An evaluation of the Dementia Carers Count Carer Support Service

FINAL REPORT

May 2026

DEMENTIA CARERS COUNT

Apteligen

Apteligen is the trading name of Apteligen Limited, registered in England and Wales under registration number 7419975.

We are a specialist impact measurement and evaluation company, working with public sector and charitable organisations, helping them to gather evidence and tell compelling and robust impact stories. We work in health and care, housing, education, arts and culture, and community development, supporting leaders to transform how they measure impact and to deliver better, more sustainable outcomes for the most vulnerable people in our society.

Any enquiries about this report should be directed to:
corporate@apteligen.co.uk

Table of contents

This report presents the findings from a mixed methods evaluation of the Dementia Carers Count (DCC) Carer Support Service. The evaluation provides a robust and triangulated assessment of outcomes and impact, and the mechanisms through which it is achieved.

Across all data sources, a clear and consistent picture emerges: the service delivers **substantial emotional impact**, **meaningful practical outcomes**, and plays a **distinctive intermediary role** within a fragmented system.

Progress and achievements

The findings from this evaluation highlight the delivery of an integrated model of support that brings together emotional support including counselling, advice, advocacy, and signposting to existing provision in a coherent and responsive way. This model has enabled the service to reach a geographically dispersed population of carers through a non-place-based delivery approach, reducing barriers associated with location and access to local provision. Carer survey findings reinforce wider qualitative and outcome evidence presented throughout this report. As shown below, carers reported particularly strong outcomes in relation to reduced isolation and emotional pressure, alongside improvements in system navigation, access to support, and confidence in managing future challenges.

Type of outcome	Survey item	% of respondents
Emotional outcomes	Felt less alone	92%
	Reduced emotional pressure	85%
Practical / navigational outcomes	Easier to know where to go for help	70%
	Enabled to get the right support	70%
	Accessed support not previously using	67%
	Able to act on advice	60%
Future resilience / confidence outcomes	Better able to plan for future challenges	68%
	Better understanding of dementia care	65%
	More confidence caring	63%

Alongside this, the organisation has developed a strong digital presence, generating over **800,000 impressions** and achieving a net growth of **3,815 followers** across platforms.

Engagement data, combined with qualitative analysis, indicates that these channels are not only effective for dissemination, but also function as an entry point into support and a space for interaction among carers.

Across all data sources, including survey responses, interviews, and social media engagement, carers report high levels of trust, satisfaction, and perceived value, suggesting that the service is consistently experienced as credible, accessible, and responsive to need.

Service	Short-term outcomes	Medium-term outcomes	Evidence
Triage call	Carers feel listened to; clearer next steps; reduced uncertainty	Faster access to support; improved anticipation of needs; increased confidence in service	Consistently evidenced
Advice and advocacy	Reduced confusion; better understanding of rights and systems; confidence to act	Greater independence; improved interactions with professionals; access to entitlements; financial and practical gains	Consistently evidenced
Emotional support including counselling	Reduced anxiety; feeling heard; emotional relief and containment	Improved coping strategies; sustained wellbeing; greater resilience and ability to manage future challenges	Consistently evidenced
Signposting / referral to existing provision	Greater clarity on services; readiness to engage; ability to initiate contact	Reduced access barriers; improved engagement; better decision-making; improved practical outcomes over time	Consistently evidenced
Overall (all services)	Carers feel respected, safe and well-supported; increased confidence in staff; positive experience across touchpoints	Increased trust in DCC; more stable caring arrangements; improved quality of life; consistent experience across services	Consistently evidenced

Key messages

The findings indicate that counselling delivers substantial and measurable impact. There is evidence of significant reductions in psychological distress and sustained improvements in coping and resilience, in as little as six sessions per client on average. Evidence from CORE-10 questionnaire responses, feedback survey data, and interviews with carers, consistently points to emotional support including counselling as a central mechanism of change within the overall service model.

Advice and advocacy operate not simply as sources of information, but as a form of system navigation. Support translates complex processes into actionable steps, sustains engagement over time, and enables carers to progress cases that would otherwise remain unresolved. Impact is both tangible and enabling. While financial gains and access to services represent important endpoint outcomes, a significant proportion of impact occurs through increased confidence, clarity, and capacity to act. These enabling outcomes underpin carers' ability to engage with systems and sustain progress over time.

A defining feature of the service is the importance of sustained engagement. Evidence across case notes and interviews demonstrates that iterative support, follow-up, and continuity are critical in maintaining momentum and preventing disengagement in the face of system delays and complexity.

The service operates as a specialist intermediary within a fragmented system, bridging gaps between services and enabling more effective use of existing provision. This role is reinforced by the interplay between emotional and practical support, where counselling enables engagement with systems and practical support reduces stress and uncertainty.

Digital channels extend both reach and accessibility, functioning as a front door to support and a space for peer interaction, help-seeking, and early engagement.

Key messages at a glance

- A critical gap exists between the support available, and the support needed for people caring for someone with dementia. Navigating a fragmented system creates psychological distress and practical barriers that existing services often fail to bridge.
- Dementia Carers Count acts as a specialist intermediary, combining counselling with system navigation (advice and advocacy) to help carers engage with complex systems that they might otherwise abandon due to uncertainty and stress.
- Outcomes are consistently strong, with measurable improvements in wellbeing, confidence, system navigation, and practical stability. Notably, counselling delivers measurable reductions in distress, while advice / advocacy leads to tangible financial and practical gains.
- Dementia Carers Count has established powerful digital channels that function as a gateway into early support and a space for connection.
- The current model is highly effective. Future focus should remain on consolidating this integrated approach, formalising follow-up pathways, and expanding reach to under-represented groups.

Strategic implications

This evaluation suggests that the current model of support is both effective and well aligned to the needs of carers and should therefore be consolidated and strengthened rather than

fundamentally redesigned. The integration of emotional and practical support emerges as a central feature of impact, and maintaining this balance will be critical to sustaining outcomes in the future.
There is a clear case for strengthening continuity and follow-up pathways. Given the importance of sustained engagement in achieving outcomes, particularly in complex cases, further formalisation of how follow-up is delivered could enhance consistency and effectiveness.

The interaction between counselling and practical support represents a key driver of impact. Opportunities to enhance coordination between these elements, for example through clearer internal pathways or shared case visibility, may further strengthen outcomes.

Social media presents a significant opportunity as an entry point into support. While it is already functioning in this way, developing clearer pathways from online engagement into structured support could increase conversion and extend reach.

The findings also point to the importance of expanding reach to underrepresented groups, particularly given the limited diversity observed within the current sample. Targeted outreach and partnership working may support engagement with a broader range of carers.

Finally, while short- and medium-term outcomes are strongly evidenced, there is scope to strengthen understanding of longer-term value and impact, including the potential to undertake an economic evaluation in relation to the monetary benefits associated with sustained wellbeing, financial stability, and reduced system escalation.

Part 1: Introduction and context

1 About this report

This report presents the findings from a mixed methods evaluation of the Dementia Carers Count (DCC) Carer Support Service. The evaluation draws on multiple sources of data collected between 2025 and 2026, including service monitoring data, carer feedback surveys, interviews with carers and referral partners, anonymised case records, and social media analysis.

The purpose of the report is to demonstrate the outcomes and impacts of the service, and how they are achieved in practice. Rather than focusing solely on outcomes, the analysis presented examines the processes through which support is delivered, the contexts in which carers engage with the service, and the factors that shape variation in experience and results.

2 Background and context

2.1 About Dementia Carers Count

Dementia Carers Count is a national charity supporting unpaid carers of people living with dementia. It operates within a complex and often fragmented health and social care landscape in which carers frequently report feeling isolated, overwhelmed, and uncertain about how to access support.

The organisation provides a combination of emotional, practical, and informational support through its Carer Support Service. This includes counselling, advice and advocacy, and signposting to existing services, delivered primarily through remote channels. The service is designed to respond flexibly to carers' needs, recognising that caring situations are often dynamic, unpredictable, and shaped by both emotional and system-level pressures.

Alongside direct support, Dementia Carers Count also plays a wider role in raising awareness of carers' experiences and influencing policy and practice. This dual focus reflects an understanding that improving outcomes for carers requires both individual support and broader system change.

2.2 The wider context

Dementia care in England is characterised by increasing demand, complex care needs, and variation in the availability and accessibility of services. Carers often act as the primary coordinators of care, navigating multiple systems including health services, social care, and welfare support. These systems are frequently experienced as difficult to access and poorly connected, placing a significant cognitive and administrative burden on carers.

Within this context, support services must address not only emotional wellbeing, but also the practical challenges of navigating fragmented pathways and progressing support across organisational boundaries. The evidence presented in this report should therefore be understood in relation to this wider system context, where outcomes are shaped both by the support provided and by the constraints of the systems which carers interact with.

2.3 Why this service is needed

The Carer Support Service is designed to address a clear gap between carers' needs and the support available through existing provision. While statutory and voluntary services offer

important forms of assistance, they are often limited in their capacity to provide sustained, personalised support across both emotional and practical domains.

Dementia Carers Count responds to this gap by offering a model of support that combines emotional support including counselling, advice, and navigation, specifically designed to reflect the unique challenges associated with caring for someone with dementia. The degenerative nature of the disease, meaning that the needs of the person with dementia and also of the carer are in flux, often changing without warning, mean it can be especially difficult to sustain the resilience and knowledge to meet challenges. Living grief and the complex emotions which come with caring for someone with a neurodegenerative disease compound the difficulty of dealing with an already complex and fragmented system. In doing so, the service aims not only to provide immediate support, but to build carers' confidence and capability to manage current and future challenges within a complex system.

2.4 Aims of the service

A central aim of the service is to **reduce psychological distress and improve carers' wellbeing**, particularly at points of crisis or transition. Through counselling and emotional support, the service seeks to stabilise acute distress, provide space for reflection, and build longer-term coping capacity. This reflects an understanding that emotional resilience is foundational to carers' ability to sustain their role over time.

Alongside this, the service aims to **enable carers to access and navigate support systems more effectively**. Through advice, advocacy, and practical guidance, Dementia Carers Count supports carers to understand their entitlements, engage with services, and progress complex processes such as benefits applications, social care access, and care planning. This includes not only providing information but translating systems into actionable steps and sustaining engagement over time.

A further aim is to **act as a bridge within a fragmented system**, connecting and signposting carers to relevant services and supporting continuity across organisational boundaries. This intermediary role is particularly important where carers face delays, unclear pathways, or barriers to access, and positions the service as a facilitator of progress rather than a replacement for statutory provision.

Lastly, the service also seeks to **extend its reach and accessibility through digital channels**, including social media. This enables carers to access information, share experiences, and seek support in a low-threshold and immediate way, complementing more formal service provision and acting as an entry point into wider support.

3 Scope of this evaluation

The following aspects of the Dementia Carers Count support service were included in this evaluation:

1. The initial point of access to support (also known as a one-off call or triage call).
2. Advice and advocacy – providing one-to-one confidential advice, guidance on practical, emotional and financial issues, and advocacy and casework on behalf of carers.
3. Counselling – six-session counselling model, delivered fortnightly for one-hour via telephone or video call by a qualified and accredited counsellor.

4. Signposting and referral to a third-party organisation / support service.

The online peer support groups for dementia carers were outside the scope of the evaluation. However, they do provide an important additional component of the support offered by Dementia Carers Count.

Part 2: Evaluation methodology

4 Data sources

A mixed-methods evaluation design was used to assess the impact of Dementia Carers Count counselling and wider support. The approach combined quantitative outcome measurement with qualitative enquiry to capture both the scale of change and the processes through which change occurred. This design supports triangulation across data sources and enables a more comprehensive interpretation of impact.

Six primary sources of data were used in the analysis presented in this report:

- **CORE-10 outcome data**: 44 routine pre- and post-intervention measures of psychological distress collected as part of counselling delivery.
- **Carer feedback survey**: 51 structured survey responses were received (approx. 10% of users contacted) capturing carers' perceptions of support across emotional, informational, and practical domains.
- **Semi-structured interviews with carers**: 13 semi-structured interviews exploring lived experience of support, including perceived impact, mechanisms of change, and ongoing challenges.
- **Semi-structured interviews with partners who refer to Dementia Carers Count**: 6 semi-structured interviews with referral partners across NHS, local authority, and voluntary sector services, providing system-level context on referral pathways, service positioning, and external constraints.
- **Anonymised case notes**: A purposive sample of 20 redacted case records drawn primarily from advice, advocacy, benefits, and one-off support work, with some overlap into safeguarding, counselling referral, and complex multi-agency support.
- **Social media analytics and engagement data**: Cross-platform metrics (Facebook, LinkedIn, Instagram, X) and qualitative analysis of user comments

This multi-source design enables analysis at both individual and system levels, and supports comparison between outcome data, reported experience, and documented practice.

5 Data analysis

5.1 Quantitative analysis: CORE-10

CORE-10 scores were analysed for carers with matched baseline and follow-up data (n=44). Descriptive statistics were calculated to summarise mean scores at each time point and the mean change in distress.

To assess whether observed changes were statistically significant, a **paired samples t-test** was conducted. Effect size was calculated using **Cohen's d for paired samples** to assess the magnitude of change. Percentage reduction in scores was also calculated at the individual level to provide an intuitive measure of improvement.

Interpretation of results considered both statistical significance and practical significance, including movement between clinical thresholds of distress where relevant.

5.2 Quantitative analysis: survey data and participant profile

Survey responses were analysed using a standard five-point Likert scale (Strongly disagree to Strongly agree). Responses were converted into:

- **Mean scores** (out of 5)
- **Percentage positive responses** (Agree or Strongly agree)

Survey items were grouped into three service domains:

- Counselling and emotional support
- Information and signposting support
- Practical and benefits support

Analysis focused on identifying patterns of consistency and variation across these domains, as well as alignment with outcome data.

A total of 51 **carers** completed the survey. The respondent group was predominantly **older adults**, with the largest proportion aged **61–75**, alongside a smaller number aged 65+ and fewer respondents in younger age groups. The sample was **majority female**, reflecting wider patterns in unpaid caring.

In terms of ethnicity, respondents were predominantly **White British**, with very limited representation from other ethnic groups. A small proportion of respondents reported having a **disability**, indicating that some carers are managing their own health needs alongside caring responsibilities.

Overall, the profile suggests that the survey largely reflects the experiences of **older, female carers**, with limited ethnic diversity. This should be considered when interpreting findings, particularly in relation to generalisability to more diverse carer populations. Due to lack of demographic representation in the sample, it was not possible to examine statistical differences between different profiles of carers.

5.3 Qualitative analysis: carer and partner interviews

Qualitative carer interview data (n=13) and partner interview data (n=6) were analysed using a **thematic analysis** approach. Themes were developed to capture both common patterns and areas of variation. Particular attention was given to identifying mechanisms of change, how carers described the relationship between support and outcomes, and how partner organisations understood the role of Dementia Carers Count within the wider support system.
Interview data were also analysed comparatively across subgroups, including carers who received counselling only and those who accessed multiple forms of support.

5.4 Documentary analysis: anonymised case notes

An anonymised sample of redacted case notes was analysed to provide detailed insight into how support was delivered in practice, particularly within the advice, advocacy, benefits, and one-off support strands. The case notes were treated as documentary evidence of service activity and case progression rather than as neutral administrative records. This allowed analysis not only of what support was offered, but how cases developed over time, how staff interacted with external systems, and where progress was enabled or constrained.

The case notes were read holistically and coded thematically, with attention to:

- **Presenting needs**, including benefits, council tax, social care access, safeguarding, and care planning
- **Type and intensity of support provided**, including one-off advice, guided applications, complex navigation, and crisis or safeguarding work
- **Case trajectory over time**, including follow-up, re-contact, escalation, and closure
- **Documented outcomes**, including successful claims, access to support, increased understanding, and unresolved or delayed cases
- **Interaction between emotional and practical needs**, particularly where counselling referral, reassurance, or wider wellbeing concerns formed part of the case

This analysis made it possible to identify recurrent case types and to examine support as a process rather than a single event. In methodological terms, the case notes strengthened the evaluation by grounding interview and survey findings in documented examples of practice, service response, and case progression.

5.5 Social media data

Social media data were analysed using a mixed-methods approach, combining quantitative platform metrics with qualitative thematic analysis in MAXQDA 24 of user engagement. Quantitative data were drawn from platform analytics across Facebook, LinkedIn, Instagram, and X (Twitter), including impressions, engagement rates, follower growth, and interaction metrics such as comments, shares, reactions, and link clicks. Follower growth was also analysed longitudinally across platforms between October 2025 and March 2026.

Qualitative analysis was conducted on a dataset of 894 user comments (880 from Facebook and 14 from LinkedIn), using a structured coding framework developed in MAXQDA. Comments were coded thematically to capture both the purpose of engagement (for example, experience sharing, advice seeking, peer interaction) and sentiment towards the organisation.

The analysis focused on three key dimensions:

- **Nature of engagement**: how carers use social media (for example, sharing experiences, seeking advice, interacting with others).
- **Role of the organisation**: how Dementia Carers Count responds to and supports users within digital spaces.
- **Sentiment and perception**: how users perceive the organisation, including expressions of trust, gratitude, or critique.

This approach enabled systematic identification of dominant patterns of engagement, while also capturing variation in user needs and responses.

5.6 Synthesis of findings

Findings were integrated through a process of **triangulation**, comparing and synthesising results across quantitative and qualitative data sources. This allowed for:

- Validation of findings across independent data streams.
- Explanation of quantitative outcomes through qualitative evidence.
- Identification of areas of convergence and divergence.

5.7 Ethical considerations

All data was handled in line with data protection and confidentiality requirements. Interview participants provided informed consent, and all identifiable information has been anonymised in reporting. Care has been taken to ensure that findings are presented in a way that does not allow individuals to be identified.

5.8 Caveats and limitations

Several limitations should be noted. First, CORE-10 analysis is based on a matched sample, which may not represent all service users. Second, survey responses reflect self-reported perceptions and may be subject to response bias. Third, qualitative findings are based on relatively small interview samples and are not intended to be statistically generalisable.

A further limitation is that case notes were sampled rather than analysed in full across the whole service, and they reflect what was recorded by staff for case management purposes. As such, they provide rich insight into documented practice and case progression but may not capture every aspect of support delivered or every outcome experienced by carers. However, the use of multiple data sources and triangulation strengthens confidence in the overall findings and supports a robust interpretation of impact.

6 Service reach and engagement

6.1 Provision of 1:1 support

During the 2025 calendar year, Dementia Carers Count provided substantial levels of direct support across multiple service strands. Internal service monitoring data indicates that **1,694 carers** were directly supported through the helpline, groups, or practitioner-led interventions, alongside **1,348 carers** who accessed the Carer Support Service (CSL).

Support was delivered through a combination of one-to-one and group-based provision. This included **210 carers** supported through the Birmingham carers hub in-person groups and **136 carers** who participated in practical and emotional support groups. In addition, digital support channels extended the reach of the service further, with **5,856 online users** accessing help and information.

6.2 Social media engagement

Across October 2025 to March 2026, Dementia Carers Count achieved substantial reach and audience growth across its social media platforms. Total follower numbers increased by **3,815**, driven primarily by Facebook growth (+3,569), with smaller gains on LinkedIn (+164) and Instagram (+133), and a marginal decline on X (−51). Content generated over **800,000 impressions**, alongside thousands of interactions, including comments, shares, reactions, and link clicks, with an average engagement rate of approximately **5.7%**.

This pattern indicates a strong and expanding digital presence, with Facebook acting as the primary channel for engagement and interaction, while other platforms contribute to reach across different audiences.

Platform	Followers (Oct 2025)	Followers (Mar 2026)	Change	Role in engagement
Facebook	12,431	16,000	+3,569	Primary engagement and interaction channel with carers
LinkedIn	1,618	1,782	+164	Professional networking and organisational reach
Instagram	3,968	4,101	+133	Supplementary audience growth
X (Twitter)	4,085	4,034	-51	Slight decline, possibly due to the reduction in public support for the X platform
Total			**+3,815**	Strong overall growth across platforms

6.3 Nature of engagement: expression, resonance, and help-seeking

Qualitative analysis of **894 comments** (predominantly Facebook) shows that social media functions as a space for **expression of lived experience**, **peer-to-peer interaction**, and **direct help-seeking**. The most frequent form of engagement is carers sharing personal experiences, particularly difficulties and emotional strain associated with day-to-day care. This aligns closely

with findings from carer interviews, where carers describe limited opportunities to articulate their experiences elsewhere.

> *"Thank you!! Thank you!! I fear a lot of voices are not heard… Often we shout but it goes nowhere.*

A second dominant pattern is **resonance and peer support**, with users responding to each other through advice, reassurance, and shared perspectives. This suggests that social media operates not only as an organisational communication channel, but as a **facilitated peer environment**, where carers exchange informal support and validate each other's experiences.

> *"What a thoughtful way to reach families who really need this kind of practical support and guidance."*

Alongside this, a notable proportion of engagement consists of **requests for advice or guidance**, including questions about entitlements, caring responsibilities, and available services. This indicates that social media acts as an **entry point into support**, surfacing unmet need and prompting interaction with Dementia Carers Count.

> *"I needed help… I've learned a lot but still feel there is more to learn."*

6.4 Sentiment and perception of the organisation

Analysis of sentiment directed towards Dementia Carers Count shows that **positive responses significantly outweigh other types of comments**. Positive sentiment is primarily expressed through gratitude, recognition of support received, and appreciation of advocacy and awareness-raising activity. Illustrative comments highlight both direct impact and perceived credibility of the organisation.

> *"I had the best help from you and your colleagues. More than any other charity."*

> *"This would have been wonderful when I was a dementia carer... amazing."*

Negative feedback is limited and tends to focus on perceived gaps in service availability (e.g. out-of-hours support) or the practical applicability of specific posts. Neutral responses often acknowledge the intent of support while highlighting that it does not fully meet individual circumstances.

Overall, this distribution suggests that Dementia Carers Count is widely perceived as a **trusted and credible organisation**, with a strong reputation among carers engaging through social media.

Summary

Synthesising these findings, DCC's social media presence functions as more than a dissemination channel. It operates as a dynamic support environment, characterised by four inter-related functions:

- Expression enabling carers to articulate experiences that may not be voiced elsewhere
- Connection: facilitating peer-to-peer interaction and informal support
- Access: providing a route into advice, advocacy, and wider services
- Engagement: reinforcing trust and ongoing interaction with the organisation

7 Impact of counselling support on carers

This chapter integrates CORE-10 outcomes, survey responses, case notes, and carer interviews to assess the impact of counselling on carers.

7.1 Scale and significance of change

Matched CORE-10 data (n=44) shows a large and statistically significant reduction in psychological distress, with mean scores falling from 20.84 to 12.80 (Δ = -8.05; t = 15.23, $p<.001$). This equates to an average reduction of around 40% per carer, with a very large effect size (Cohen's d = -2.30).

In practice, this represents a meaningful shift from moderate or severe distress into milder ranges for a substantial proportion of carers. Importantly, improvement is not confined to a small subgroup; gains are widespread across the sample with minimal deterioration.

Survey results mirror this pattern. Emotional outcomes are consistently high (means range 4.00–4.54), with 2 out of 3 carers reporting positive change. Specifically, 92% of carers reported feeling less alone and 85% reported reduced emotional pressure following support. These reductions align with interview accounts:

> *"It made the difference… between me either being broken or able to cope." [Carer K]*

> *"It's like talking somebody down from the brink." [Carer D]*

Overall, the evidence indicates that counselling is delivering robust, measurable improvements in wellbeing at scale.

7.2 How change happens in practice

Interview data shows that Dementia Carers Count's counselling support works through a sequence of mechanisms that move carers from overwhelm to active coping. Evidence from anonymised case notes reinforces and grounds these mechanisms in day-to-day practice, showing how emotional support is often intertwined with real-life pressures and decision points.

7.2.1 Stabilisation at points of crisis

Carers commonly access Dementia Carers Count's counselling at moments of acute strain. Sessions provide immediate containment and emotional regulation, creating the conditions for further change:

> *"Very helpful in acknowledging how I was feeling about stuff and the difficulties of it..." [Carer L]*

Case notes frequently capture points where carers are dealing with escalating situations such as hospital admissions, care breakdowns, or sudden deterioration, indicating that Dementia Carers Count counselling is often accessed (and accessible) at moments of heightened risk, pressure, and uncertainty.

7.2.2 Validation and sense-making

Carers' feedback strongly suggests that Dementia Carers Count's counsellors enable carers to articulate and process complex experiences. This is not passive listening; it is structured reflection that helps carers make sense of what is happening.

> *"she reflected back to me... that was extremely helpful to sort of get permission to say, no this isn't possible for me to do as much as I was doing" [Carer J]*

> *"...she was reflecting what I'd said and validating me." [Carer K]*

Case notes show carers grappling with multiple competing demands (for example, managing care arrangements while navigating benefits or service access). This reinforces the importance of the space that Dementia Carers Count offers its carers: a space to process and prioritise.

A critical shift occurs as carers reassess what is reasonable to expect of themselves, supported directly through structured conversations with Dementia Carers Count's counsellors. This reduces guilt and emotional burden while opening up more sustainable approaches to care.

> *"It's okay to not do it all yourself." [Carer J]*

In case notes, this is often visible in decisions such as seeking external help, considering residential care, or recognising limits to what can be managed alone, indicating that these shifts are not abstract but actively facilitated through counselling sessions.

7.2.3 Behavioural change and decision-making

Evidence from multiple sources shows that these cognitive shifts, developed through engagement with counsellors, translate into action: setting boundaries, seeking support, and making clearer decisions. Case notes illustrate how carers move from uncertainty to action following counselling

input, for example progressing applications, contacting services, or making care decisions that had previously felt overwhelming.

This pathway explains the scale of CORE-10 improvements and the consistency of positive survey responses, demonstrating that positive outcomes are closely linked to the work undertaken within counselling sessions rather than occurring independently of them.

Case study 1: Counselling – from crisis to sustained coping

A carer supporting a partner with advancing dementia sought support at a point of acute strain, reporting escalating anxiety, sleep disruption, and a sense of being unable to cope. Baseline CORE-10 scores were in the moderate–severe range. Over a short course of counselling (six sessions), the carer described moving from feeling "on the brink" to being able to manage day-to-day demands.

Through structured reflection with a counsellor, the carer was able to reframe expectations, recognise limits, and prioritise support. This translated into concrete actions documented in case notes, including contacting services for respite, progressing care arrangements, and setting clearer boundaries within the caring role.

At follow-up, CORE-10 scores had reduced into the mild range, reflecting a substantial improvement in psychological distress. The carer described the impact as enduring, noting increased confidence in decision-making and an improved ability to cope with ongoing challenges. This case illustrates the pathway identified in the analysis: stabilisation, validation, reframing, and sustained behavioural change.

7.3 Enduring impact and capacity building

Counselling is experienced as more than short-term relief. Carers describe lasting changes in how they approach ongoing challenges, with 55% now feeling more confident in their caring role.

> *"The effect is long lasting… it helps you get through something that you know is really tough." [Carer D]*

This indicates that counselling builds capacity: carers leave with language, strategies, and perspective that continue to be applied as circumstances evolve. Given that caring demands often increase over time, this sustained benefit is a critical outcome in its own right.

Notably, these gains are achieved within relatively short engagement (average 5.8 sessions), indicating that the Counselling model is both impactful and efficient.

7.4 Counselling as a foundation for wider support

Evidence also shows that counselling strengthens carers' ability to engage with other forms of support. Emotional stabilisation increases the capacity to navigate services, complete applications, and make decisions.

"...through the process of talking to the counsellor ...she put me in touch with the team who could talk through the financial situation" [Carer L]

Case notes provide concrete examples of this interaction. In several cases, carers move from emotional overwhelm to gaining mental space to actively engage with practical processes such as Attendance Allowance applications, council tax reductions, or care planning. Counselling appears to give carers the strength, purpose, and confidence to take these steps, rather than replacing the need for practical support.

Survey data supports this interaction: while emotional outcomes are consistently high, as previously stated, counselling also functions as a foundation that enables other interventions to be effective.

"The counselling support I received helped me across the board, especially as I started to lose confidence in my ability to make a positive difference for my mum. It was invaluable, friendly, kind and inspiring. Thank you" [Survey response 1]

7.5 Consistency of impact and sources of variation

Impact is consistently strong across emotional outcomes, with variation largely linked to external factors rather than counselling itself. Where broader changes are limited, this is typically due to system constraints such as service availability or financial barriers.

Case notes provide additional context for this variation. In some instances, carers continue to face delays, complex processes, or unresolved issues despite receiving support. This highlights that while counselling can significantly improve coping and decision-making, it does not remove structural barriers within wider systems.

Furthermore, the findings suggest that the timing of counselling also matters. Counselling accessed at points of crisis or transition appears to deliver particularly strong gains, suggesting that responsiveness and access are key to maximising impact.

"...some have been responsive and DCC certainly was for the counselling." [Carer D]

Summary

The evidence supports a clear model of impact, evidenced through the following core mechanisms of change:

- Validation and structured reflection
- Reframing of expectations and roles
- Behavioural change and improved decision-making
- Sustained coping and resilience over time
- Stabilisation of distress at critical moments

Specifically:

- Counselling delivers substantial reductions in psychological distress and improves carers' ability to cope with ongoing demands. 92% report feeling less alone and 85% report reduced emotional pressure.
- CORE-10 shows a large, statistically significant reduction in distress (mean decrease 8.05 points), supported by consistently strong survey outcomes.
- Change occurs through a clear pathway: stabilisation, validation, reflection, and reframing into more sustainable care approaches.
- These shifts translate into concrete actions, including seeking support, progressing care arrangements, and engaging with services.
- Impact is both immediate and sustained, building longer-term coping capacity rather than providing short-term relief.
- Gains are achieved within relatively short engagement, indicating an efficient and effective model.
- Counselling enables engagement with wider support, acting as a foundation for advice, advocacy, and practical support.
- Overall, counselling is a central mechanism of impact, supporting both emotional resilience and effective navigation of complex care situations.

8 Impact of advice, advocacy, and practical support on carers

This chapter brings together evidence from case notes, carer interviews, and survey data to examine the role and impact of advice, advocacy, and practical support. The analysis focuses on how this support operates in practice, the types of outcomes achieved, and the factors shaping variation in impact.

While often described as 'information and signposting to existing provision', the evidence indicates a more complex function, involving navigation of fragmented systems, translation of eligibility and processes, and sustained support over time. Therefore, the analysis focuses on four distinct case types through which support is delivered:

- One-off advice cases: single interactions providing guidance or clarification
- Guided application cases: structured support across multiple contacts (e.g. benefits applications)
- Complex navigation cases: ongoing support across multiple systems and services
- Crisis or safeguarding cases: urgent, high-risk situations requiring multi-agency coordination

8.1 Nature of need: navigating complex and overlapping systems

Across case notes, carers rarely present with single, discrete queries. Instead, needs are typically multi-layered, involving combinations of benefits, social care access, housing, safeguarding, and health-related concerns. For example, referrals frequently include requests for support with Attendance Allowance, council tax reductions, and care planning simultaneously, often alongside emerging risks or deterioration in the cared-for person's condition.

This complexity is reflected in carer interviews, where participants describe uncertainty not only about what support is available, but how different parts of the system connect:

> *"...there is a degree of confusion about who's saying, or who's responsible for what, because, you know, there's no reason why they would be joined together" [Carer D]*

Survey findings reinforce this pattern. Carers reported a moderate increase in confidence in navigating services following support (mean scores between 3.6- 4 out of 5). Specifically, 70% of carers reported improved understanding of where to go for help, while 67% accessed support they were not previously using. This pattern is consistent across all questions relating to knowing where to go for help and accessing appropriate services, indicating that support contributes to improved system navigation and understanding.

In this context, the role of the service extends beyond providing information to enabling carers to make sense of, and engage with, a fragmented system.

> *"I feel incredibly grateful and relieved that I came across the organisation because I was able to access counselling free of charge. I was able to talk to people who understood the condition and able to signpost as well to a degree. It's helpful." [Carer L]*

Case notes also highlight situations where caring arrangements are informal, fragile, or unsupported, for example where neighbours or acquaintances assume caring roles without formal authority or legal protections. In these cases, complexity is heightened by uncertainty around responsibility, decision-making, and long-term sustainability.

Case study 2: Guided application – securing financial stability

A carer approached the service for help with Attendance Allowance and council tax support, reporting uncertainty about eligibility and difficulty completing forms. Initial contact involved clarification of criteria and step-by-step guidance on presenting needs.

Over multiple contacts, staff supported the carer to complete the application, gather evidence, and submit documentation. Case notes record follow-up calls and liaison with external agencies to track progress. The application was subsequently successful, with Attendance Allowance awarded and backdated payments issued, alongside a council tax reduction.

The carer reported that prior to support the process felt "overwhelming" and unlikely to progress. Following engagement, they described increased confidence in navigating similar processes in future. This case demonstrates both endpoint outcomes (financial gain) and enabling outcomes (confidence, understanding), and the role of sustained, iterative support in achieving them.

8.2 Mechanisms of support: translation, navigation and advocacy

Analysis of case notes indicates that support is not delivered as discrete pieces of advice, but as an active, ongoing process that enables carers to engage with complex systems. Three interrelated mechanisms are evident, each operating in practice rather than in isolation. These are discussed below.

8.2.1 Translation of systems and eligibility

Staff routinely interpret complex criteria and processes, translating them into accessible and actionable guidance. This goes beyond providing information. It involves helping carers understand thresholds (for example, what constitutes eligibility for Attendance Allowance or council tax exemption), advising on how to frame needs within application forms, and clarifying what evidence is required. In several cases, carers initially believed they were ineligible or unsure how to proceed and only progressed once criteria had been broken down and explained in practical terms.

> *"...also said to me 'are you getting carers allowance' and I said 'no' I said I didn't think I was entitled to it ... it was nice because he opened up to things that I didn't think were available to me" [Carer F]*

8.2.2 Navigation and coordination across systems

Support is typically iterative. Case notes show repeated contacts over time, including follow-ups, reminders, and liaison with external agencies such as local authorities, the Department for Work and Pensions, and healthcare services. This reflects the reality that carers are not navigating a single pathway, but multiple, often disconnected processes. Staff act as a consistent point of contact, helping carers track progress, understand next steps, and avoid disengagement when systems are slow or unresponsive. Survey shows that 70% of respondents felt it was easier to know where to go for help, following help from Dementia Carers Count. Furthermore, 60% of respondents said that they were helped to reach other services when needed and to access services which they were previously unaware of. This is reflected in carer accounts:

> *"It was eye-opening… how to approach different aspects of seeking advice." [Carer E]*

Evidence shows that carers are not simply given directions, they are supported to understand how to move through the system. Survey results support these findings, with 44% of carers stating that they feel more independent in dealing with services and more able to challenge professionals.

8.2.3 Advocacy and escalation where required

In more complex cases, staff move into an advocacy role. This includes chasing responses from councils, supporting safeguarding referrals, and ensuring that cases progress when carers are unable to do so independently. This is particularly evident where there are delays, risks, or breakdowns in communication between services. While not formal case management, this role represents an important extension beyond advice.

> *"He helped me fill in the form… that was a blessing." [Carer B]*

These mechanisms together suggest that the service operates as an intermediary within the system, translating complexity into action and sustaining engagement over time. Case notes illustrate this clearly in practice, for example where staff guide carers step-by-step through Attendance Allowance applications across multiple contacts or repeatedly follow up with councils regarding tax reductions and safeguarding concerns when responses are delayed. In these cases, progress is not driven by a single interaction, but by sustained involvement that keeps cases moving forward.

8.3 Outcomes: tangible gains and process-based impact

Case notes provide further evidence of tangible outcomes in a number of cases. To reiterate, these include successful benefit claims, financial gains through backdated payments, and access to entitlements such as council tax reductions. For instance, several cases document various allowances being awarded following structured support with applications, sometimes with backdated payments that result in a meaningful increase in household income. In other cases, council tax reductions or exemptions are secured after sustained engagement with local authorities. In several instances, carers moved from uncertainty about eligibility to receiving confirmed awards, indicating a direct financial impact of support.

In addition to financial gains, some outcomes have immediate practical impact on daily life. For example, access to Blue Badge provision reduces physical strain and enables carers and cared-for individuals to access services and appointments more easily, highlighting the tangible, day-to-day benefits of support.

However, focusing solely on end outcomes underestimates the extent of impact. A significant proportion of change occurs through what might be described as process-based outcomes. These include:

- Increased confidence in engaging with services and professionals
- Improved understanding of eligibility, processes, and entitlements
- Reduced uncertainty about next steps and available options
- Greater ability to follow through on complex administrative tasks

Survey findings reflect this dual pattern. Carers report a clear improvement in their ability to navigate services, with mean scores increasing from approximately 3 to 4 on a 5-point scale following support, particularly in relation to knowing where to go for help and accessing appropriate services.

At the same time, outcomes linked to financial relief or resolution of issues remain more variable. This confirms the earlier findings that final outcomes are contingent on external systems, including processing times, eligibility thresholds, and local service availability.

Carer interviews reinforce this distinction. While some describe clear gains, others emphasise the importance of simply being able to progress a situation that previously felt stuck or unmanageable.

> *" I felt really burn out by everything because I wasn't having a break so ...rob called me and he said I would benefit from some counselling and so he put me in touch with ... who had really good advice" [Carer F]*

> *"It took them a little while, but they did resolve it for me such that we now get a discount on our council tax" [Carer A]*

This suggests that impact should be understood as both **endpoint outcomes** (e.g. benefits awarded) and **enabling outcomes** (e.g. confidence, understanding, momentum), and that these operate in a mutually reinforcing way rather than as separate effects.

Case notes and interviews indicate that without these enabling shifts, carers are unlikely to reach endpoint outcomes at all, as processes stall or are abandoned. Equally, achieving endpoint outcomes reinforces confidence and reduces uncertainty, creating a feedback loop that strengthens carers' ability to navigate future challenges. This highlights that effective support is not only about securing outcomes, but about building the capability and momentum required to reach them. Both dimensions are therefore necessary for carers to navigate complex systems effectively and sustain engagement over time.

Case study 3: Complex navigation – sustaining momentum across systems

A carer supporting a parent with complex needs presented with multiple overlapping issues, including care coordination, benefits, and emerging safeguarding concerns. Initial attempts to engage services had stalled due to delays and unclear processes.

DCC support involved ongoing navigation across systems, including repeated contact with local authority services, clarification of assessment pathways, and guidance on next steps. Case notes document multiple touchpoints over several weeks, with staff maintaining momentum through follow-up and escalation where required.

While final outcomes were still in progress at the point of closure, the carer reported a significant shift from feeling "stuck" to being able to move the situation forward. This included progressing assessments, re-engaging with services, and gaining clarity on entitlements.

This case illustrates the importance of **process- based impact**, where progress is achieved through sustained engagement rather than immediate resolution. It highlights DCC's role in enabling carers to persist within complex systems and to convert uncertainty into actionable steps.

8.4 Long-term outcomes: iterative and sustained engagement

A defining feature of this strand is that support unfolds over time. Case notes show that many interactions are not resolved in a single contact but involve multiple touchpoints over weeks or months. Case note evidence shows that this persistence often involves repeated follow-up across extended periods, including multiple contact attempts, reminders, and liaison with external agencies to ensure cases progress rather than stall.

This reflects the reality that many processes carers are engaging with, particularly benefits and social care, are inherently slow and iterative. Delays, missing information, and reassessments are common, requiring sustained engagement rather than one-off input.

Dementia Carers Count service plays a key role in maintaining momentum across this period. Case notes show repeated attempts to contact external agencies, chase responses, and re-engage carers when processes stall. Without this follow-up and continuity, there is a clear risk that carers disengage or abandon processes altogether, particularly where they are already under pressure.

Carer interviews highlight the importance of this sustained support:

> *"...they did say to me... I was very welcome to go back, which has been lovely to know that the door's not shut. It's on the area I'm looking to and that's big thing mentally" [Carer F]*

This suggests that impact is cumulative. Progress is built through a series of interactions rather than a single intervention, and the value of the service lies in its ability to stay alongside carers as they move through complex processes.

8.5 Interaction with counselling support

Evidence from interviews indicates that practical support is closely linked to emotional capacity. Carers often describe feeling overwhelmed or uncertain prior to receiving support, which can limit their ability to engage with administrative or system-level tasks.

Where emotional support including counselling is also accessed, emotional stabilisation appears to enable more effective engagement with practical processes. Conversely, practical support can reduce stress by resolving uncertainty and clarifying next steps.

> *"...it brings a different perspective and it's helpful to get perspective from others and to hear the experience of others and sometimes to be able to share your own experience to help others or to a map that's you know positive" [Carer E]*

This interplay suggests that practical and emotional support are mutually reinforcing, rather than separate strands of provision.

Case study 4: Crisis and safeguarding – advocacy at points of risk

A carer reported escalating risk related to the cared-for person's behaviour and deteriorating condition. Immediate concerns included safety within the home and lack of response from statutory services.

DCC staff supported the carer to initiate safeguarding processes, provided guidance on managing immediate risk, and maintained contact with relevant agencies. Case notes record repeated attempts to secure responses and ensure that concerns were escalated appropriately.

Although outcomes were dependent on external agency action, the carer reported feeling supported and better able to manage the situation while processes unfolded. The intervention enabled the case to progress within safeguarding pathways and reduced immediate uncertainty.

This case demonstrates the service's capacity to operate in high-risk contexts, combining **advocacy, coordination, and emotional support**. It also highlights the limits of influence within statutory systems, and the importance of sustained involvement in ensuring that cases do not stall at critical points.

8.6 Constraints and variability

Variation in outcomes is evident across all data sources and is shaped largely by factors beyond the service itself. These include delays in benefits processing, complexity of eligibility criteria, financial thresholds limiting access to support, and variability in local service provision.

Case notes repeatedly show situations where progress is slowed by external systems, including waiting for decisions, chasing responses, or navigating unclear processes. For example, staff often need to contact councils multiple times to progress applications or clarify next steps, and in some cases must manage delays of several weeks before outcomes are confirmed. In some cases, carers are required to gather additional evidence, wait for reassessments, or manage delays that extend over several weeks.

Carer interviews reflect similar experiences, with some participants describing situations where advice was helpful but did not immediately translate into change due to cost, ineligibility, or service availability. Rather than indicating limitations of the service, these patterns highlight the context in which it operates. The service is often working at the boundary between carers and complex systems, where outcomes are not fully within its control.

> *"What's been tricky about my situation is that I don't live in the same local authority as my parents... so it became quite complicated to be a carer that's not in the same location" [Carer L]*

Importantly, even where final outcomes are uncertain or delayed, intermediate benefits such as increased understanding, reduced anxiety, and clearer direction remain evident. This reinforces the role of the service in enabling engagement, even where it cannot determine final outcomes. Overall, variability should be understood as a function of system complexity rather than inconsistency in service delivery.

Summary:

- Advice, advocacy and practical support act as a critical intermediary function, enabling carers to navigate complex and fragmented systems rather than simply providing information.
- Support extends beyond signposting to existing provision to include translation of eligibility, step-by-step guidance, sustained navigation, and light-touch advocacy where cases require progression or escalation.
- Delivery is iterative and process-based, with many cases involving multiple contacts over time; this sustained engagement is essential in maintaining momentum through delays, administrative complexity, and system barriers.
- Case note evidence shows that without ongoing follow-up and continuity, many cases would be unlikely to progress, highlighting the importance of persistence and relational support.
- Clear tangible outcomes are achieved, including successful benefit claims, backdated payments, and access to entitlements such as council tax reductions, resulting in meaningful financial and practical gains.
- A significant proportion of impact occurs through enabling outcomes, including increased confidence, improved understanding of systems, and clearer direction on next steps.
- Survey findings indicate a measurable improvement in navigation capacity (mean scores increasing from approximately 3 to 4), particularly in knowing where to go for help and accessing appropriate support.
- Interview evidence shows that even where immediate resolution is not achieved, the ability to move forward and make progress represents a meaningful outcome in itself.
- Endpoint and enabling outcomes are closely interlinked: confidence and understanding enable access to benefits and services, while achieving these outcomes reinforces confidence and reduces uncertainty.

9 Partner perspectives

This section examines how Dementia Carers Count is positioned within the wider support landscape, drawing primarily on partner interviews (n=6) and triangulating these accounts with case notes, carer interviews, and survey findings. The analysis moves beyond descriptive accounts of partnership working to interrogate how Dementia Carers Count functions within a fragmented system, the forms of value it adds, and the conditions under which this value is most fully realised.

9.1 Geographical coverage

Analysis of postcode data from the carer survey, alongside references within carer and partner interviews, indicates that Dementia Carers Count is operating across a broad geographic footprint rather than within a single local area. Survey responses span multiple regions of England, including London, South East, South West, North West, Yorkshire, and the Midlands. While based on a relatively small sample, this distribution is consistent with interview evidence suggesting that the service supports carers across dispersed locations and is not confined to a particular locality or commissioning boundary.

Partner accounts further reinforce this interpretation, describing a service that is accessed and valued across different areas and organisational contexts. This wide reach appears to be enabled by a delivery model that is not tied to place-based provision, allowing Dementia Carers Count to respond flexibly to need wherever it arises. The data sources suggest that the service has developed a de facto national presence, with the capacity to support carers across varied geographic contexts while maintaining consistency in approach and quality of support.

> *"DCC has become crucial as a referral route for us because there is nobody else in certain areas of Kent now who can provide that level of support to the carers specifically around benefits, advice and filling in forms and.... the stuff that really we'd taken for granted for all this time" [Partner A]*

9.2 Specialist dementia-informed practice

A further dimension of value identified by partners is Dementia Carers Count's specialist expertise in dementia, particularly its integration of carer-focused and condition-specific knowledge. Partners highlight that this dual perspective enables support that is both practically relevant and sensitive to the trajectory of dementia and its implications for carers.

> *"It's that dementia knowledge and the coping strategies...being able to cope, especially with behavioural changes, the sundowning" [Partner B]*

> *"it's like a specific dementia carers counselling service, which nobody else offers. So I think that's slightly added value" [Partner E]*

This is borne out in the wider evidence base. Carer interviews demonstrate how emotional and practical needs are intertwined, while case notes show that support frequently spans care planning, benefits, safeguarding, and service navigation within a dementia context. The implication is that Dementia Carers Count's effectiveness is not only a function of *what* it does, but of *how* it frames and sequences support in relation to the evolving nature of dementia care.

9.3 Intermediation in a fragmented system

Across partner interviews, much like in the carer interviews, Dementia Carers Count is consistently characterised as an effective intermediary that balances on the precarious boundaries between statutory services, community provision, and informal care. Rather than duplicating provision, partners describe Dementia Carers Count as enabling movement across organisational interfaces that are otherwise difficult for carers to navigate. This intermediation is not merely relational but functional: it involves translating requirements, sequencing actions, and maintaining continuity across discontinuous systems.

> *"So we had a chat with him (the carer client) .Once we found out what DCC could offer our carers, which is something that we couldn't offer, we absolutely wanted to make sure that we had a referral route into DCC" [Partner A]*

This account aligns with case note evidence, which documents repeated liaison with local authorities, the Department for Work and Pensions, and health services, as well as iterative follow-up to sustain case progression. It also corroborates carers' findings in Chapter 6, where participants described a shift from diffuse uncertainty to clearer, actionable pathways following engagement with Dementia Carers Count. Some cases involve emerging or potential safeguarding concerns, reinforcing the need for timely coordination and escalation within statutory pathways.

In this sense, Dementia Carers Count's contribution can be understood as reducing transaction costs within the system, both cognitive (understanding what to do) and procedural (actually doing it).

9.4 Depth, continuity, and the limits of statutory capacity

Similarly to carer interviews, partners emphasise that Dementia Carers Count's distinctiveness lies in the depth and continuity of engagement it can offer. In contrast to statutory services, which are often constrained by time and caseload pressures, Dementia Carers Count is described as able to sustain involvement over time, revisiting cases, chasing responses, and supporting carers through protracted processes.

> *"So with dementia carers count, the opportunity came along to look at that as a partnership service for us. It was a missing piece in the jigsaw" [Partner F]*

Case notes substantiate this characterisation. Many cases involve multiple contacts over weeks or months, including step-by-step support with applications, repeated contact with external agencies, and escalation where progress stalls. This continuity appears critical to outcomes: without it, processes risk stalling or being abandoned. The analysis therefore suggests that Dementia Carers Count does not simply add capacity to the system, but adds a *different kind* of capacity, oriented towards persistence, follow-through, and relational continuity.

9.5 Early intervention and preventative function

Partners frequently position Dementia Carers Count as enabling earlier and more appropriate intervention. By supporting carers to understand options and act sooner, Dementia Carers Count is seen as reducing the likelihood of escalation, crisis, or inappropriate service use.

> *"the carer just needs a bit of emotional support every now and then...they can absolutely be referred to DCC to get that to try and minimize the frequency and numbers of people that we're checking in with" [Partner A]*

This claim is supported by triangulated evidence. In the counselling strand, support is often accessed at points of acute distress, enabling stabilisation. In the advice and advocacy strand, early engagement supports progression of applications and access to entitlements before situations become entrenched.

9.6 Outcomes and the co-production of impact

Partners also recognise both tangible and enabling outcomes arising from Dementia Carers Count's work. Tangible outcomes include access to benefits and services, while enabling outcomes include increased confidence, clarity, and capacity to engage. Crucially, partners also acknowledge that outcomes are co-produced with external systems and are therefore contingent.

> *"...the carers will come to us and say, oh, I've had a really good, lengthy conversation with DCC. They're really kind, they're really nice and they've helped me throughout my journey" [Partner D]*

Case notes illustrate this co-production clearly. Even where Dementia Carers Count provides sustained support, progress may depend on response times, eligibility decisions, or availability of local provision. This introduces variability in endpoint outcomes. However, enabling outcomes, such as increased understanding and momentum, are consistently observed and appear less dependent on external factors. This distinction mirrors the analysis in the advice and advocacy chapter and reinforces the importance of viewing impact as both processual and outcome-based.

9.7 Boundaries, constraints, and realistic expectations

Partners articulate a clear awareness of the limits of Dementia Carers Count's influence within the system. While Dementia Carers Count can facilitate access and sustain engagement, it cannot resolve structural constraints such as waiting times, eligibility thresholds, or service gaps.

> *"I feel that as part of strategies, things like Dementia Carers Count should be put in as a service that links within strategies within local authorities. Because it's not only added value, but it's about that specialism that the authorities and services don't have" [Partner F]*

Rather than diminishing perceived value, this recognition appears to situate Dementia Carers Count's role more precisely: as enabling progress within constraints rather than controlling outcomes. Case notes and carer interviews provide convergent evidence of these constraints, including delays, repeated follow-up, and cases where outcomes remain uncertain despite sustained input.

The implication is that Dementia Carers Count's effectiveness should be assessed not solely on endpoint outcomes, but on its capacity to mitigate the effects of system fragmentation and support dementia carers to persist within it.

Summary:

- DCC operates as a specialist intermediary within the wider system, enhancing system functioning rather than duplicating existing provision.
- Its core contribution lies in three interlocking functions: facilitating navigation across organisational boundaries, sustaining engagement over time, and integrating emotional and practical support in a dementia-informed way.
- Impact is both direct and indirect, combining tangible outcomes (e.g. access to services, financial gains) with increased capability among carers to engage with complex systems.
- DCC augments rather than replaces statutory provision, addressing gaps in continuity, translation, and relational support.
- Its greatest value is realised where support is sustained over time and aligned with points of need, enabling carers not only to access support but to do so more effectively.
- Overall, the service strengthens carers' resilience and system engagement, supporting more effective navigation of complex and evolving care situations.

10 A distinctive model of support

The findings presented throughout this report point to a clear and consistent conclusion: Dementia Carers Count delivers impact through a distinctive model that combines emotional support, practical navigation, and sustained engagement over time. This model is not defined by any single intervention, but by how different elements of support are integrated and sequenced in response to carers' needs.

Three features of this model stand out as particularly distinctive:

- **Specialist dementia expertise**: support is grounded in a deep understanding of dementia and its progression, enabling advice, advocacy, and emotional support that is tailored to the specific realities of dementia caring rather than generic carer support.
- **Dementia-focused emotional support offer**: the service provides a rare combination of counselling that is both clinically informed and specifically attuned to dementia, integrating emotional support with practical understanding of caring roles, behavioural change, and disease trajectory.
- **Accessible, non place-based delivery model**: as a primarily phone-based service, Dementia Carers Count is able to reach carers regardless of geography, including those who are unable to access, or who may be excluded from, local, place-based provision. This enables a de facto national reach and reduces barriers related to location, transport, and local service availability.

At its core, the service operates as a **specialist intermediary within a fragmented system**, translating complexity into action and enabling carers to move forward in situations that would otherwise stall. This role is evident across all strands of the analysis: counselling stabilises and builds capacity, advice and advocacy convert understanding into progress, and social media provides an accessible entry point into support.

What differentiates the service is not only what it delivers, but how it delivers it. Support is **relational, sustained, and responsive**, allowing carers to engage at points of crisis, remain supported through periods of uncertainty, and build confidence over time. This combination of depth and continuity represents a form of capacity that is often not available within statutory provision.

11 A coherent model of impact

The evidence supports a coherent model of impact, in which outcomes are generated through a sequence of interrelated processes:

- **Stabilising distress and creating space for engagement**
- **Translating complex systems into understandable and actionable steps**
- **Sustaining momentum through follow-up, coordination, and advocacy**
- **Enabling both tangible outcomes and longer-term capability among carers**

Within this model, emotional and practical support are not separate functions, but mutually reinforcing components of a single pathway. Counselling enables carers to engage with systems, while practical support reduces stress and uncertainty, strengthening overall resilience.

Importantly, impact is both **tangible and enabling**. While financial gains, access to services, and resolved cases represent clear endpoint outcomes, a substantial proportion of impact occurs earlier in the process, through increased confidence, clarity, and ability to act. These enabling outcomes are critical, as they underpin carers' capacity to navigate ongoing and future challenges.

12 The role of the service within the wider system

The findings consistently position Dementia Carers Count as addressing a structural gap within the wider support system. While statutory and voluntary services provide essential components of care, there remains a disconnect between them that carers must navigate.

Dementia Carers Count operates within this space, reducing both the cognitive and practical burden of navigating services. In doing so, it enables more effective use of existing provision rather than duplicating it. This intermediary function is particularly valuable in contexts characterised by:

- Fragmented pathways
- Unclear responsibilities
- Delays and administrative complexity
- Variability in local provision

By supporting carers to persist within these systems, the service contributes not only to individual outcomes, but to improved functioning of the system as a whole.

13 Key strengths of the current model

The evaluation highlights several core strengths that underpin the effectiveness of the service:

- **Depth and continuity of support**: sustained engagement enables cases to progress over time and prevents disengagement
- **Integration of emotional and practical support**: addressing both wellbeing and system navigation needs
- **Responsiveness at points of need**: particularly at moments of crisis or transition
- **Ability to translate and navigate complexity**: making systems accessible and actionable for carers
- **Strong trust and credibility among carers**: reflected in consistently positive feedback across data sources
- **Effective use of digital channels**: extending reach and providing a low-threshold entry point into support

These strengths collectively define the service's unique value and should be understood as central to its impact.

14 Considerations for future development

While the findings unequivocally demonstrate the significant and enduring impact of Dementia Carers Count service portfolio, several areas emerged where the service could be further strengthened. These are not intended as critiques, but as opportunities to consolidate and extend an already effective model.

Within this, the evidence from this evaluation also points to a need to articulate the primary aims and scope of the service. For example, does Dementia Carers Count see this as a specialist short term intervention that sits alongside and complements more universal support for carers (provided by, for example, local carer support organisations)? Or is it an alternative to other support services (given that many are struggling to meet the increasing demand associated with caring for someone with dementia) which might offer support for carers over a longer period of time? Or some combination of the two? Clarity in this regard may help to inform how Dementia Carers Count wishes to respond to the following:

- **Strengthening continuity and follow-up**
  Given the importance of sustained engagement, there is scope to further formalise follow-up pathways, particularly for complex or high-risk cases. This could help to ensure consistency in how ongoing support is provided and prioritised.

- **Enhancing integration across support strands**
  The interaction between emotional support and practical support is a key driver of impact. Strengthening coordination between these elements, for example through more structured referral pathways or shared case visibility, could enhance overall effectiveness.

- **Leveraging social media as a front door to support**
  Social media is already functioning as an entry point for many carers. Developing clearer pathways from online engagement into structured support could increase conversion from initial contact to sustained engagement.

- **Addressing accessibility and timing of support**
  Some evidence points to gaps in availability, particularly outside standard hours. Exploring flexible or extended access models may help to reach carers at points of greatest need, although this would need to be considered alongside the potential cost implications.

- **Expanding reach to under-represented groups**
  Current data suggests limited diversity among service users. Targeted outreach and partnership development could support engagement with a broader range of carers and / or facilitate more targeted engagement with particular minority groups.

- **Strengthening evidence on longer-term outcomes**
  While short- and medium-term outcomes are strongly evidenced, there is an opportunity to build further understanding of longer-term impact. This could potentially include an economic evaluation of the service's impact, in which it would be possible to monetise the prevention aspects of the service (through sustained wellbeing, financial stability, and reduced system escalation) and the avoidance of more costly interventions over a longer period of time.

15 Concluding reflections

Overall, the evaluation demonstrates that Dementia Carers Count delivers meaningful and sustained impact for carers through a model that is both effective and distinctive. Its strength lies in its ability to respond to complexity, to remain alongside carers over time, and to translate fragmented systems into navigable pathways.

In a context where carers often feel isolated, overwhelmed, and uncertain, this combination of support provides not only immediate relief, but a foundation for ongoing resilience and engagement. The findings suggest that the service is not only meeting existing need, but addressing a critical gap within the wider system, with clear potential for further development and scaling.

Apteligen Limited
Suite 7a, Building 6
Croxley Park
Hatters Lane
Watford WD18 8YH
email: corporate@apteligen.co.uk
www.apteligen.co.uk