was collecting responses from September 2021 to May 2023: we closed Wave 1 in February 2023 to allow respondents time to complete Wave 2 by May 2023.

The survey had a response rate of 61% at Wave 1 and 48% at Wave 2 (see Table 2), which can be considered an excellent response rate (Wu et al. 2022²). However, fewer than 20% of all carers who contacted the Service opted-in to the evaluation.

Table 2: Carer survey sample sizes

Contacts received from the Service	Effective sample*	Wave 1 responses		Wave 2 responses	
		N	%	N	%
1,504	1,361	831	61	398	48

* contacts minus opt-outs, bounce-backs etc.

The survey questionnaire [Wave 1](#) and [Wave 2](#) had three main sections:

1. Demographic and background questions about the carer and the person they care for.
2. The Wellbeing Scale of the Carer Wellbeing and Support Questionnaire (CWS). This is a psychometrically validated measure originally developed for carers of people with mental health problems, including dementia. It has been

² Wu, M. J., Zhao, K., & Fils-Aime, F. (2022). Response rates of online surveys in published research: A meta-analysis. *Computers in Human Behaviour Reports*, 7, 100206.

demonstrated to have good reliability and validity and was developed with carers to reflect important aspects of their wellbeing and quality of life³.

3. Experiences with the Service.

We used descriptive statistics such as simple distributions and cross-tabs, and regression to analyse and present the survey responses (see Annexe 1). When we refer to a correlation as “significant” it means that the relationship between variables (e.g. carer or cared for person’s characteristics, self-reported outcomes) are statistically significant. However, a relationship between variables (whether statistically significant or not) does not indicate causation.

This section presents the key characteristics of survey respondents, an analysis of carers’ needs and self-reported wellbeing, and their experience of support and its impact.

3.1. Characteristics of survey respondents

The majority of respondents were aged over 65 years, retired and caring for a partner or spouse, providing 50 or more hours of care a week (62%). Additional caring responsibilities for either another adult or a child were reported by 17% of respondents. Two thirds (65%) of respondents were female and 45% also had a disability or long-term condition. At Wave 1, 25.5% of respondents were working either full time (10.5%) or part time (15%). The main characteristics of survey respondents are summarised in Annexe 2.

Sixty-five percent of respondents cared for older adults aged over 65 and almost 30% supported someone with three or more conditions / disabilities. The most common conditions were dementia, physical disability and long-term health conditions/frailty (see Annexe 3).

3.2. Carers’ self-reported wellbeing

The Wellbeing Scale⁴ of the Carer Wellbeing and Support (CWS) questionnaire has 32 items covering eight domains:

- carer role
- carer’s relationship with cared for
- carer’s relationship with family and friends
- financial situation
- health
- own safety
- safety of cared for person

³ Quirk, A., Smith, S., Hamilton, S., Lamping, D., Lelliott, P., Stahl, D., Pinfold, V. and Andiappan, M., 2012. Development of the carer well-being and support (CWS) questionnaire. *Mental Health Review Journal*.

⁴ Wu, M. J., Zhao, K., & Fils-Aime, F. (2022). Response rates of online surveys in published research: A meta-analysis. *Computers in Human Behavior Reports*, 7, 100206.

- caring-related stigma and discrimination

Each item is scored on a five-point scale with 0 representing 'high levels of concern' and 4 'no concern at all'. Total scores can therefore range from 128 to 0, where 128 represents no concerns at all and 0 represents very high levels of concern across all domains of life and relationship with the cared for individual. Carers in our sample reported moderate levels of wellbeing with large variations in either direction: a sizeable group of respondents had very low levels of self-reported wellbeing, while a similarly sized group had high levels of wellbeing. Table 3 gives a summary of the CWS scores. There was also an increase in self-reported well-being between Wave 1 and Wave 2; however, this was not statistically significant.

Table 3: CWS scores at Wave 1 and Wave 2

	Wave 1 (n=780)	Wave 2 (n=400)
Mean	69.4	76.7
Max	128.0	128.0
Min	3.0	4.0
St dev	27.2	27.6
Median	68.0	78
Quartile 1	50.0	56.7
Quartile 3	91.0	98.0

Carers were also asked to rate their general well-being during the previous four weeks. About a quarter of respondents reported positive / good wellbeing, and a similar number indicated poor well-being (Table 4).

Table 4: Self-rated wellbeing at Wave 1 and Wave 2

	Wave 1 (n=780)	%	Wave 2 (n=400)	%
Excellent	9	1.2	7	1.8
Very good	60	7.7	41	10.3
Good	139	17.8	90	22.5
Fair	345	44.2	159	39.8
Poor	207	26.5	94	23.5
Prefer not to say	20	2.6	9	2.3

Younger carers, those caring for parents or people with mental health needs, had significantly lower scores and wellbeing

Younger carers (aged under 50 years), those caring for parents, or people with mental health needs had significantly lower CWS scores and reported lower well-being.

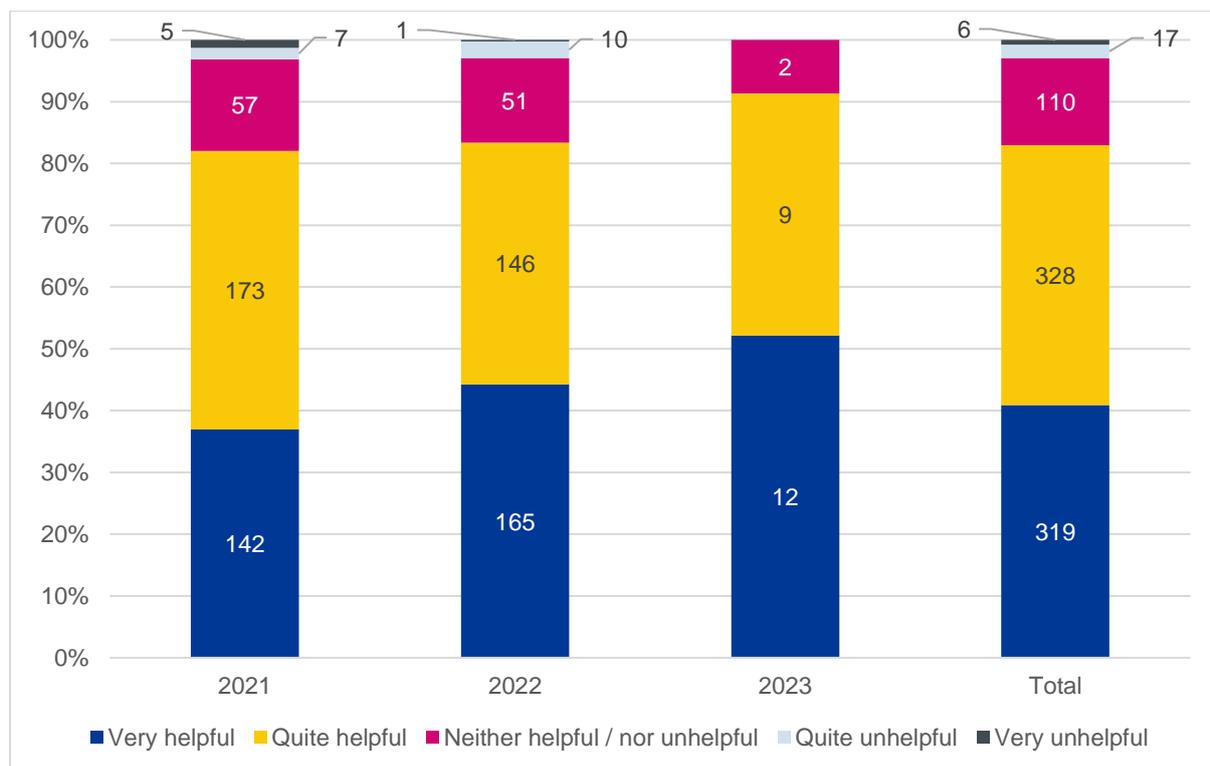
The majority of carers who were working alongside their caring role were happy with this and wanted to carry on working; only 7% of full-time and 15.3% of part-time

workers said they wanted to stop working. In contrast 45% of those caring full-time indicated that they would like a job outside their caring role.

3.3. First contact and satisfaction

Most respondents found their first contact with the Service “very helpful” or “quite helpful” and this was consistent between 2021 and 2023 (Figure 1).

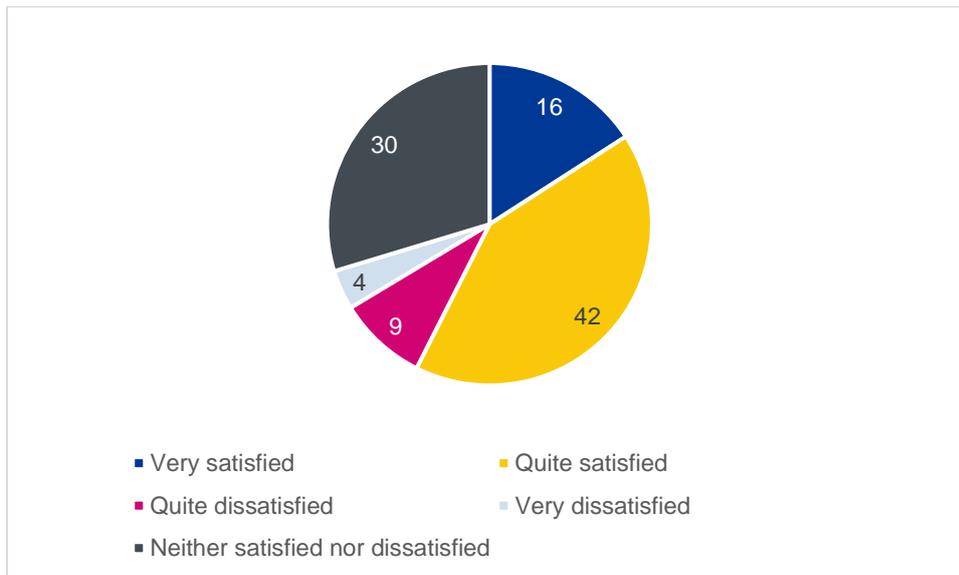
Figure 1: Helpfulness of first contact



Those going on to receive support from the Service reported generally positive experiences in Wave 2:

- 67% said that the support helped them continue caring
- 61% said they received all of the support at the right time, 25% received some of it at the right time
- 57% were quite (41%) or very (16%) satisfied.

Figure 2: Satisfaction with support



People caring for someone with dementia were significantly more satisfied (on all above aspects) than were carers supporting people with other needs.

People caring for someone with dementia were more satisfied with CMN

3.4. Impact of support on wellbeing

To analyse changes in self-reported wellbeing over time, we linked responses from Wave 1 and Wave 2 and information from the Service’s data⁵. Scores are summarised in Table 5; they were similar to the non-linked datasets.

Table 5: CWS scores at Wave 1 and Wave 2, linked samples (n=399)

	Wave 1	Wave 2
Mean	70.3	76.7
Min - Max	3 - 128	4 - 128
St dev	27.2	27.6
Median	70.0	78
Quartile 1	50.5	56.7
Quartile 3	91.0	98.0

⁵ We used a unique, pseudonymised tracking number allocated to each participant invited to take part in the survey to link individual response sets from Wave 1 and Wave 2. Participants who only took part in Wave 1 were excluded from this sub-sample. We then used individuals’ CMN ID to link our survey data with selected variables from the administrative dataset.

We also examined CWS scores and self-reported wellbeing according to whether the respondent received support from the Service (see Table 6 and Table 7).

Table 6: Relationship between CWS and carer support (self-reported)

CWS Score		Wave 1	Wave 2
Received support	Yes (n=264)	68.7	77.1
	No (n=135)	73.4	76.0
	Total (n=399)	70.3	76.7

Table 7: Relationship between CWS score and carer support (administrative data)

		N	Wave 1	Wave 2
Has a Carer Star Action Plan to receive support from the service	Yes	112	59.9	68.3
	No	287	74.3	80.0
	Total	399	70.3	76.7

There was a clear and considerable increase in the self-reported wellbeing of respondents between Wave 1 and Wave 2, and the difference was substantially larger for those who received services, these were not statistically significant. The size of the dataset does not allow a more detailed analysis of outcomes by types of support.

3.5. Conclusions from the carers' survey

Findings from the longitudinal survey of carers in contact with the Service suggest that:

- the Service is effective in reaching a diverse group of carers, including those with substantial and complex needs due to low levels of wellbeing, their age, or the intensity of their caring role.
- Our survey offers triangulated evidence that more intensive support (i.e. Carer Star Action Plan) is targeted at those with higher needs (i.e. lower wellbeing).
- There is also tentative / emerging evidence that suggests that those receiving support report better wellbeing.
- Generally, support from the Service is regarded positively by carers who report high levels of satisfaction and perceived positive impact. More than two thirds of those who received support said it helped them to continue caring.

When interpreting the findings of the survey we would highlight some important caveats. Firstly, the survey was implemented on a rolling basis, with approximately six months between Wave 1 and Wave 2 responses. This makes it difficult to control

for changes that took place during the survey such as the Covid-19 pandemic and its aftermath or the cost of living crisis unfolding from the end of 2022. It is likely that these have impacted the self-reported wellbeing of respondents. Secondly, although the survey highlights potentially important and significant relationships between wellbeing and support, it does not tell us about the causal mechanisms and effects. Finally, the sample size was relatively small; although response rates to the survey were excellent, only 20% of all eligible carers consented to participate in the evaluation.

4. Analysis of data collected by the Service

We analysed data of nearly 8,000 carers referred to the Service before April 2023. Of the 7,956 carers included in the dataset, less than half (n=3,172) received support beyond an initial assessment of needs (triage) and low-level signposting. Of those receiving support, two thirds (n=2,081) were categorised as “low risk” – previously known as Cohort 2 – and one third (n=1,091) were “high risk” – previously cohorts 3 and 4 – and eligible for more intensive support from the Service.

Carer Star data is available for the majority of “high risk” and some “low risk” carers. Carer Star 1 scores are available for 1,136 carers; the average score is 22.4, suggesting low to moderate levels of wellbeing. Scores and changes for carers with at least two or three data points are summarised in Figure 3 and Figure 4.

Figure 3: Carer Star scores for carers with at least two scores (n=660)

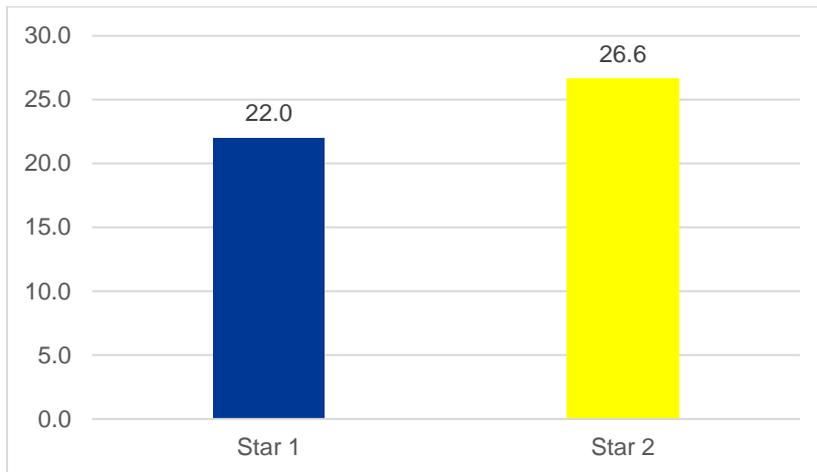
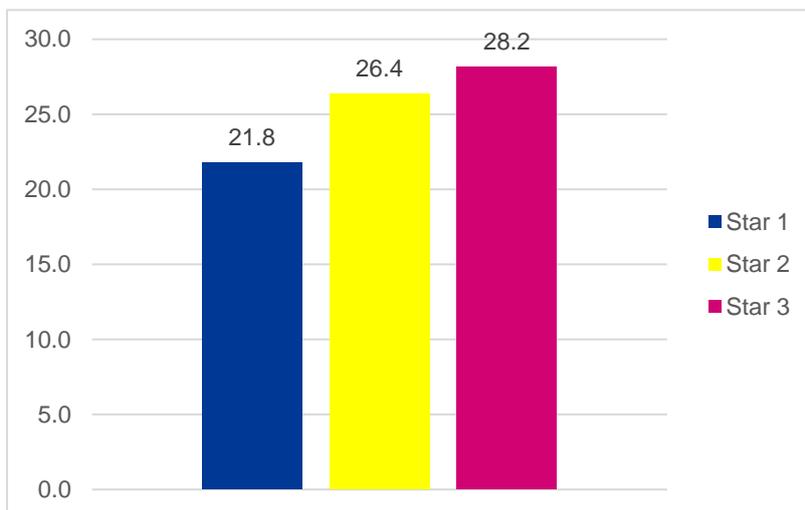
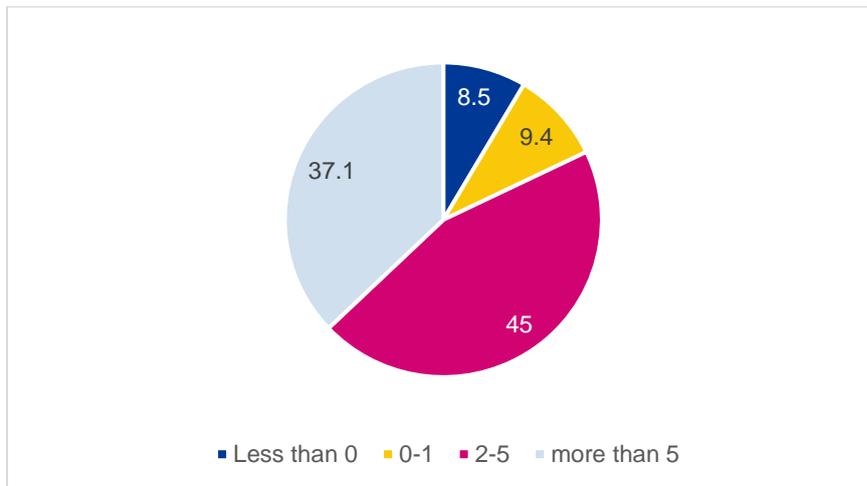


Figure 4: Carer Star scores for carers with three scores (n=352)



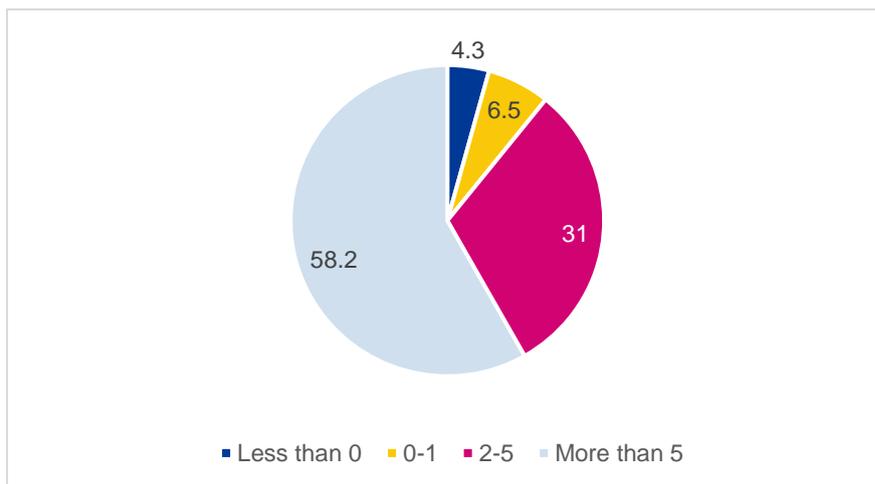
The data show large and sustained improvements in wellbeing over time during and following the intervention. The differences between Star 1 and Star 2 scores range from -8 to 18, with 60% of carers showing an improvement between 3 and 8 scores. However, 8.5% of carers had a negative score, indicating worsening wellbeing and 9.4% had no or very limited improvement (see Figure 5).

Figure 5: Improvements between Star 1 and Star 2 (% of carers, n=660)



Between Star 1 and Star 3, 58.3% of carers have had an improvement of more than five scores (see Figure 6). Score differences ranged between -6 and 20.

Figure 6: Improvements between Star 1 and Star 3 (% of carers, n=352)



Information about 6-month sustainment checks were available for 811 carers, 12-month checks for 464 carers. The large majority (85%) carers were still caring at both time points. Most common reason for “breakdown” is the death of the cared for person (nearly 50% at 6 months and 36% at 12 months), followed by admission to residential care due to deterioration of the condition of the cared for person (25% and 39%); both of these categories are recorded as “unavoidable”.

Of the 118 “breakdowns” recorded at the 6-month sustainment check, only nine were “avoidable” (7.6% of breakdowns), 1.1% of all sustainment checks.

Table 8 summarises the distribution of breakdowns recorded. The picture is largely similar at 12 months, when only five out of 69 breakdowns were recorded as avoidable (7% of breakdowns and 1.1% of all sustainment checks).

Table 8: Number of breakdowns by reason

	Recorded reason	at 6 months		at 12 months	
		N	%	N	(%)
Avoidable	Caring responsibilities transferred to another person (unpaid)	1	0.85	.	.
	Deterioration of relationship between carer and cared for	7	5.8	5	7.2
	Increased demand in other areas of carers life (work/ education/ new parent)	1	0.85	.	.
Unavoidable	Death of the cared-for person	56	47.4	25	36.2
	Death of the carer	5	4.2	1	1.4
	Deterioration of mental health of carer due to stress, fatigue	2	1.7	.	.
	Deterioration of physical/ mental health of cared for	30	25.4	27	39.1
	Deterioration of physical/ mental health of carer (organic)	9	7.6	3	4.3
	Other	7	5.9	8	11.6
	Total	118	100	69	100

A brief analysis of carers star scores and sustainment suggest no relationship between the two; star scores at time 1 and 2 do not seem to have a predictive value for breakdown (Table 9 and Table 10).

Table 9: Sustainment at 6 months and Carer Star 1

Sustained at 6 months	Carers Star 1	
	N	Mean
No	118	21.9
Yes	693	21.9
Total	811	21.9

Table 10: Sustainment at 12 months and Carers Star 1 and 2 scores

Sustained at 12 months	Carers Star 1		Carers Star 2 Total Score	
	N	Mean	N	Mean
No	69	22.45	54	26.15
Yes	395	21.75	386	26.35
Total	464	21.85	440	26.35

4.1. Conclusions from the analysis of secondary data

The administrative programme data suggest wellbeing improvements across the carer cohort accessing support. However, our analysis was limited by our lack of access to granular data for the Carers Star (i.e. domain scores). Carer Star scores are not benchmarked against comparable cohorts elsewhere. This would be necessary to get a more reliable and valid picture of programme impact.

Some of the improvements recorded, especially between Star 1 and Star 3, seem very large. Therefore further analysis / quality checks would be recommended to ensure that the administration of Carer Star 3 is minimises potential subjective bias (see section 6.2).

The majority (85%) carers were still caring 6 and 12 months later, that is, the caring relationship had been sustained post support. Most common reason for “breakdown” is the death of the cared for person, followed by admission to residential care due to deterioration; both of these categories are recorded as “unavoidable”.

Carers Star scores do not seem to predict carer breakdown at sustainment check

There is a mismatch between the definitions and categories of breakdown used in the baseline assumptions and during implementation. Avoidable breakdown is a relatively rare outcome at just 7% of all breakdowns compared to the initial assumptions of 13% and 26%. The baseline – on which the predicted cost savings are based – appears to include some of the categories currently recorded as “unavoidable” – deterioration of physical or mental health of carer and cared for. As a result, some of the outcomes and savings from the implementation of the SIB might be overstated.

5. Findings from the Council case file analysis

We analysed the case records of 61 individuals in the Council’s Liquidlogic Adult Social Care System (LAS) in June 2023. IPC researchers were granted supervised access to LAS and information from LAS was extracted using a [template](#) in Microsoft Excel.

The aim of the LA case-file analysis was twofold. Firstly, we intended to identify a “counterfactual” cohort of carers who did not receive any support, build up a full picture of the caring situation, and explore differences in the trajectories of the two cohorts, including breakdown of the caring relationship. Secondly, the LA case file analysis aimed to explore in more detail the relationship between needs, costs, and services and attempt to identify approaches to quantify the impact of carer support from a local authority cost perspective.

Our sample consisted of 61 individuals in contact with the Council and supported by unpaid carers: 36 cases were selected via carers’ records in our case file analysis (“the Service sample”), and 25 were selected using a stratified random sampling to match the demographic characteristics of the linked Service -LA records (“LA sample”). The sample was varied in terms of gender (47.5% were female), age, needs, relationship to carer, and district (see Annexe 4), reflecting the full spectrum of local authority adult social care provision.

The date of first assessments ranged from 2008 to 2023. Around 60% of the sample had their first Care Act assessment (or equivalent) in 2020 or later. Four people were referred to a Care Act assessment by the Service.

One of the main findings of the case file analysis is that the recording of contact with the Service in the Council case notes is inconsistent and unreliable. The data do not allow us – as we had hoped - to compare the cohort of carers with and without support from the Service (see Table 11). In the NCC sample, only 36% of cases recorded that the carer was in contact with / receiving support from the Service

(either in the carer's or the cared for person's case file), whilst 30.6% of the cases did not mention carer support from the Service at all. In a quarter of the cases, it was noted that the carer was signposted to the Service for an assessment/support, but there was no information recorded on the outcome of this.

Table 11: Contact with the Service mentioned in LA records

	Service sample (n=36)		LA sample (n=25)		Total (n=610)	
	N	%	N	%	N	%
Yes	13	36.1	4	16.0	17	27.9
No	11	30.6	9	36.0	20	32.8
Only referral is mentioned	9	25.0	4	16.0	13	21.3
Declined carer support from the Service	3	8.3	8	32.0	11	18.0

Information about carer assessment was recorded in two thirds of cases and most of the assessments were undertaken by the Council either as a separate carer assessment or a combined assessment for the carer and the person they care for (Table 12).

Table 12: Carer assessments by type

Type of carer assessment	N	%
Carer assessment by the Service	6	9.8
Carer assessment by the Council	11	18.0
Combined assessment by the Council	14	23.0
No assessment (refusal etc.)	6	9.8
No information	20	32.8
Referral to the Service	4	6.6
Total	61	100.0

The majority of case notes had information about the carer and acknowledged the carer's needs (n=45, 74%). Sixty-four per cent (n=39) mentioned carer "fatigue", "breakdown", "burnout" or "risk", and more than half (n=34, 56%) identified a change in the cared for person's needs, the carer's capacity to continue caring, or both since the last review (see Table 13). A third of the sample had progressing needs.

Table 13: Changes in the carer's capacity or cared for person's needs

Carer's capacity:	n/a	No change	Change	Total
Cared for person's needs:				
Increased		14	8	22
Stayed the same		20	11	31
n/a (i.e. not had a review yet)	5	2	1	8
Total	5	36	20	61

In the Service sample 24 cases had at least one sustainment check and five were recorded as “unavoidable breakdown” (21%) due to either the death of the cared for person or an increase in their needs. There were no cases of avoidable breakdown in the sample.

Seventy-two per cent (n=44) of care plans addressed sustainability and resilience by putting support in place that aided the continuation of the caring relationship and helped the cared for person to remain at home. We found no evidence that the Council care plans address the sustainability of the caring relationship in 13% of the cases, the majority of these declined local authority support, typically due to concerns about self-funding (10%).

Contingency support (e.g. respite) was included in 40% (n=24) of all care plans / support packages. Cases that were identified as “high risk” of carer breakdown/fatigue were more likely to have contingency support (see Table 14).

Table 14: Relationship between contingency support and reference to risk/fatigue

	No reference to fatigue		Risk of fatigue		Total
	N	%	N	%	N
No contingency	10	62.5	12	40	22
Contingency	6	37.5	18	60	24
Total	16	100	30	100	46

To assess whether contingency support contributed to sustainability, we categorised cases by the level of support they would need without the care provided by the carer. The majority of cases would need more intensive or 24-hour care and support, and those with contingency days were somewhat more likely to need 24-hour care and support without the unpaid carer (see Table 15).

Table 15: Relationship between contingency and need for support in the absence of unpaid care

Support needs without carer input:	24-hour care and support		More intensive support		Unclear		Total
	N	%	N	%	N	%	N
No contingency	4	18.2	9	40.9	9	40.9	22
Contingency	9	37.5	10	41.7	5	20.8	24

The average cost of care packages by main need are summarised in Table 16. There was substantial variation in the cost of care packages both between and within categories of need.

Table 16: Average cost of care packages by need (£, rounded to the nearest 100)

Category of need	Average of Cost of care Package (£)	Min of Cost of care Package (£)	Max of Cost of care Package (£)	Average of Change (£)	n
Learning disability support	29,400	10,215	79,250	-6,700	7
Mental health support	15,300	2,900	44,375	5,000	5
physical support - access and mobility only	23,000	1,700	68,000	8,900	6
physical support - personal care support	23,800	1,300	87,500	11,650	16
social support - support for social isolation / other	15,300	15,300	15,300	n/a	1
support with memory and cognition	22,900	5,000	70,466	6,700	6
Grand Total	23,300	1,300	87,500	6,200	41

The cost of the care package increased in 18 cases (29.5%) from the previous year, eight cases (13%) were new care packages, and the cost of the care package reduced in 13% of the cases (see Table 17).

Table 17: Changes in the cost of care packages

	Change from previous year		Average of Change	Min of Change	Max of Change
	N	%	£	£	£
Decrease	8	13.1	-10,500	-30,000	-800
Increase	18	29.5	17,000	1,730	72,700
New package	8	13.1	10,500	4,200	31,000
No change	9	14.75			
Unclear - fluctuating need	2	3.3			
N/A - no support or self-funding	16	26.2			
Total	61	100.0	6,165	-30,000	72,700

5.1. Conclusions from the Council case file analysis

The analysis of the Council case files highlights that the relationship between needs, support, and costs is complex, and the narrow definitions of 'avoidable' and 'unavoidable' carer breakdown do not provide adequate scope to assess the financial impact / benefit of carer support. An important limitation of the data was the lack of reliable information / recording of support from the Service to carers in the Council case files.

An alternative way to consider the benefits and value of carer services is to estimate the notional value of unpaid care (including the cost of supporting the carer to continue caring) and compare it to the cost of care that would be needed in the absence of support from the unpaid carer. Targeted support for carers of people with more intensive and complex needs – in the form of contingency / respite – appears to be an effective way of sustaining the caring relationship and avoiding or delaying higher costs. Similarly, early identification of risks (such as carer fatigue) and needs (e.g. unmet care and support needs) via holistic / whole-family assessments or better information sharing/joint working between the Service and the Council has the potential to support sustainable and resilient caring relationships.

6. Findings from the analysis of the Service's case files and carer interviews

In addition to the analysis of a sample of the Council case files, we undertook extensive analysis of carer case files held by the Service in 2021 and 2023. In the formative report, we identified a number of interim conclusions based on our analysis of a stratified random sample of 66 case files from the Service and interviews with a sample of 15 carers. Our key findings from year one highlighted:

- the Service were very proactive during the initial six months, and they kept in regular contact with the carer.
- There were multiple examples of the Service responding to the practical needs of carers in a timely manner, and also offering innovative approaches to 'having a break' such as use of leisure services to support carer wellbeing. This ability to provide practical and immediate support was effective at reducing the presenting issue and stress point for carers.
- Services were offered from a pre-determined 'menu' of services and this was not always well-tailored to individual needs.
- There was poor targeting of support, with no discernible pattern of different and more intensive, longer duration support for carers with high level needs and high risks of breakdown.
- There was limited evidence that support was focused on developing carer resilience and wellbeing.
- It was extremely difficult to know from the case files what – if any – social care and support was being provided to the cared for person, either privately arranged or funded by the local authority.

The analysis concluded that the Service was successful in offering short-term practical support and flexible breaks for carers to have time for themselves, but this was not part of a continuing system of support that could sustain carers over time, after their involvement with the service ended.

6.1. Year three case file analysis

In 2023 we revisited the 66 case files from year one alongside a newly selected sample of 100 further cases to examine support provided by the Service and its impact on a varied group of carers.

Our reanalysis of year one case files was focused on the sustainment of caring. The '**sustainment check**' undertaken at 6- and 12-month intervals asks whether the carer is still caring, and the answer is a binary yes or no choice. This is a procedural element for the Service and their contractual reporting. However, we suggest there may be a missed opportunity to use the sustainment check more dynamically. If the check was adapted to explore with carers how they were coping and whether their circumstances had changed, this could be a positive check to explore individual risk and to respond appropriately with either additional signposting or support. This

could be an important component in adapting support and preventing the likelihood of 'breakdown'. We found:

- 21 cases had received a 12-month sustainment check, and five were no longer caring. In two cases this was due to death of the cared for person, while another two entered permanent residential care, and another did not return home from hospital and was moved out of area by their family. These were all categorised as "unavoidable".
- Of the 15 cases where the carer was still caring at the time of sustainment checks (one other was unclear if still caring), the process revealed nothing about the circumstances of carer and cared for and whether the carers were coping.

The procedural and administrative nature of sustainment checks is arguably also reflected in the numbers of cases who return to the Service for support either via self-referral or are re-referred by a professional. We found that seven out of the 21 cases (33%) that had a 12-month sustainment check returned. Although some changes in circumstance are sudden, other situations might have been anticipated and preventative support put in place that could potentially avoid carers being re-referred because they have 'reached breaking point'.

The decision to 'close' a case, when carers appear to have ongoing needs at the end of their care and support plan, raises questions. Carers who are re-referred appear to have to start anew with being assessed, which seems to be cumbersome and a surprise to some carers who thought they were 'in the system'. It cannot be assumed that those who are not re-referred are managing – simply that they are continuing to care because they feel they have no alternative. Typically, re-referral occurs because of a sudden change of circumstances or intensification of need. The response to carers who were re-referred continues to be primarily in the form of **low-level support and signposting**.

6.1.1. Characteristics of carers sampled

Key characteristics of carers and caring relationships in the case file sample are summarised in Annexe 5.

30% of carers in the case file sample had been caring between two and 5 years

The sample of carers in the case files included a range of situations and circumstances and was broadly comparable to the total cohort of carers registered with the Service. More than two thirds of carers – 118 (71%) – were female, and 48 (29%) were male. For many people caring was a long-term commitment. The highest proportion (30%) had been caring between two and five years and more than one in five had been caring for at least 10 years. A similar proportion (23%) were relatively new to caring.

Carers generally had an older age profile, with an average age of 60.7, but there was a considerable spread of ages from 18 to 88.

Carers were most likely to be caring for a partner (53%), followed by a parent (24%), or an adult child (14%). Those caring for another household member were typically the most heavily committed with hours of caring responsibilities. The most frequent need for care was associated with a physical disability (30%), closely followed by dementia (27%), or mental health needs (18%).

It was striking that almost three quarters of carers (73%) had a long-term health condition or disability themselves, and often this was associated with the older age of carers. Indeed, carers often had multiple and complex needs arising from both poor physical and mental health.

73%
of carers in the case file sample had a long-term health condition or disability themselves

Carers were spread widely and evenly across Norfolk districts roughly following the distribution of population across the county.

The likelihood of the cared for person receiving support services was almost equally split between those who did receive support (45%) and those who did not (44%).

Throughout our analysis we encountered some limitations in the data where information was not recorded in the case files, or where it was equivocal. This was apparent, for example, in recording whether the cared for person receives services (missing for 11% case files) or the duration of the caring relationship (missing in 13% of reviewed case files).

6.1.2. The process of support

Some methodological and procedural changes to the organisation and delivery of support by the Service had been introduced between since the interim report, and some changes were still being implemented. In particular, the Service had dropped the cohort classification of carers. In the combined case file analysis we found that 84% of carers progressed from triage to initial assessment (“Part A”), and 72% had a full assessment (“Part A” and “Part B”).

In some situations, it appeared appropriate that only triage took place, such as where a carer did not identify any specific needs, or if they declined assessment or stated that they felt they were managing at this point in time but would return if they needed support. However, in some situations the reasons *not* to proceed to an assessment were not apparent from the case files.

Making decisions about the likelihood of carer breakdown as the gateway to full assessment arguably requires a level of judgement as well as an interpretation of the meaning of ‘risk of breakdown’ (an issue we will return to below). Some cases were dealt with at Part A with information and signposting rather than by progressing to Part B even when there appeared to be significant carer needs. Some other cases that *did* progress to Part B resulted in a low-level action plan of information and signposting which seemed to address their identified needs only partially.

Signposting can be helpful, but it puts the onus on the carer to follow up actions for themselves. As our interviews with carers identified, by the time carers get to Carers Matter Norfolk they have usually already been through multiple hoops and typically lack the energy or resources to pursue further suggestions for themselves. As we have noted, many carers are elderly (often very elderly) and being given information and signposting alone is likely to be burdensome and ineffective. Our analysis found many examples where carers (particularly but not exclusively elderly people) did not follow up on signposting which might have led them to other information or support. As highlighted in the interim report, interviews with carers further underlined the challenges of acting on signposting and other information, and our [2023 interviews](#) (completed with 8 carers who volunteered to be interviewed) identified the same experiences, for example:

Many elderly carers did not follow up on signposting which might have led them to other information or support

It was really nice to have those things sent to me, but it felt like work that I had to do and I really just wanted somebody to say, there's this thing, and I'm going to apply for it for you, and I'm going to let you know what happens, and you can take it or leave it. (...) I wanted someone else to do the research because I just didn't have the capacity to cope with looking up something else. [Caring for partner with mental health needs]

And

At that point they gave me leaflets. They gave me booklets and they sent me emails and then I was kind of blown away with the amount of information I was being given. [Caring for partner with dementia]

6.1.3. Quality and timeliness of support

The terms 'strengths-based' and 'person-centred' are increasingly part of the social care discourse, but it is important to be clear about the meaning of such terms and the implications of adopting these as practice principles. A strengths-based assessment builds a picture of the carer's individual and community networks and assets that they can draw on (such as other family members, friends, neighbours etc), while a person-centred approach explores the carer's wishes and interests, and develops a clear sense of what might help address their needs and improve their wellbeing. Support can be better designed to fit individual circumstances and preferences by following these principles and building on the foundation of existing support and resources to deliver personalised outcomes.

Compared to year one, our year three analysis found more assessments were strengths-based and person-centred: 47% compared to 27% of cases previously. However, for more than one in five carers

47%
of assessments were judged to be strengths-based compared to 27% in 2021

(21%) this was only partially true, and it was thought not to be the case for almost 18% of carers.

Carers who were interviewed also commented on the support made available to them that was specifically intended to help them to address their own well-being. **Carers' needs and wishes were often modest**, as the following comments illustrate:

“But one of the biggest unmet needs I have is that space and time to myself. And just to breathe and to exist, and also to get some form of work done.”
[Caring for adult children with mental health needs]

“I applied for [a Millennium grant], and I was granted that, which was great because I used that towards doing some stuff in the garden, which I really like to do.” [Caring for partner with mental health needs]

“... a few times a year, I'd get a massage (...), and it de-stressed me, I get migraines as well, and so that helped with them. But of course they're really expensive, and so the health and well-being fund managed to pay for, I think it was 3 massages which was really helpful”. [Caring for parent with mental health and additional medical needs]

Another carer described the experience of a day long carer break:

“I just felt as if a 10 tonne weight had gone off my shoulders and I loved it (...) So we had the one day which was a success. So then I started to look because I could have six days, they said. So then I looked for another five days, things that I wanted to do myself, so I could go out and somebody would be with [my husband].” [Caring for partner with dementia]

Another carer also used time away from caring to do something for themselves:

“They taught me to use a mindfulness programme which helps me no end. On a Wednesday I get 3 hours respite, to allow me to go and do some shopping or whatever. But I'll do my shopping online and I drive my car into the forest. (...) And I sit there and I just relax and with the mindfulness programme, and it lifts my spirits in a way you can't imagine.” [Caring for partner with MS]

As in our interim report, we acknowledge the value and positive impact that can be achieved by the Service offering flexible and tailored person-centred support such as this to carers. But, we raise concerns about carers being offered short-term help that may alleviate their immediate needs but that does little to support them in the longer term. We return to this issue later in our analysis.

6.1.3.1. Carers receive timely help

Whether support from the Service is timely is a critical issue for carers who have often been through complicated journeys trying to navigate their way to some help. We assessed the timeliness of support in terms of referral to triage; from triage to assessment, and from assessment to action plan. We did not assess the timeliness of external support or referrals, although as we comment elsewhere, we were aware of the delays in such external support that were out with the control of the Service. However, the lack of capacity in other services has significant implications for referral pathways and carer wellbeing.

40%
of carers received
timely support, up
from a third in year 1

Our case file analysis found that the timeliness of support was partial (30.72%), or there was insufficient information recorded (7.83%) to make a judgement. For just under 40% of carers, however, the support received did appear to be timely. This indicated an improvement since the interim report when timely response was found in about one third of cases, and at that time the impact of the

Covid-19 pandemic was affecting the response and the availability of some support. Timely response can also be affected by the availability of carers to respond to contact attempts from the Service.

Triage and assessment A typically take place close together, and often on the same day, but there can be a delay in progressing to assessment B and then subsequently in developing or implementing any action plan. For carers waiting on support such delays can be frustrating, as this interviewee commented:

There was quite a lag between me first making contact with the Service and then the second contact at which point I was already not in a great place, and at that point I got put on for carers assessment, but it might have been more appropriate to have had it earlier from the first contact. [Caring for adult children with mental health needs]

The same carer commented that they were not initially offered assessment when they approached the Service:

Carers assessment wasn't really mentioned in that first call. I just explained what my situation was and they said OK, well just, call back if you've got any questions or if you fancy a chat when you are around or anything like that. It's all something and nothing you know what I mean? I paid them no mind. And until I was realising I was actually really burning out. At that point I really did need some sort of input. [Caring for adult children with mental health needs]

We found 23 cases in the sample (13.8%) where carers had been re-referred to the Service following the closure of their care plan; typically these re-referrals reflected a change of circumstances of the carer or an unexpected intensification of the needs

of the person they care for. In some situations, however, the re-referral indicated a carer desperate and apparently not being supported. For example, an external referral from the Council commented that the carer “... *has been requesting support from various services including Carers Matter and Adult Social Services for a long period and now feels that she’s at breaking point.*”

The re-referral was followed by an assessment identifying support needs but nothing seemed to happen and the next contact two months later found the carer refusing to continue caring because of an abusive relationship with the cared for person. Some other cases that were re-referred also appeared to reflect situations where the carer’s needs had intensified in ways that were highly likely and predictable, and which might have been avoided with additional support at an earlier stage.

Another aspect of the timeliness, is the duration and intensity (e.g. frequency) of the support. Our case file analysis found fewer than a third of carers (31.5%) appeared to be getting the right amount of support in terms of the duration and intensity of support matching their assessed needs. This was partially true for a further 21%, while it was difficult to make this judgement for lack of information in almost another 30% of cases, and support was judged insufficient for 13%. Where carers appeared to have significant needs, but were either not progressing to assessment or were only being given information and signposting would indicate insufficient support, as would situations where carers had ongoing needs but received a one-off or occasional response to that need.

31%
of carers getting
the right amount
of support

6.1.3.2. Carers receive support that is well-tailored to their needs

A related question is how ‘well-tailored’ the support offer is for carers - that is, how well the support is matched to the carer’s identified needs and how these are addressed in a strengths-based and person-centred way. Here again we found a mixed picture; half the case files indicated carers receiving the right support that matched their assessed needs, and this was partially true for a further 39%, and only 6% were judged not to be receiving appropriate support.

Whether carers get the help that they need or want also reflects the nature of their needs and whether those are primarily for advice and information that can be responded to via a low-level action plan, or if they have more substantive needs. As this carer described, having initially been given information, they realised that this was insufficient to support them:

They'd sent me some information in that first assessment phone call. There was various different things they sent me links for and then they were going to catch up with me after a period of time and see if I'd accessed any of those things. See how I felt about what was happening, and so then on my second kind of telephone assessment with them my mental health was really deteriorating by that point and they felt that they needed to kind of keep me on, and they assigned a support worker to me at that point. [Caring for partner with mental health needs]

What determines whether or not carers are offered more than information and signposting? It seems likely that in part this is influenced by how able carers are to articulate what they need and to make a case for getting support. This same carer commented on how they had experienced signposting and the difference it made when they could access something further:

“Sometimes when you’re signposted, it almost feels like you’re kind of pushed aside a little bit, like you know ‘well, we’re not going to deal with you, but here’s some things if you want to go and look at them. See you later’. (...) So when I had that second phone call, that kind of check-in, I felt really pleased that I had managed to get across the fact that I needed more than just signposting.”
[Caring for partner with mental health needs]

Not all carers are as able to identify their needs or to argue that they need some actual help and intervention, and this may be a critical reason why the offer to carers varies in content, intensity and duration, and why people’s experiences and outcomes are different as a consequence. Some carers certainly described their bewilderment with the Service, and found that what support might be available was not explained to them, as these comments illustrate:

“Why am I getting a plan, how is that going to help me? It didn’t really give me in practical terms, what that might look like. People kept saying to me, what do you need and like? I have no idea what I need. I’m a mess, everything was a mess and it was a case of give me some examples of what you can do? (...) You know, when you don’t know what’s available, how can you choose from the menu?” [Caring for relative with learning disabilities]

Another interviewee recounted a similar experience:

“I did give Carers Matter a phone call once (...) and I said, everything’s a bit busy and I’ve got help coming in and I’m just managing, but what does Carers Matter do? And, she said, well, what do you need? And I said, well, I don’t know what you do. I don’t know what I need, and it was a very brief phone call.”
[Caring for partner with Parkinson’s]

The varied experience of carers in their contact with Carers Matter suggests there is considerable difference in the skills and approaches of different carer practitioners or coordinators. There is an element of happenstance in encountering the person who can understand a carer’s needs and ask the right questions to explore what support might be most valuable. In the absence of active listening skills and constructive engagement, there are missed opportunities to identify what matters and support carers accordingly. This carer commented:

I think it would have been nice if they phoned me to say we're still here. If they'd asked me how things were going at the moment, I would have been able to explain the situation and they may have been able to detect something that they could help with. [Caring for partner with Parkinson's]

Practical needs can often be responded to relatively easily and quickly, and we commented positively in our interim report on the value of providing practical and immediate help with household items and via Health and Wellbeing grants to enable carers to access leisure facilities or activities for example, and support with digital connectivity. Similarly, the Service provided invaluable help in supporting carers with benefits applications (Carers Allowance; Attendance Allowance; PIP; Blue Badge etc), and in OT referrals for equipment and adaptations. Our wider analysis of case files once again supported this finding.

Good assessments that were outcomes focused and addressed carer's needs, interests and aspirations focused on 'what matters' to carers. Examples of where supporting carers' wellbeing was addressed included:

- Support for carer to pursue interest in gardening.
- Support for sports and exercise class participation and membership.
- Support with costs of leisure activities.
- Replacement care to enable carer to pursue hobbies.
- Access to Spa treatments or massages as stress relief.
- Referrals for counselling sessions.
- Bereavement support.
- Referrals to peer support (including Carers Cuppa).
- Support with driving lessons to increase independence and ease of transport.
- Support with accessing motability scheme.
- Training in use of IT and digital technology.
- Help with managing home and garden demands.
- Support with overnight or longer break away from caring demands.
- Dog walking support.

Our interviews with carers provided further insight on the importance of the right help at the right time, and carers reflected on the – mainly positive – help they had received from the Service, often contrasting this with the lack of help they had been offered elsewhere. Carers' experiences of support from the Service were also important in recognising and valuing their carer identity. As this carer commented:

I just feel so grateful to them because they have been there, I have felt seen and heard by them. (...) that's all people want, isn't it, to feel that somebody gets them and they're hearing what you're saying." [Caring for partner with mental health needs]

And as another observed:

Everything helps at this stage. [the Service] organised some counselling for me, I'd gone through the NHS seeking some psychological support because I could feel I needed it. And they said, basically I didn't meet the threshold. (...) Carers Matter have found or have sourced 12 sessions of counselling for me." [Caring for adult children with mental health needs]

Being treated as the focus for support was also a welcome and often unfamiliar experience for carers who were more accustomed to services and support being directed to the person they cared for:

I just couldn't cope with anything. So, to have an organisation come in that was supporting me and really just me, but ultimately has a knock on effect for everyone else. I can't care in the way that I want to if I'm not looked after either." [Caring for partner with mental health needs, 2022-23]

And:

It made a big difference for me because it gave me a space to talk about how I was feeling to somebody. Just somebody there for me to talk to that doesn't have any judgement or doesn't have an agenda. (...) They helped us with information around PIP payments, and making sure we were getting the right benefits that we should be getting. (...) I felt like somebody was validating how I was feeling [Caring for partner with mental health needs]

As other carers commented, being treated as important and valued made a big difference:

What changed for me? First of all, I felt cared about (...) I felt that someone was really on my side, if you like. They were in my corner, and that's made a tremendous difference to my attitude to life. [Caring for partner with MS]

And

But they were patient and never pushed. You know they would call periodically and having that check-in would be the thing that I needed. (...) I felt really validated." [Caring for relative with learning disabilities]

6.1.3.3. Support services focus on building resilience and sustainability

To what extent support was focused on building carers' resilience and sustaining them in their role revealed a mixed picture. In our interim report we identified that most support was not focused in this way, or the evidence was partial; in only about

a fifth of cases was support directed towards developing resilience and sustainability. Our analysis of the larger case file sample in year three found a similar situation, with more than 60% of files not supporting this, or doing so partially, while just over 27% *did* provide positive evidence that support was directed at building resilience and sustainability of carers. This finding might seem to contradict some of our other findings reported above where carer support appeared to be relatively strengths-based, timely and well-tailored to their needs. However, we conclude that the support is often insufficient in quantity or duration to enable carers to build their capacity and resilience, and this story was evident both in the case files and from our interviews.

Time and again we found support for carers that might address their immediate or practical needs but did not address underlying issues around ongoing stress and the unremitting demands of caring. Where carers were coping – as they often were – with the intensifying needs of a cared for person, the growing pressures were often not addressed by ongoing support. The interventions that carers valued highly – in particular the chance to have a break from the regular demands of caring – often appeared to be offered on a sporadic or unpredictable basis. A carer who had benefited from three massage sessions commented on their value but was aware that this support was not continuing:

No, they haven't got enough funding for that. So it's just kind of I think once a year you can apply or something like that. And then anyone who hasn't had it before gets priority." [Caring for parent with mental health and additional medical needs]

Another carer also commented on the value of having a 'day out' to look forward to, but this was some months into the future and it had required some initiative from the carer to seek out the opportunity:

I contacted [the Service] because they had mentioned you could go for a spa day or you could go for afternoon tea or something like that. So myself and a friend, we're going for a spa day and they've organised a voucher that's been paid for. Which is lovely." [Caring for partner with mental health needs]

Such opportunities are indeed welcome and can be beneficial, but it is unclear how much difference they make to carers where the ongoing daily demands are unchanging (or intensifying), and where the possibility of another break in the future is uncertain. Another carer had made use of 6 breaks provided through replacement care but was aware that this was ending:

So the carer breaks are brilliant. One more session there and then they go; they turn into a pumpkin! [Caring for relative with learning disabilities]

Furthermore, where carers are encouraged to prioritise their wellbeing and to engage with opportunities such as Carers Cuppa, or to follow up on signposting, the emphasis on the carer sorting things out for themselves is often unhelpful for people already feeling overwhelmed by their situation.

Financial help can also be important to some carers struggling with costs and worried about austerity pressures, and again there seemed to be a random element to how such support was distributed. This carer commented:

And they got me £250 towards our gas and electricity because [my partner] was cold all the time; we had the heating up full whack day and night, and that was not cheap. And they got me £100 worth of Tesco vouchers. [Caring for partner with chronic illness]

And another reported a similar experience:

Last Christmas, I suddenly got £100.00 of Tesco vouchers, I couldn't believe it. (...) That was the first time I'd actually got anything what I call physical from somebody. I'd had an awful lot of talk, and an awful lot of emails, and brochures and booklets, but not anything tangible. (...) And that really hit me because I thought, well, there is an organisation out there that will actually help. They understood. [Caring for partner with dementia]

Support for carers' resilience was also evident in less tangible ways, and particularly in the quality of the contact with the Service, or with a particular Family Carer Practitioner. Keeping regular contact with a carer could be invaluable in supporting carers and avoiding crises arising. Comments from carers we interviewed underlined the value they attached to such interaction:

They send me a text message probably if not every week, every other week, and just ask how I'm doing." [Caring for partner with mental health needs]

And they've been really helpful if I need to unload, I feel comfortable enough (...) around them. But then also knowing that if I need help with referral they'll help me fill out the forms and use the right kind of buzzwords and be really professional about it. [Caring for parent with mental health and additional medical needs]

Very, very caring. They made me feel that they cared about me and were concerned about me, wanting to help me. [Caring for partner with MS]

However, other carers reported a less positive experience, for example:

[the Service] did keep in touch with me, but not as often as I would have liked. I did have to chase them a couple of times and say, have you forgotten me because they said something and it hadn't materialised. [Caring for partner with chronic illness]

This carer also commented on feeling 'abandoned' by the Service when the person they cared for died and they were no longer a carer:

I know the words, 'Carers Matter' but I was literally not a carer as soon as [husband] died, I was literally no longer a carer. Those two words together, 'Carers Matter', mean that as a carer, as an ex-carer even, as a bereaved carer, I should have mattered. I did speak to [the Service] and I said to them because they'd managed to secure some funding for me to have some bereavement counselling but I've not heard a word." [Caring for partner with chronic illness]

In our interim report we had also highlighted the importance of ongoing support for carers following the end of an intensive period of caring – whether that ended with the cared for person needing to move into permanent residential care, or with bereavement of the carer. We recognise that this is not within the contractual requirements of the carer offer, but we would emphasise the importance of continuing to provide a tapering amount of support to carers following the ending of their caring commitment. It is likely that this would enhance people's wellbeing and support former carers in processing grief and loss.

6.1.3.4. Support for carer and cared for person is well co-ordinated

It was often difficult – or impossible – to determine from the case files whether the cared for person was being supported by social care services, and if so how well this took account of the needs of the carer. As we have reported above, we examined a matched sample of the Council case files in an attempt to explore this in more depth. We found evidence that Council and carer support from the Service were not well coordinated, and this could have a negative impact on the support for carers.

Information about any services provided to the cared for person was based on carers' knowledge and recollection, but there was frequent confusion about whether the support was provided through the local authority (even if delivered by an independent care provider), by the NHS (e.g. mental health) or if services were arranged and paid for by the household themselves (self-funders). We identified 15 people (9%) who were likely to be paying for their own support which ranged from cleaning and domestic help to support with personal care. Other people who anticipated that they would be classed as self-funding if they were assessed by the local authority, were sometimes avoiding using services because of affordability concerns. In just under 5% of cases (n=7) we noted that carers/care recipients were refusing care and support even though there was a clear need - assessed or stated. Typically, this was because the family or the cared for person did not want external

care or “strangers” coming into the family home or providing them with personal care, or because they thought they were able to cope with the situation at present.

On some occasions there had been a history of receiving services, but this had stopped following a refusal to have further support either by the cared for person or carer. Eight such refusals (5% of cases) were recorded. In other situations, the cared for person was awaiting support and had been assessed as eligible but no care provider was available to deliver the support.

Interviews with carers also shed further light on some of the experiences of receiving support, and the difficulties of being on waiting lists for support for the cared for person, for example this carer supporting a partner with mental health needs explained:

I ended up making complaints (...) he was finally allocated a care coordinator with the community team. So we waited 18 months for that and I had a couple more conversations around support for me, but again it didn't materialise.”
[Caring for partner with mental health needs]

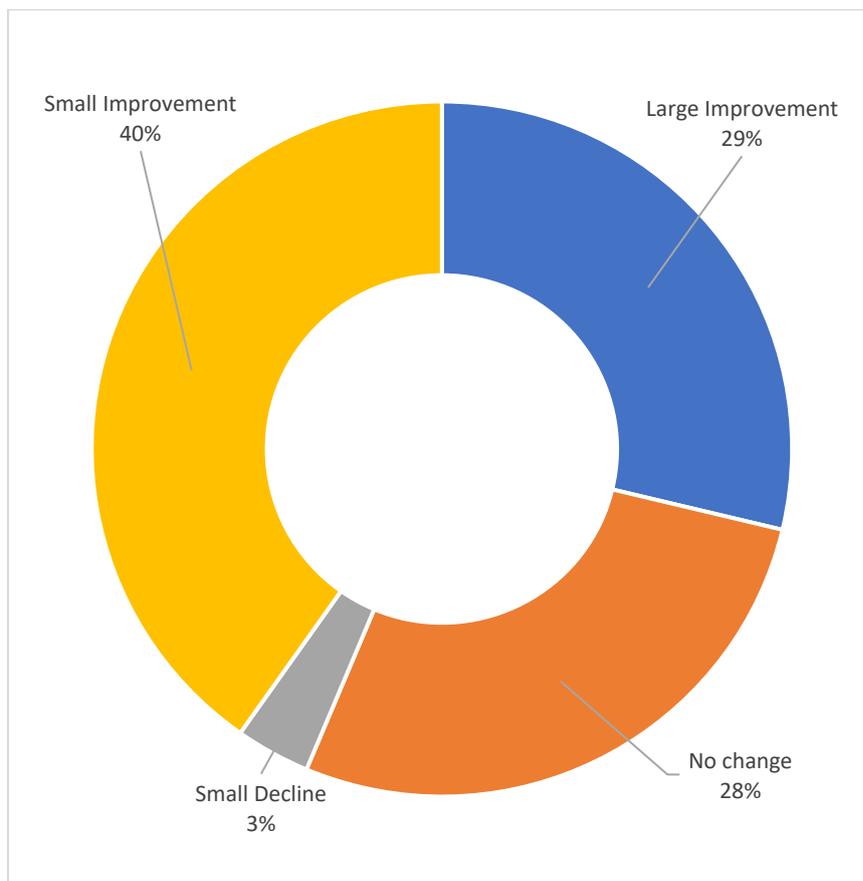
One indicator of the poor coordination of support for the cared for person and the carer was indirectly visible in the journeys that people sometimes took to get access to the Service. Interviews with carers told of circuitous routes and happenstance in arriving with the Service rather than a clear referral route arising from the person they cared for receiving an assessment and support, and the existence and needs of a carer being identified at that point in time.

6.1.4. Impact and benefit of support from the Carers' Service

Quantifying the impact and benefit of the support received is a complex question and we need to interpret the data with care because we were unable to test for statistical significance owing to small numbers. However, some promising findings, and noteworthy relationships between carer wellbeing and support can be identified.

One measure of change over time is that used by the Service themselves: the ‘Carer Star’ assessment tool. Analysis of carers’ action and review star scores⁶ indicated that almost 29% of carers experienced a large improvement in their scores (which we have defined as an increase of more than 5 points). The same proportion experienced no change in their scores between initial assessment and star review. Nearly two-fifths experienced a small improvement (2 to 5 points). While a little over 3% demonstrated a small drop in their scores.

⁶ We focused on the difference between first and second scores because these were available for most carers and were more likely done collaboratively.

Figure 7: Carers star scores, change over time

Average scores changed from 22 to 25 (star scores can potentially range from 5 to 40, higher scores indicating better wellbeing). The average of star scores across all carers was 22, and 25 at review, but there were differences between different groups of carers:

- Carers supporting people whose main need was a learning disability had the lowest average starting scores (17), but showed the greatest average improvement of 6 points (24).
- Carers supporting people with a main need around dementia had average starting scores of 21, and an improvement to 25; the same pattern was apparent for carers of people with mental health needs.
- Carers of people whose main need was autism, had higher average starting scores of 23 and an improvement of 2 points to 25. Carers of people whose main need was physical disability demonstrated the same pattern.
- Carers of people whose main needs were frailty due to age had the highest average starting scores (25), but small average improvements (28). This group of carers was the least likely to show large improvements, and one of the most likely to experience no change over time.

We can also look at changes in average Carer Star scores against whether the cared for person received support:

- There was an *inverse relationship* between a large score improvement and receipt of services; 41% of carers where the person *was not receiving support* recorded large improvements, compared with 24% of those where support *was* provided.
- Carers of people not receiving services were also more likely to show no improvement (38%) compared with those receiving support (27%).
- Where the cared for person *was* receiving support, carers were more likely to show a small improvement (46%) compared to those who were not receiving support (22%).

Furthermore, carers of people who started receiving care and support during contact with the Service reported a slightly larger average increase from a lower starting score (20 to 24), meanwhile “refusers” of care and support had a higher starting score but reported smaller increases (22 to 24). However, the small numbers and the lack of statistical significance must be noted here.

Carers Star scores do not seem to predict the breakdown of the caring relationship

These findings might seem surprising or counterintuitive, but it is likely that people who *were* receiving social care support had more intensive or complex needs than those who did not. Support directed towards carers of people with lower level needs might be expected to be able to make a greater contribution to improving their wellbeing than in situations where the carer was already under considerable strain.

6.1.5. Carers matter Norfolk support and impact on carer breakdown

One of the key objectives of our evaluation was to test and validate the hypothesis that increasing the wellbeing of carers results in them being more able to sustain their caring role, and reduces the likelihood of ‘carer breakdown’ (i.e. the carer is no longer caring for the person at home). In the course of their assessment, carers – almost without exception – expressed their willingness to continue caring if at all possible, although many included the caveat that they needed support to do so. Just two carers in the case file sample indicated they were no longer willing to care and were overwhelmed by the long-term demands they were coping with, their circumstances (such as unsuitable housing and the impact of Covid-19 pandemic lockdowns) and the lack of support for the cared for person. Willingness to continue caring was unclear with a small number of case files, but overall 95.5% indicated a willingness to continue.

95%
of carers willing to
continue caring

Such aspirations were also largely matched in practice:

- At the six month sustainment check 11 (almost 8%) of carers were no longer caring.
- At the 12 month sustainment check another eight carers were no longer caring.

These are defined by the Service as 'carer breakdown', but of this total of 19 carers no longer caring after 12 months, the majority of 'breakdowns' were the result of unavoidable circumstances:

- Eight (42%) were due to the death of the cared for person.
- Six (32%) were due to the deterioration of the physical/mental health of the cared for person.
- Three (16%) were for the potentially avoidable reason of deterioration in the relationship between carer and cared for,
- And in two cases the breakdown was categorised as "other" or unclear reason.

Furthermore, the 'breakdown' of the caring relationship was not reflected in or predicted by deteriorating carer star scores. Carers who were no longer caring at 12 months had average scores of 21.9 and 25.7 at review. These were the same as for those who were still caring (21.7 average initial score and 25.1 at review).

6.2. Conclusion from the case file analysis and carer interviews

In this section we have drawn together our findings from analysis of the Service's case files and qualitative interviews with a small sample of carers. We revisited our year one sample of 66 case files, as well as undertaking additional analysis of a further sample of 100 case files in year three.

The distinction between different levels of assessment for carers is made at an early stage and determines whether they progress from triage to Assessment A and Assessment B (where the Carers Star is utilised). This requires a judgement to be made at an early stage of contact with the carer regarding their likely needs and whether these are low level (information and advice only) or require additional support. This can lead to premature and inappropriate decisions to offer signposting alone which is insufficient to meet needs of some carers. This was reinforced in reflections from interviews where carers drew attention to being signposted and told to come back if they needed to, when they had wanted additional help from the outset. As we have also highlighted, reliance on signposting puts considerable focus on carers taking the initiative and having the energy to pursue information for themselves, when they may be ill equipped to do so. The Service is able to provide a good quality information and advice service to carers who are able to follow up on links and signposting and who have relatively straightforward needs for resources. Whether carers with additional needs get the tailored support they need that is timely and sufficient depends to a considerable extent on the ability of the carer to identify and articulate their needs, and on the skills of individual Carer Practitioners in appropriately responding to these. There is a considerable element of happenstance in whether these circumstances align.

Organisational and system changes introduced by the Service, including changes in the approach to assessment, have the potential to be more person-centred and strengths-based, enabling the carer to tell their story (without having to repeat it at different stages of the process) and identify what matters to them and where they need most support.

The value of the Service in supporting carers – particularly around practical help, or breaks from caring – was underlined in interviews. It was also clear that carers' experience of the Service was often the first time they had felt listened to or supported in their own right. In both years we found positive examples, but we also highlighted the difficulties for carers where such support was short-term or intermittent, and where there was no continued pattern of support. The short-term nature of carer breaks, or exceptional arrangements being made for specific needs of the carer (such as attending their own medical appointments), rather than having a regular and reliable pattern of support, is a clear limitation in the level and duration of support. The closure of support at the end of an action plan signifies that the objectives of the plan have been delivered; it does not indicate that the carer has no ongoing needs for support. The re-referral of carers to the service is one indicator of continuing needs requiring ongoing support.

Positive changes in carers' wellbeing as recorded on the Carers Star provide a tangible indicator of impact. The most common pattern in our combined case file analysis was for carers to experience a small improvement (between 2 and 5 points), which was the experience of 39%. Almost 29% experienced a large increase in scores (more than 5 points), while the same proportion experienced no change between initial assessment and review. Carers who showed the largest increases in scores were more likely to be supporting a person who was not receiving adult social care support. This is likely to reflect lower level needs where support with wellbeing could make a greater contribution than for carers already coping with higher levels of intensity and complexity. However, we have also identified some risk of potential subjective bias in various case notes, where practitioners might have influenced carer's self-rated wellbeing – consciously or subconsciously – or where Outcome Star 3 scores were completed by practitioners after, rather than contemporaneously during a conversation with the carer, or where there was dissonance between the carer's self-rated score, and that rated by the assessor. Therefore, further analysis and quality checks by the commissioner would be recommended to minimise potential bias in the administration of the Carers Outcome Star.

The assumption that carer support would have a significant impact in reducing the incidence of carer breakdown was not supported by our findings. More than 95% of carers continued to indicate their willingness to care, although this was often conditional on being supported to do so. Breakdown of care – or situations where the carer was no longer caring at the time of 6 or 12 month sustainment checks was very rare. The great majority of these situations were due to unavoidable circumstances – either the death of the cared for person, or substantial deterioration in their condition necessitating permanent residential care. We identified only three cases where there was a potentially avoidable situation where caring finished because of a breakdown in the relationship. All caring takes place within the context of a relationship and the circumstances and history of that relationship will mean that for some there are limits to what can be expected and a point at which 'breakdown' is both predictable and the best outcome. In very few cases it is possible that additional support would have enabled the carer to sustain their relationship for longer, but at significant emotional and psychological cost. It was also clear from our findings that wellbeing scores on the Carers Star did not provide an indicator of risk of carer breakdown.

7. Findings on professional stakeholder views

This section presents the findings on professional stakeholders' awareness and perceptions of the Service based on a survey of referring professionals and interviews with senior leaders from the Council and the Service's partner organisations.

7.1. Survey of referring professionals

The [survey](#) was conducted during June and July 2023. The invitation with the survey link was distributed by the Council and the Service to relevant professionals and voluntary sector organisations. In total, 62 responses were received: 50 were complete and 12 were partial responses (this will be reflected in the varied number of responses for specific questions).

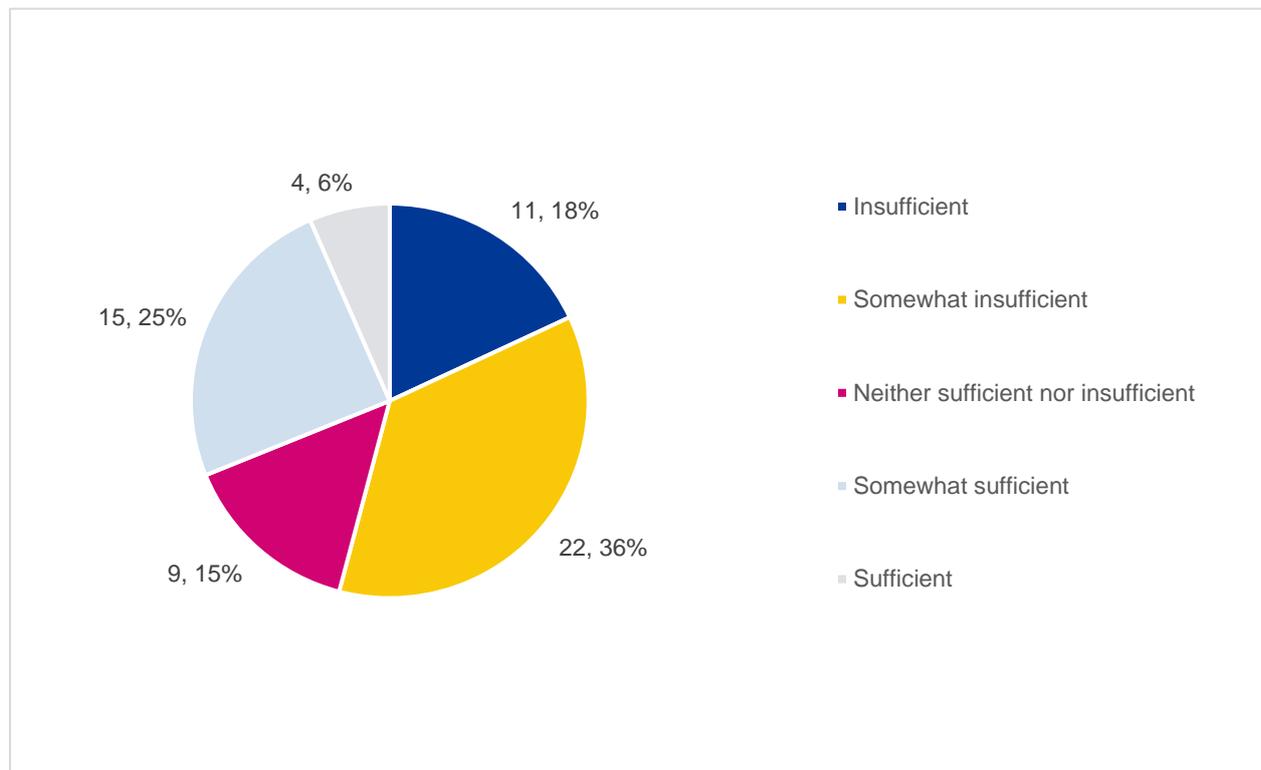
The majority of responses came from professionals working for the Council (71%), and only two responses were received from professionals working for one of the seven district councils in Norfolk. Twelve responses came from voluntary and community sector organisations (19%) and four (7%) from the NHS. Respondents were spread across Norfolk, covering all seven districts as well as the county as a whole.

About a third of respondents (n=19) described their role as assistant practitioner, nine people (15%) were social workers, five occupational therapists (or OT managers), five integrated care coordinators and four service managers. The remainder included varied roles such as dementia advisor, nurse, community connector, CEO of VCSE organisation, and support worker.

7.1.1. Availability of support for unpaid carers

The first part of the questionnaire asked about respondents' views on the general availability of support for unpaid carers in Norfolk. The majority felt that this was insufficient or somewhat insufficient, however, about a third believed it sufficient (see Figure 8).

Figure 8: Respondents’ rating of availability of support for unpaid carers (n=61)



Respondents were given the opportunity to identify the key gaps that they had noticed in support for unpaid carers through a free text response. Responses have been summarised into themes, the frequency indicating the number of mentions related to particular themes (see Table 18). The two most commonly mentioned issues were lack of knowledge and awareness of what is available and lack of local respite care options (supply). Identification of carers and financial advice and support were also in the top 5 themes.

Table 18: What (if any) are the main gaps in support for unpaid carers?

What are the main gaps in the availability of support?	Number of mentions
Awareness of what support is available and how to access it	16
Lack of local respite care options (including daycare, overnight, ad hoc respite e.g. when unpaid carer has an appointment themselves)	16
Timely identification of unpaid carers and then easy, timely access to support	9
Sufficient financial support with caring e.g., to pay for paid carers, unpaid carer organizations	6

What are the main gaps in the availability of support?	Number of mentions
Financial advice/guidance specific to unpaid carers (e.g., benefits, attendance allowance, employment)	6
Limited access to support in most areas of the County/inconsistent provision	4
Face to face and practical support for unpaid carers (e.g., form filling)	4
Carer's Assessment - capacity to undertake and raise awareness of them	4
Availability of carer support groups	4
Lack of affordable care or support	3
Support for unpaid carers of children/young people with additional needs, support for parent carers	3
Support specifically for carers of people with mental health conditions or addiction	2
Lack of volunteer support	2
Mental health support for unpaid carers	1
Care packages that are sufficient for the needs of the cared-for individual	1

65%

of professional referrers thought that lack of availability of support for carers **had a negative impact on their service**

Respondents were also asked to consider whether the availability (or lack) of support for unpaid carers had an impact on their organisation. Two thirds (65%) of respondents believed that limited availability of support for carers had a negative impact, with further detail provided in free text responses. A number of respondents mentioned the impact on the carer's health and access to NHS treatments, highlighting:

they need to be able to attend appointments and be assured that if they need treatment there will be someone available to step in.

I have had a carer who was taken off a NHS waiting list for surgery because she could not guarantee she could get care for her husband when needed and could not leave him alone.

Radiotherapy treatments involve daily attendance for 1-6 weeks, depending on cancer type/treatment and patients will often get fatigued and have other side effects but they still have to provide full time care and therefore do not have time to look after themselves sufficiently. This will negatively impact on the patient's recovery time and ability to adhere to advice given by our team.

Others mentioned the increased risk of carer breakdown and the situation escalating into a crisis requiring urgent admission to residential care:

Quite often the referrals we receive are when carers who have reached crisis point without support and have to approach for intervention which requires an immediate large response, which can be challenging for the cared for, rather than more measured increase in support.

One respondent highlighted that although carer support was beneficial for carers, it made little or no difference to demands on the county council.

Meanwhile others thought that that the role of Carers Matter Norfolk had a positive impact through creating a more streamlined pathway for carers, which also has the potential to free up practitioners' time:

The Service is great to signpost carers to. It is useful that it is always there as a resource and can free up practitioner's time where they would otherwise be carrying out carer's assessment. It prevents burnout and signposts various sources of support.

In relation to the benefits of supporting unpaid carers in general, the most commonly mentioned benefit was its the impact on systems – social care and the NHS – and potentially easing pressures on these. However, a similar number of (combined) responses considered the individual outcomes and impact on wellbeing for both carers and cared for people (Table 19).

Table 19: What are the benefits of supporting unpaid carers?

Benefits of supporting unpaid carers	Number of mentions
Alleviates pressure/cost on the social care system and/or NHS	24
Individuals stay at home/can be cared for by family and friends, familiarity is beneficial	14
Carers feel valued and supported, and consider their own health and wellbeing	14

Benefits of supporting unpaid carers	Number of mentions
Unpaid carers feel able to continue providing care for longer	12
Avoids carer breakdown/crisis, and emergency placements/packages being needed	12
Allows carers to access practical support and information when needed	3
Increases the support network around unpaid carers and those they care for	1
Carer and individual cared for become known and understood by local services	1
Allows unpaid carers to access financial support	1

7.1.2. Awareness of the Service and other support for unpaid carers

The second part of the survey asked about respondents' awareness and experiences with the Service. All but one respondent were familiar with the Service⁷ and 72% (n=43) had referred or recommended the Service to an unpaid carer in the past 12 months.

Depending on whether they made any referrals or signposted carers, respondents were shown two different sets of questions. Those who had not made a referral were asked about their general understanding of the service. Those who had made a referral were asked about their general understanding of the service, as well as their views and experiences with the Service.

7.1.2.1. Respondents WHO HAD NOT made a referral / recommendation in the past 12 months (n=15)

The majority of respondents who had not made a referral / recommendation in the last year reported a good awareness and understanding of eligibility and scope, and expressed no concerns about referrals to the Service. One respondent commented that their "*understanding from family members, the Service are absolutely brilliant*".

However, some gaps were highlighted in relation to understanding the division of responsibilities between the Council and the Service in relation to carer assessments, which was also mentioned in free text responses.

⁷ Due to the self-selecting sample of survey respondents, this figure should not be generalised to indicate general awareness of Carers Matter Norfolk among all professionals in Norfolk.

I am still a bit confused so to explain it to clients without going investigating is difficult.

Unsure how they [the Council and the Service] are linked from a corporate viewpoint. Is Carers Matter purely voluntary? If not where does their funding come from? Are they completely separate from the Council?

I think it's always important to offer this but I would like more knowledge of what concrete support they could give. Do they offer training?

When asked whether they felt that, currently, unpaid carers are aware of where they can access help as a carer for their caring role or wellbeing, most respondents (n=13; 87%) felt this was not the case.

7.1.2.2. Respondents WHO HAD made a referral / recommendation in the past 12 months (n=43)

In contrast to those who had not made recent referrals, those with more recent experiences were more likely to report good awareness of the distinction between the Council and Service responsibilities in relation to carers: more than half were completely or very aware; however, 21% still said they were not so or not at all aware.

Some comments where respondents were not so aware of the differences were also illustrative of the wider challenge of offering holistic (whole-family) support to carers and the people they support in a system that is not fully joined-up.

Referrals usually come back from Carers Matters Norfolk to say the situation is "too complex".

I tried to refer on our internal system requesting carers support and was told we can't do that. We have to ask client to make contact with Carers Matter.

Difficult to know which one [i.e. Service or the Council] to approach in the circumstances, especially as support is needed quickly.

The respondents who had referred / recommended in the past 12 months were also asked about their perspective on carers' awareness of the support available to them. Similarly, to those who had not referred to Carers Matter Norfolk, the majority thought that unpaid carers were not aware of available help (n=36; 88%) and only 10% (n=4) said they were.

7.1.3. Professionals' views about the quality of support offered by the Service

Respondents who had made a referral or recommended the Service in the past 12 months (n=42) were asked about their experiences and the (potential or perceived) impacts of the support on the people they referred.

A common observation was that referrers have limited knowledge and insight into the quality and suitability of support to carers. Feedback from carers was mostly gained informally via conversations, only one organisation reported the use of a validated/formalised tool to measure carer wellbeing.

Another key reflection on the service is the variability of experiences – both carers' and referrers' – and how well the Service responds to diverse needs. Those respondents who had some insight into the service, reported at least some positive experiences and impacts.

When asked to consider the features that are most impactful in relation to improving carers' wellbeing (Table 20) and maintaining their caring role (Table 21), similar themes were highlighted: financial information and signposting, the relational aspects of support, and helping carers to navigate the complex systems of health and adult social care.

Table 20: Features that help carers to improve their wellbeing

Themes/categories	Number of mentions
Financial advice/support	5
Helping carers open up about issues, providing empathy (emotional support)	4
Respite/sitting service	4
Providing information on sources of support, including support groups	3
Practical advice/support	2

Table 21: Features that help carers to maintain their caring role

Themes/categories	Number of mentions
Helping carers open up about issues, providing empathy (emotional support)	5
Providing information on sources of support, including support groups and advice in how to navigate fragmented services	6
Financial advice/support e.g., helping with benefits forms	3

7.1.4. Reaching unpaid carers: what works well and what could improve

All (n=62) respondents were asked to identify up to five features of the Service that "worked well" in reaching a diverse group of carers, including those previously

unidentified. Responses were summarised thematically (see Table 22). The most frequently mentioned feature was the fact that the Service is easily contactable via a range of channels and carers can access support in a format most convenient for them.

Table 22: Features that work well in reaching diverse groups

Themes/categories	Number of mentions
Range of channels to access the service and receive support, including website, telephone Advice line, email support, leaflets	7
Emotional support (including counselling)	5
Providing information on support available and signposting	5
Financial support (Health and Wellbeing Fund)	4
Practical support e.g., form filling, planning	2
Professional, effective service	2
Assessment and support tailored to carer's situation	2
Connecting with local support groups	2
Publishing a Carer's Handbook	2

Respondents were also asked to identify a number of areas where changes could be made to reach more carers including those from diverse backgrounds. Here, the most mentioned features were targeted outreach including those often described as “hard-to-reach” as well as making the service more accessible for carers with communication difficulties or those less able to use technology (see Table 23).

Table 23: Features that could improve to reach diverse groups

Themes/categories	Number of mentions
Quicker responses to contacts from carers and referrals	3
Considering/targeting diverse groups in the community and specific client groups who might include hard-to-reach carers	3
Advertising more widely, attending community events	3
Supporting Peer Groups/Carer Groups	2
Editing referral form e.g., so it does not require an email address	2

Themes/categories	Number of mentions
Working with other professionals, sharing assessments	2
Considering diversity within the Service as an organization, including within the workforce and in their policies/procedures	2

7.1.5. What has changed for carers

The concluding question of the survey asked all respondents (n=62) to share any further thoughts or feedback regarding the support available to carers, the current situation of unpaid carers, and how this has changed since the implementation of the new carers' service in Norfolk (in 2020). Responses (n=18) highlighted:

- Despite some progress, there is still insufficient recognition and support for unpaid carers: The contribution of unpaid carers are not yet adequately recognized or valued. The hoops they have to go through to access support are inadequate and demoralising for many.
- Challenges faced by unpaid carers: Carers face various challenges, such as the lack of access to respite services, affordable transport in rural areas, and difficulty in accessing the carers assessment process. The unavailability of respite services due to crisis cases or home closures adds to these challenges and the risk of breakdown, as well as a negative impact on carers' health and well-being.
- Need for better communication and support: improved communication between services and agencies is crucial to make it easier for carers to access the support they require. The lack of communication and awareness between agencies and carers contributes to a sense of neglect and frustration. Communication from the Service to other services about assessment outcomes/plans would also be helpful.
- Importance of co-production and transparency: the importance of involving carers in the decision-making process and service design, ensuring transparency and meaningful co-production. The involvement of carers in service design and governance is crucial to providing effective and relevant support. Although the Service has made real improvements in provision, "demonstrable co-production appears to have reduced".
- Positive impact of existing support services: despite the challenges, there is 'anecdotal' evidence that many carers find the support provided by the Service helpful and valuable.

7.1.6. Conclusions from the professionals' survey

The survey repeated the questions of the first professional survey conducted in early 2022. While the first survey was mostly circulated by the Service, the second survey was shared by the Council to a larger and more diverse group of professionals. Nevertheless, the key findings and conclusions are similar:

- The Service responds to a clear demand: it is an established service but more could be done to raise awareness of the support offered among partner agencies and carers.
- There is scope for more seamless collaboration and joined-up / joint working with other agencies to improve outcomes for unpaid carers and the people they support. Information sharing, especially between the Service and the Council but also other partners are key areas to improve both the efficiency and the impact of the service.
- The Service is viewed positively, most professionals recognise and value its services. Compared to the first survey, fewer respondents highlighted waiting times reflecting a clear improvement in this area.

7.2. Interviews with professional stakeholders

Alongside the survey, further qualitative insights were gained from [semi-structured interviews](#) with senior stakeholders. These interviews took place in 2023 with leaders from within the Council adult social care (n=5) and with partner organisations (n=2). Interviews were digitally recorded, transcribed and thematically analysed using NVivo software. The reflections of senior stakeholders can be viewed alongside those captured in the professional survey, and they provide more qualitative depth in offering perceptions and understanding of the role and contribution of the Service to supporting carers in Norfolk. We do not identify individual interviewees, but quotes are attributed to Council leaders by the designation of 'L' and numbered 1 to 5. While those with partner organisations are labelled 'P' and numbered 1 to 2.

Our thematic analysis highlighted the four key areas that are discussed in more detail in the rest of this section:

1. Understanding carers' needs, including the differential needs and experiences of carers of different client groups.
2. The contribution made by the Service to supporting carers.
3. Model of carer support offered by the Service.
4. Relationship or coordination between the Service and the Council.

7.2.1. Understanding carers' needs

The offer for carers in Norfolk reflects the wider context within which caring is understood, how the statutory requirements of the Care Act are interpreted, and the core objectives of providing support. It is important to acknowledge that the social impact bond and Norfolk Carers Partnership was developed as a deliberate strategy to address what was recognised to be a historically poor response to carers in the County, as this comment makes clear:

I'll be very honest with you. I arrived in this place and I was just utterly shocked at how rubbish we were with carers (...) I thought we were absolutely rubbish and needed to do something quite radical. [L1]

In terms of the numbers of carers who are being identified and have contact with a service, there has been a significant improvement. At the same time, however, it was also recognised that the prime focus needed to be on carers under the greatest pressure, especially those providing in excess of 50 hours care each week, for whom caring has a major impact on their lives and choices.

Such outreach would need to include, for example, more work with GPs and with the health service to improve the early identification of carers. This interviewee commented on the challenges in reaching the right carers:

I suspect we do miss people yes, but then equally it's difficult because the other side of that is, are we the right service for those people, because actually we're supposed to take the people we can maintain the caring relationship for, and actually the more complex cases sit with the Local Authority. [P2]

This also raises major questions around trade-offs between breadth and depth. The carer population in the County is substantial, and all carers have some needs and entitlements under the Care Act, but offering an equitable response to all is not possible beyond a certain basic foundation, primarily consisting of information and advice:

If you're going to provide any service at all, the only real, mass market kind of approach you can offer is information and advice and that has to be via phone and digital approaches, you just don't have enough staffing in that space to really hit a substantial quantity of people. [L1]

Information *is* vital, whether that is about other services and resources, or about how to lift or move someone safely, the nature of needs associated with specific conditions (such as dementia), or advice about access to community facilities and whether there is wheelchair access. Information and advice is most likely to have an impact when provided early:

It's about providing all that information and advice that affects someone's whole life. So it could be around housing, it could be around money (...). If we get that early information, you can help link people with services they need to reduce the other stresses, which helps them keep coping in their caring role. [L3]

An interviewee commented on the need for better awareness raising both about caring in general, and about the role of the Service in supporting carers:

We're relying on people already knowing about us a lot and it's what you know (...). I think at the moment most of the carers that are coming through are professional [referrals], which for me feels like it's too far down the line. I think

we need to do a lot more at that kind of early stage where people don't necessarily realise they are carers, but actually they are. [P1]

The tensions and trade-offs between reaching more carers in Norfolk and broadening the offer that is made beyond information and advice were clearly acknowledged by leaders. One interviewee noted that compared to some other local authorities the response to carers might not appear very good, especially the limited availability of respite services.

However, there was some scepticism about the value of providing support through “tokenistic one-off gestures” where goods or services were paid for but with insufficient attention to understanding what this was intended to achieve. Although these might seem attractive, they cannot be scaled, thus their impact is likely limited.

The issue of scope and scale was particularly evident around respite. A relatively small number of carers can access contingency respite provision from the local authority; this is a costly resource and one which is hard to deliver when providers may also have insufficient residential capacity. How respite might be reimagined to benefit both carers and cared for is a central issue:

A lot of carers say the care that they receive [at residential respite] worries them, it's not bespoke, it's not personalised (...). Maybe we need a better offer which means we could give [respite] to more people by having a bespoke approach that's actually the cared for person doesn't leave their home. It's the carer who leaves the home [and has a] rest, holiday, visit relatives or the rest of things they might not have been able to do. [L1]

Ultimately, the role and purpose of carer support can only make so much difference as this partner acknowledged:

I think it's really hard. It's a hard service to provide because ultimately you can't take away the problem, can you? You can't stop them needing to be a carer. So I think what we do is we give them the tools to make that as easy as possible and it's never going to be easy, but actually if just knowing that there's support out there I think helps carers to feel like they're not alone and there's somebody out there they can turn to if they need it.” [P1]

The objective of working with carers to support them in their caring role also raises questions about the limits to expectations on carers and the importance of balancing best interests and well-being outcomes:

There are some people actually that it's not appropriate to maintain a caring role for whatever reason. It may be the behaviour of the cared for, the

complexity [of their needs] etc. It may be that it's not in the carer's best interests because of their health." [P2]

Finally, in addition to carers having some universal needs – such as for information and advice - it was also recognised that carers are a diverse group and their particular circumstances will vary enormously. Caring for people with different needs (e.g. learning disabilities, mental ill health etc.) also has implications for carers. Interviewees highlighted the particular challenges facing carers of people with mental health needs; carers of people in transition from children's to adults' services, and young carers, and how these are interlinked with the needs of those they support. This has significant implications for meeting carers' needs appropriately.

7.2.2. The contribution made by the Service to supporting carers

The Service was described as “a really important part of the mix” in ensuring that carers do get support and are “not just left to care” as one of the leaders described:

We do try and add value to families by connecting them into things, not just simply making a referral into Carers Matter or carrying out a carer's assessment and putting in a commissioned service, then that's it. We do try and think creatively and try and explore a range of different options and support. [L4]

The support offered by the Service was seen as valuable:

They put in place lots of useful things like their information and advice line, they have their Handbook. All these things are really useful and we regularly will refer to them and tell our families about all of this. [L4]

Interviewees also emphasised the value of less tangible elements of support from the Service, such as direct and personal contact with the Community Team:

“Sometimes with carers it's often about just having the opportunity to talk to somebody. That's often what they've told us in the past. It's just that opportunity to talk and unload and get somebody thinking about them (...). It may be that call back at some point later (...) and they're just touching base and they're keeping an eye just to say, how are you getting on?” [L2]

There is a time limit to support and Cares Matter Norfolk needs to close cases in order to keep the service open to other carers. However, it was also recognised that closure of cases should not happen if the actions on a plan have not been completed or resolved. Indeed, this is central to prevention:

That's what we would hope then stops that revolving door, and we should only see carers come back if (...) their needs have genuinely changed. [P1]

The introduction of the on-line self-assessment model for carers should not only speed up the process for carers and route them to the right part of the service, but should also enhance the person-centredness of assessment. The new approach has the potential to focus much more deliberately on the carer's situation:

"I think this new system is much better at leading us down that route of strengths-based, person-centred working, really looking at the needs of the carer and supporting those needs rather than what our process tells us to put them through. I think we're getting a lot better at that. We've had lots of training recently through the Local Authority about a strengths-based approach, writing really good action plans that are really clear and concise and, so definitely much better. I think it's a lot more proportionate now in terms of (...) the needs of the carer." [P1]

At the same time, however, it is possible that self-assessment requires considerable motivation and self-direction from carers who might be lacking in energy, or where their experience of trauma compounds their isolation, as this comment cautioned:

"In order to self-score yourself and fill in a form, you need to be relatively motivated. But if you have to be relatively motivated to get through the door then actually what you're doing is excluding the people that are perpetually excluded because generally they're not that motivated and that's not a criticism, that might be because of where they are, how much capacity they have, all that sort of thing." [P2]

7.2.3. Model of support

Having a specialist organisation assume responsibility for carers, including for statutory functions such as the provision of information and advice, and undertaking Carers Assessments, was seen as both a strength, but also – potentially – a weakness. On the one hand, there are benefits in the perceived independence, or arm's length nature, of the organisation:

I think there's also something about just having that slight separation, that independence, which is really helpful in some ways, (...) and I think possibly carers are reassured by the fact that it's separate from the Local Authority as well, that there's a level of independence." [L2]

This separation also gives some protection to the resources allocated to carers:

I suppose one of the other benefits, of course, is that you've got a dedicated staff, whereas if we have it back in the Council, it gets put in the pot with everything else. If it's outsourced, you can't control it in quite the same way and you can't move the resource to another pressure point in the service. [L2]

Another interviewee also remarked on the capacity that the Service created, and that having that available externally avoided the potential risk of carers becoming lost or overlooked because of capacity pressures within the Council. Furthermore, the Service offers greater expertise and specialism around carers, but although this is a positive feature, it could also mean that there is reduced carer-awareness within the Council:

Interviewees indicated a general awareness of the role of the Service. There was a general sense that what was offered was 'a good thing' but were relatively vague about any more substantive evidence of performance, which appeared to be largely anecdotal.

I've not had any team managers or practice consultants come back to me and say it doesn't work. (...) So I'm assuming it generally works when we do make the referrals. [L2]

Based on my understanding and sort of conversations with the team, I don't have any concerns around their ethos or of how they go about their work. [L4]

(...) we don't have any complaints about Carers Matter, but we also don't really know what work they are doing as they don't feed back (...) and a carer has said nothing comes out of it. We just get a few leaflets via e-mail. [L5]

This led some interviewees to the conclusion that there needed to be greater awareness about the Service's role and responsibilities, including more direct communication between teams and the Service.

One of our interviewees offered reflections on the particular model of commissioning that had been adopted for the carers' service in the form of a social impact bond (SIB). This was seen as a radical model that might offer a way of improving an historically poor offer for carers, as they described:

"But I do think that where the Service offers us something slightly different is why we went for the SIB and went for that approach was we felt that they could make an ongoing relationship with people, you know, by changing that phone approach by having that live intervention. We felt that actually there was a better chance of having a more realistic you drop in, drop out, drop in again as you need advice and information so it becomes a bit more of a you use when you need to use kind of thing or you need to check something out." [L1]

Although it was recognised that this was work in progress and “it’s got a way to go,” it was also believed that:

“The figures do suggest something. We’re doing something right. We’ve gone from around 1000 carers being assisted and aided to about five and a half thousand I think was the last figures the Service gave me, so we’ve seen an increase in people making contact and being assessed and receiving advice and information.” [L1]

Focusing on a foundation of information and advice as the key component to reach out to as many carers as possible appears to be successful. It is less clear, however, whether this is sufficient to offer the “protective and preventative approach” that is at the heart of the SIB and the business case developed by the Council.

The same interviewee commented that this is also a learning experience for the Service and that gradually over time they would expect that outcomes would improve, and “somehow or other it would save money”:

This act of faith in improvement over time suggests considerable confidence in the model and the capacity for it to evolve. What it doesn’t address is how to square the circle of breadth and depth of approach (and the tensions between those objectives), or what the organisation may need to develop this dual approach more deliberately. It seems likely that this would require a reconsideration of what ‘prevention’ means in carers services, and how that can be evidenced.

The SIB was always to save money and of course the only way you could really make a viable case that could save money is it’s got to hit as many potential carers as possible to have the biggest preventative effect. [...] We can all pull out the odd case and point to it and say look at that one; that’s saved us some cash, but you know, can you scale it up? Can you replicate it? And the chances are it’s very difficult to replicate some of those cases. [L1]

Another interviewee who was closely involved with auditing the Service performance described how they used data to identify training requirements in order to deliver practice improvements (such as around increased personalisation, or better risk assessment). They also commented positively on the substantial increase in activity, and the ‘vast improvements’ in numbers of people accessing information and advice, but contrasted this with the “pitiful amount of carers assessment and work with carers prior to their involvement” and questioned what this demonstrated:

So, we know that we’re seeing a lot more people with them, but also we need to think about you know, they may be seeing a lot of people, but is that actually effective? [L3]

Another important aspect of the model that interviewees remarked on was the flexibility and adaptability of the organisation, including rapid response to issues identified by monitoring and audit, and the ongoing professional development of staff (e.g. the establishment of 'Lunch and Learn' sessions where other agencies would be invited to share expertise and knowledge about specific issues, such as NHS Continuing Healthcare etc.).

The main thing for me is the responsiveness. If there's a quality thing then I can raise it and it just gets done and in the local authority systems that could take a very long time. [L3]

7.2.4. Relationship between the Service and the Council

As we have reported on in our analysis of both sets of case files, a lack of coordination was apparent between the two organisations. At the most basic level this could mean that neither was aware of the involvement of the other agency in supporting carers, quite apart from any attempt to achieve any joining up or overall coherence of support. These issues were also identified by some of our interviewees who were keen to avoid blaming others for difficulties and emphasised that "everyone is working the best they can in challenging circumstances." Nonetheless, as this comment highlights, there are some structural and legal barriers but also evidence of good working relationships:

I've been advocating for a long time for them to be able to have access to our case recording system, but there's lots of confidentiality reasons why that can't happen. (...) I have a direct link with Carers Matter and we have a good relationship in order to deal with those. So often she'll flag up to me and say we need to look at this safeguarding issue, or this particular case needs to come back to the Council because of X, Y and Z, and we agree those things between us and I'm obviously able to bridge the gap. [L3]

Workaround arrangements require conscious commitment from both sides and they cannot be fully effective because they rely on the quality of informal relationships, they do not allow individual practitioners to view relevant information; or delays are caused by waiting for permission to share information. The new IT system has therefore included the creation of a portal:

The Council employees can log onto the portal; they can share the relevant information in a safe space without breaching confidentiality of the case recording system. [L3]

The complexities of working in a truly holistic and joined-up way were highlighted by some participants, who commented on the difficulties of knowing what happened to carers in the absence of shared access to files or joint assessments:

So when you see an assessment for someone with a learning disability, you'll quite often see bits about the carer in that assessment, but we're not necessarily recording it separately [for the carer]. So you couldn't go into a carer's file necessarily and see what support they are getting [from the Council], but you might see it in the cared for person's file." [L5]

The same interviewee also commented on the importance of the Service needing to be up to date and familiar with strategic policy direction to avoid conflict of interest.

Another interviewee believed that things are 'sort of joined up' but there can be duplication or overlap of responsibilities, for example around carers assessments, and resultant confusion created by 'different stories.'

I guess where the Service have carried out an assessment, they've inevitably had conversations (...). which may not be lined up with conversations that we've had with the carers and therefore there's the potential for there to be some confusion. [L4]

This interviewee also acknowledged that there was probably more that could happen to improve communication between the social work team and the Service in looking at the needs of the cared for person and of the carer more holistically. They observed:

This conversation is making me think as well that there's all sorts of potential positives that could happen around the Service having more of a direct line at team level through the various things that we have, you know, reflective practice (...) Actually there is more we should be doing to make sure that we're joining up the work of Carers Matter with operational delivery. [L4]

The opportunities for widening the scope of reflective practice to include the Service with social work teams would seem to be an area worth exploring further.

7.2.5. Conclusions from interviews with professional stakeholders

The qualitative interviews undertaken with senior stakeholders provided a rich seam of insights and reflections. Perceptions of the role and contribution of the Service were overwhelmingly positive, although it was also apparent that this judgment was often made in the absence of robust evidence, but was based on a general 'sense' of the situation. At the same time, reflections were not uncritical. We have highlighted the considerable numerical expansion in carer support that has been achieved by the Service but acknowledge that this started from a low base.

There are tensions in the requirements of providing both breadth and depth of support for carers. Reaching out to many more carers with advice and information is an achievement, but meeting the specific and individual needs of carers requires a

personalised and targeted model of support. This is the purpose of assessment and understanding individual circumstances, but offering this level of support creates resource challenges within the Service and in partner organisations.

Some of the frustrations identified with the operation of the Service were primarily the result of systems and processes that were not the best fit for the purposes and the challenges of providing a truly joined up service across systems. We recognise that the Service introduced extensive changes to address these gaps and these were still taking effect. However, these seem to have the potential to improve the flexibility and responsiveness of the carer offer across Norfolk.

8. Conclusions

The focus of this report, and of the evaluation undertaken between 2020 and 2023, has been to examine and understand the delivery and outcomes of support for carers, commissioned by the Council from a partnership of voluntary sector organisations using a social impact bond mechanism. We have presented our findings drawn from several strands of inter-linked methodologies designed to illuminate some central questions. In this final concluding section of the report, we revisit the aims and objectives of the model and consider how it has performed on the basis of the evidence we have collated and analysed.

The Service had a number of objectives to deliver a better model of support for carers, including:

- Creating a universal service for carers with a single point of access, and a simplified pathway to access other services.
- Improving carer identification and contact, and identifying carers that were in most need of support, and at high risk of breakdown.
- Improving the wellbeing of carers and sustaining them in their caring relationship (defined as preventing carer breakdown).
- Operating a 'carer-centric' (person-centred), and strengths-based approach to identify intended wellbeing outcomes, and the assets available to support these goals.
- Identifying simple needs and requests for information (low level support) and distinguishing these from needs requiring specific help and interventions (high level support).
- Providing time limited support intended to build resilience and independence of carers.

The Council commissioned the service with an expectation that improved carer wellbeing would have potential benefits to reduce the costs to adult social care if carer breakdown could be prevented or delayed, and the need for adult social care would be reduced. Savings of £8m over the lifetime of the social impact bond were anticipated.

We have found a mixed picture of achievement and outcomes. There are certainly some positive impacts of the Service shown in both the qualitative evidence from carers, and in quantifying the improvements in wellbeing, as measured by improved wellbeing scores on the Carers Star. However, we also found that low Carers Star scores are not a reliable predictor of the likelihood of 'carer breakdown'.

Actual breakdown of caring is a rare occurrence because of the continued commitment of most carers. Only 19 carers (11%) in our sample of 166 case files were no longer caring after 12 months. Where 'carer breakdown' did occur, this was primarily unavoidable and was either due to the death of the cared for person (42%), or deterioration in the condition of the cared for person (32%) which made continued caring at home unsustainable. In only 3 cases (16%) was there a potentially avoidable reason where the breakdown was the result of a deterioration in the relationship between the carer and cared for person.

We suggest that the assumptions made by the Council about the potential scale of 'invest to save' opportunities offered by the Service reflect some flawed assumptions in the scale of carer breakdown (estimated at 2,200 a year in the service modelling underpinning the commissioning). Indeed, this raises significant questions about the validity and reliability of reducing carer breakdown incidence as an indicator of service outcomes at all.

We have not been able to examine the counterfactual scenario, or what would have happened in caring situations if the Service had not been available to individuals. Clearly, there would be major ethical issues in undertaking any such experiment where access to services is withheld. We had attempted to examine indirect indicators of the impact on adult social care through our analysis of the Council case files but were limited by the lack of information contained about carers' needs or support.

What works best in supporting carers is a question that is much debated both in practice and research communities. It is a complex question and one where the evidence base is relatively weak, not because of lack of exploration but because of the difficulties of demonstrating causality or even impact. As we highlighted in our Rapid Research Review undertaken in 2020 as background to this evaluation, the risks of carer breakdown are often a reflection of a crisis in carers' own health status. The factors that are most likely to sustain carers over time include being able to take a break from caring and developing effective psychological coping strategies.

Our analysis of the Council case files found that carers identified as at higher risk were more likely to have 'contingency support' such as respite, and this would appear to be effective in sustaining caring. Without the input of carers, the need for more costly packages of support (including 24 hour care) would be greater for those people whose carers had contingency support, than for those who did not.

If contingency support for the cared for person is the key intervention that can help in supporting carers at high risk, it is inappropriate to expect that the level and type of support offered by the Service could or should reduce the demands and costs likely to fall on adult social care. Perversely, good carer service could increase the demands on social care, not least because of their role in identifying unmet need

through carer contact and referring the cared for person to the Council for Care Act assessment and support. We found evidence of such referrals in the course of our evaluation and have commented on them in the report.

As we have indicated throughout the analysis, there are many positive outcomes of the Service, and we would particularly highlight the following features:

- The Service has considerably expanded the reach of support for carers and is continuing to increase the identification of carers.
- Awareness and knowledge of the Service is increasing among carers, and with other stakeholders.
- The process of contact with the Service is undergoing change; there have been revisions to streamline the service and to reduce delays in responding to requests.
- There have also been (very recent) changes in the approach to assessment and the introduction of a self-assessment process that has greater potential to empower carers and enable them to identify what matters to them most, and to reduce the requirement for them to repeat their story multiple times.
- The practical support and flexibility of response that the Service can offer to carers is highly valued.
- The Service has shown improvements in the level of person-centredness, timeliness and targeting over its course.
- Support from the Service has positive impacts on carer wellbeing, and these are reflected in improvements in Carer Star scores over time. Almost a third (29%) of carers experienced a large improvement in scores (more than 5 points), and two fifths (39%) experienced a small improvement (2 to 5 points).

We have also reflected on other findings which are less positive, including:

- Many carers still experience difficulties in accessing support or finding their way to the Service.
- There are some tensions between the breadth and depth of the carer offer and improving the reach of the service to more carers while also offering something that is more than just information and advice. This raises questions about the effectiveness of targeting support to carers in most need.
- Support for higher risk carers – or those with greatest needs – is not always well targeted and some people with assessed needs are offered only low-level support when they need additional support.
- Carers report variable quality of response from individual practitioners, which may reflect differences in skills and competence which should be addressed through further training.
- The short-term nature of the Service support plans can leave carers with ongoing and underlying needs that are not addressed and necessitate re-referral.
- Support for carers is largely not focused on building resilience and is often of insufficient duration or intensity to enable this to occur. The reliability of regular breaks from caring for carers in greatest need should be improved, rather than this being offered on an unpredictable, ad hoc or limited basis.

- The Service is likely to be able to make the greatest difference to carers with lower-level needs. We found an inverse relationship between Carer Star score improvements and receipt of services by the cared for person. We believe this is indicative of service receipt reflecting higher intensity or complexity of need. The benefit of support to carers with lower level need might be expected to be higher than for carers already experiencing considerable strain.
- Sustainability checks on carers at 6 and 12 months could be significantly enhanced to be more than an administrative process linked to evidencing avoidance of care breakdown, and used as a dynamic opportunity to review carers' wellbeing and further enhance their resilience.
- Carers appear to experience a sudden loss of support in situations where caring ends because of the death of the cared for person, or admission to permanent residential care. Attention to carers' wellbeing in this immediate aftermath is lacking and could be important in preventing mental health deterioration.
- Support for carers, and the people they support, between the Service and the Council is poorly coordinated; the lack of transparency and communication between respective file systems is a significant limitation in achieving joined up and coherent care and referral pathways. There is also considerable scope for improving knowledge and mutual awareness between the organisations and opportunities to involve the Service in understanding strategic policy objectives and to share in the Council training opportunities might be better developed.

We are aware that much of the period during which our evaluation took place was exceptional. The sudden impact of the Covid-19 pandemic could not have been predicted at the outset, and clearly there were negative consequences for carers both in increased pressures around covid, and in resulting delayed service responses. This makes comparison over time problematic because of the changing circumstances experienced. The impact on carers – both in the County and more widely – is still reverberating, and the return to a 'steady state' is a slow process. At the same time, substantial changes in the structure and model of the Service have contributed to this state of flux. While the changes that have been recently introduced are likely to be positive, and are indicative of organisational learning and responsive adaptation, the process has inevitably been disruptive.

Several of the objectives and outcomes for the Service can be said to have been delivered in part, or to be work in progress towards delivery. The exception to this is the expectation by the Council that the service would be effective in preventing carer breakdown and would deliver substantial cost savings. We believe that avoiding carer breakdown as a prime focus for the service was a distorting objective. The scale of potential carer breakdown appears to have been significantly over-estimated at the outset, and hence the anticipated potential for savings was also disproportionate. Moreover, as we have argued above, where breakdown does occur it is largely for unavoidable reasons. Opportunities for enhancing carer wellbeing offer the greatest prospects for positive outcomes and continuing to invest in contingency and respite support for carers facing more intensive demands, alongside a service able to offer low level and flexible support to an increasing number of carers is likely to be the most positive way forward.

9. Annexes

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Annexe 1: Statistical methods used in the analysis of survey data

Regressions analysis

Regression analysis is a statistical process to mathematically establish the relationship between different factors and highlights potentially important relationships. For example regression analysis can be used to examine what socio-demographic characteristics or features of services (i.e. independent variables) are most likely to predict wellbeing outcomes (i.e. dependent variable).

The regression can use both dummy and categorical variables. A dummy variable (or indicator variable) takes on the values 1 or 0, representing whether a condition is present or not (such as female/male, in work/out of work, etc.)

In the context of regression:

$$y = \beta_0 + \beta_1 x + e$$

Where:

- y is the dependent variable (for example an outcome measure, such as Carer Star, Carer Wellbeing Score etc.).
- x is the independent variable (such as gender, receiving a service or not etc.)
- β_0 is the intercept (it is a constant value which represents the value of the dependent variable if all independent variables are 0).
- β_1 is the coefficient of x which we are testing for significance.
- e is the error term.

After running a regression, it's customary to inspect the p-value (probability) linked to β_1 to discern if the coefficient of x is statistically significant. If the p-value falls below a designated significance threshold (often set at 0.05 or 0.10), we'd reject the null hypothesis asserting β_1 equals zero. We'd then infer that there's a statistically significant difference in 'y' when comparing $x=0$ to $x=1$, quantified by β_1 . In other words, this shows us how likely this result is if there is no relationship between the two variables.

For example:

$$\text{Wellbeing} = \beta_0 + \beta_1 \text{Female} + e$$

- When Female=0, Wellbeing is expressed as $\beta_0 + e$.
- When Female=1, Wellbeing is conveyed as $\beta_0 + \beta_1 + e$.

Here, β_1 illuminates the difference in wellbeing between males and females.

However, some variables have more than two categories, such as age groups, districts etc. In situations where we encounter multiple ("n") categories, we integrate n-1 dummy variables into the model:

$$y = \beta_0 + \beta_1 x_1 + \dots \beta_{n-1} x_{n-1} + e$$

Each β_i delineates the discrepancy in 'y' between instances when $x_i=1$ and $x_n=1$. To elaborate, suppose we categorize age as: 18-25, 26-35, 36-49, 50-65, 66-75, 76-85, and 86-95. For these seven categories, we introduce corresponding dummy variables: AGE1, AGE2, ..., AGE7. In the regression model, only six dummy variables (n-1) - AGE1 to AGE6 - are incorporated:

$$\text{Wellbeing} = \beta_0 + \beta_1 \text{AGE1} + \beta_2 \text{AGE2} + \beta_3 \text{AGE3} + \beta_4 \text{AGE4} + \beta_5 \text{AGE5} + \beta_6 \text{AGE6} + e$$

Here, β_1 showcases the difference in wellbeing between those aged 18-25 (when AGE1=1) and those aged 86-95 (when AGE7=1), β_2 indicates the difference between those aged 26-35 (when AGE2=1) and those aged 86-95 (when AGE7=1), etc.

Mean analysis

In our analysis, we segmented the dataset to compute the means for each unique group based on several variables: age, gender, relationship to the care recipient, patient's health status, care intensity, employment status, and district. This methodology enabled us to pinpoint both central tendencies and variations inherent to each category, thereby granting a more nuanced insight into the prevailing trends and distinctions between the groups.

Annexe 2: Characteristics of survey respondents in Wave1 and Wave 2

		Wave 1 (n=780)		Wave 2 (n=400)	
		N	%	N	%
Gender					
	Female	506	64.9	249	62.3
	Male	271	34.7	147	36.8
	Prefer not to say	3	0.4	4	1.0
Age					
	18 - 25	12	1.5	4	1.0
	26 - 35	24	3.1	10	2.5
	36 - 49	77	9.9	30	7.5
	50 - 65	303	38.9	144	36.0
	66 - 75	200	25.6	122	30.5
	76 - 85	145	18.6	76	19.0
	86 - 95	19	2.4	13	3.3
	Prefer not to say			1	0.3
District					
	Breckland	117	15.0	58	14.5
	Broadland	136	17.5	66	16.6
	Great Yarmouth	67	8.6	29	7.3
	King's Lynn & West Norfolk	111	14.3	60	15.0
	North Norfolk	116	14.9	54	13.5
	Norwich	106	13.6	53	13.3
	South Norfolk	119	15.3	76	19.0

		Wave 1 (n=780)		Wave 2 (n=400)	
	Out of County	6	0.8	4	1.0
Relationship to cared for person. The carer is:					
	Their child	184	23.6		
	Their parent	111	14.2		
	Their partner / spouse	432	55.4		
	Other (e.g. friend)	51	6.5		
	Prefer not to say	2	0.3		
Number of hours caring per week					
	9 hours or less	23	3.0	24	6.0
	10 to 19 hours	73	9.4	28	7.0
	20 to 34 hours	69	8.9	31	7.8
	35 to 49 hours	88	11.3	35	8.8
	50 or more hours	486	62.3	251	62.8
Has a disability, illness or long-term condition					
	No	343	44.0		
	Yes	353	45.3		
	Not sure	57	7.3		
	Prefer not to say	27	3.5		
Employment status					
	Retired	377	48.3	219	54.8
	Working full time	82	10.5	37	9.3
	Working part time	116	14.9	50	12.5
	Caring full time	54	6.9	31	7.8
	Keeping House	61	7.8	23	5.8

		Wave 1 (n=780)		Wave 2 (n=400)	
	Unemployed	46	5.9	15	3.8
	Not working due to disability	15	1.9	15	3.8
	Other (e.g. volunteering, studying)	17	2.2	7	1.8
	Prefer not to say	12	1.5	3	0.8

Annexe 3: Characteristics of cared for persons

		Wave 1 (n=780)		Wave 2 (n=400)	
		N	%	N	%
Age					
	under 18	4	0.5		
	18 - 25	49	6.3		
	26 - 35	40	5.11		
	36 - 49	60	7.7		
	50 - 65	115	14.7		
	66 - 75	126	16.1		
	76 - 85	227	29.1		
	86 - 95	140	17.9		
	96 or older	15	1.9		
	Prefer not to say	4	0.5		
Needs					
	Dementia	312	40.0	169	42.3
	Autism	28	3.6	32	8.0
	Learning disability	83	10.6	36	9.0
	Physical disability	299	38.3	157	39.3
	Frailty	229	29.4	142	35.5
	Mental Ill Health	249	31.9	112	28.0
	Long-term health conditions	328	41.8		
Number of conditions					
	2	250	32.3		
	3	155	20.1		

		Wave 1 (n=780)		Wave 2 (n=400)	
	4	52	6.7		
	5 or more	21	2.7		

Annexe 4: Characteristics of the Council case file sample

	N	%
Age		
18-64	25	41.0
65-74	9	14.8
75-84	15	24.6
85+	12	19.7
Relationship to carer. They are the carer's:		
Child	11	18.0
Parent	17	27.9
Partner	30	49.2
Sibling	2	3.3
Other	1	1.6
Main category of need		
Learning disability support	7	11.5
Mental health support	8	13.1
physical support - access and mobility only	8	13.1
physical support - personal care support	22	36.1
social support - support for social isolation / other	1	1.6
support with memory and cognition	15	24.6
District location of cared for person		
Breckland	6	9.8
Broadland	8	13.1
Great Yarmouth	3	4.9

	N	%
King's Lynn & West Norfolk	21	34.4
North Norfolk	6	9.8
Norwich	11	18.0
South Norfolk	6	9.8

Annexe 5: Characteristics of the case file sample from the Service

Carers characteristics (N=166)

	N	%
Gender		
Female	118	71%
Male	48	29%
District		
Breckland	20	12%
Broadland	20	12%
Great Yarmouth	18	11%
Kings Lynn & West Norfolk	38	23%
North Norfolk	21	13%
Norwich	24	14%
South Norfolk	23	14%
Out of County	2	1%
Relationship to cared for person		
Partner	88	53%
Parent	23	14%
Child	40	24%
Sibling	3	2%
Other	12	7%
Carer has a long-term health condition or disability		
Yes	122	73%
No	40	24%
Not recorded	4	2%

Characteristics of the caring relationship (N=166)

	N	%
Main need of cared for person		
Autism	7	4%
Dementia	45	27%
Frail elderly	17	10%
Learning Disability	12	7%
Mental Health	30	18%
Physical Disability	50	30%
Other	5	3%
Duration of caring relationship		
Under 2 years	39	23%
2-5 years	50	30%
6-10 years	21	13%
More than 10 years	35	21%
Not recorded	21	13%
Hours caring per week		
Less than 10	2	1%
10-24	2	1%
25-50	48	29%
50+	111	67%
Not recorded	2	1%
Whether cared for person receives services		
Yes	74	45%
No	73	44%
Not Recorded/unclear	19	11%

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