



SIDECAR

Scales measuring the Impact of **DE**mentia on **CAR**ers

Implementing SIDECAR into Practice A Toolkit

The SIDECAR Toolkit

How to get the best out of a survey designed *by carers for carers*.

Welcome to the SIDECAR Toolkit, a guide to using a free survey designed to assess the quality of life of unpaid family carers of people living with dementia.

This set of resources is based on research with voluntary sector organisations who used SIDECAR for a period of a year. It draws on insights from both staff and carers of people living with dementia. It provides guidance on:

- How and why SIDECAR was developed.
- How SIDECAR can be used and its benefits.
- How scores generated by SIDECAR can inform services and carer support.

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What is SIDECAR and why was it developed?

Carers of people living with dementia have the legal right to an assessment of their needs and many voluntary sector organisations provide them. However, the assessments are usually focused on carers' practical needs. Research shows that it is important to take a holistic approach, including psychological and social needs as well.

SIDECAR (Scales measuring the Impact of Dementia on CARers) is a survey that takes this holistic approach to measure quality of life, identifying the practical, psychological and social/information needs of carers of people living with dementia. The survey has 39 statements, split across three sections:

- Direct impact of caregiving (SIDECAR D), focused on practical needs.
- Indirect impact of caregiving (SIDECAR I), focused on psychological needs.
- Support and Information needs (SIDECAR S)

Each section includes statements with which carers are asked to either agree or disagree – for example, “Almost all of my conversations are about dementia or caring” or “I find it hard to understand how dementia affects the person I care for”.

You can download a copy of the SIDECAR survey [here](#).

How was SIDECAR developed?

SIDECAR was developed in collaboration by the Universities of Leeds, Bradford, Bangor, Birmingham, Cambridge, and Exeter.

Forty-two carers were involved in developing the initial statements. All statements were generated using the carers' own words, and represented the main issues they had faced in their carer role.

After this, twenty-two carers reviewed the statements to check the questions made sense and to see whether they preferred a binary scale – *agree or disagree* – or a scale with more options: *strongly agree, agree, neutral, disagree, strongly disagree*. Most preferred the binary scale.

To test the survey, 566 carers across England and Wales responded to the seventy statements. Analysis of results reduced the statements to thirty-nine. Further tests showed SIDECAR was an accurate measure of carers' quality of life and sensitive to changes in caring roles.



Why use SIDECAR?

Feedback from people with whom we tested SIDECAR indicates that by asking questions “designed by carers for carers”, SIDECAR can explore the lives of unpaid family carers in all their complexity, offering a detailed understanding of care-related issues.

With sections on social engagement, emotional wellbeing, and information needs, SIDECAR can provide a comprehensive “snapshot” of carers’ circumstances, in a way that few other approaches can manage so efficiently.

“From a carer’s point of view, seeing those questions written down, it was almost like a relief, because they were the things that people don’t talk to you about. They’re the things that doctors don’t ask you [and] that medical people won’t ask you when they come in.”

Dementia Support Advisor

By using SIDECAR to identify specific care situations that might benefit from additional support, it is possible for organisations to enhance carers’ quality of life over time, as well as that of the people living with dementia they care for. This might involve putting in place suitable support packages that have not previously been considered.

Even without additional support, some carers value the act of completing SIDECAR with a dedicated support advisor and report that it makes them feel valued and less isolated.

“I felt that it was a consequence of SIDECAR that I did have one-to-one support, which was great. It’s nice. I felt valued and cared for.”

Carer for a person living with dementia

Having identified needs through SIDECAR, organisations might expand or improve their support services, focusing on both the social and emotional wellbeing of carers.

For instance, SIDECAR statements about financial circumstances might encourage the organisation to focus on providing advice about power of attorney or welfare support packages. Statements about social isolation might prompt the organisation to “signpost” carers to national telephone support helplines.

“Knowing about power of attorney or knowing about social services, and actually some carers are, like, ‘I don't think I have had a clear information about that.’ So SIDECAR led to having chats about that or making referrals for certain things.”

Dementia Support Advisor

Organisations can use SIDECAR alongside their existing surveys and tools, helping staff to deliver accurate and time-efficient assessments. The survey’s two-option response design allows for a rapid review of carers’ circumstances and their support needs, directly addressing the issues that matter to each person.

"Some of the questions on SIDECAR perhaps helped us to do a better Carers Needs Assessment ... I can ask some of the questions as part of the Carers Needs Assessment, like when you say, 'Do you struggle managing time for yourself?' and things like that. The survey words it a little bit differently, because it's focused. So sometimes I apply that question in that context."

Dementia Support Advisor

SIDECAR also provides organisations with information about carers' experiences that can be scored. Repeat scores can be used to find out how carers' quality of life changes over time, or as a result of the support you provide. This can give you hard data to demonstrate the effectiveness of your services, as well as helping identify areas to develop in the future to offer more effective support. This information can be useful when applying for funding from commissioners and other agencies.

"I've just shared the scales with two commissioners ... They were talking about, 'How do we evaluate the effectiveness of all our carer services?' ... So, I sent them SIDECAR. I felt confident enough about the scale to say this is something that we should be using."

Dementia Support Manager

In summary, SIDECAR can be used in the following ways:

- Measuring individual carer's needs
- Assessing how their needs change over time
- Establishing specific services a carer might need
- Identifying carers who urgently need support
- Starting conversations with carers
- Assessing the effectiveness of services provided by carer organisations
- Gaining an understanding of carers' needs in a whole region
- Collecting data for commissioning/funding reports

Who should use SIDECAR?

SIDECAR can be used by any organisation wishing to develop and enhance the support services it provides for carers and the people living with dementia they care for.

These organisations are usually community support groups such as the many Carers Centres found in UK cities and towns. It can also be used by anybody in the health and social care system with an interest in supporting carers of people living with dementia.

Staff at voluntary sector organisations or other health and social care professionals are the people most likely to benefit from including SIDECAR in their daily work, alongside other assessment tools.



SIDECAR can be completed independently by carers. This might be when the carer, busy in their role, has little time to spare to meet with an advisor or if they prefer to respond to the survey in private. Most carers prefer filling in the survey with an advisor, however.

The three different parts of SIDECAR can be used in any way that staff prefer, either as a complete survey to explore all aspects of carers' situations (their social engagement, emotional wellbeing, and information needs) or as separate parts to focus on specific issues.

Staff working for voluntary sector organisations have found that, as well as agreeing or disagreeing with the survey's statements, many carers prefer to discuss each in detail. This can lead to a more complex understanding of their situations, allowing appropriate support to be put in place.



What are the benefits of using SIDECAR?

Carers who have completed SIDECAR report positive impacts, particularly how it encourages them to think about and value themselves when, in the past, they have had to focus exclusively on the person living with dementia.

Many carers reported feeling less isolated after completing the survey and took comfort from feeling understood.

“SIDECAR is just another confirmation that I shouldn’t feel guilty about taking half an hour to go and do something, or saying to the kids sometimes, ‘I can’t do it. You need to do this today because I need to do things for me.’ ”

Carer for a person living with dementia.

SIDECAR can also have a positive impact on people being cared for by helping carers to look after themselves and avoid the kind of crises that sometimes arise in complex care situations. The survey can help to identify areas of support required. This can lead to suitable services being put in place by voluntary sector groups and other agencies.

“Thinking of that lady who scored high on SIDECAR, her husband [living with dementia] is now coming to our group more often, you know, and we’re looking for more groups for him. So, the outcome is that the person living with dementia is getting more support.”

Dementia Support Advisor

Once SIDECAR has become part of their daily working practices, staff from voluntary sector organisations report many benefits. That said, it can take them some time to grow familiar and confident with using SIDECAR.

Some staff have found the survey helped them to learn more about carers who seek their support. This can lead to adaptations of existing services or more suitable support packages being put in place, sometimes by “signposting” carers to other agencies.

Many staff have found SIDECAR fits well alongside other assessment tools, helping them to carry out quicker and more comprehensive explorations of carers’ situations and their support needs.

“I think overall, it was a useful process for me as a worker. I learnt a lot more about dementia and the carer by doing this piece of work with them ... I mean, some of the questions on the SIDECAR survey perhaps helped us to do a better Carers Needs Assessment.”

Dementia Support Advisor

Once SIDECAR is successfully integrated in the voluntary sector organisation, management staff report benefits in the way the group operates.

Getting a better understanding of the lives of carers accessing their services has enabled staff to allocate resources to their needs, as well as providing evidence of the organisation’s effectiveness in supporting carers.

“We’ve identified through [SIDECAR] that there’s a gap in terms of psychological support for carers, and the needs are there. So, it gives us extra evidence to say, actually, I think we need to do more of these carer support groups, and we can design more interventions ... To evidence that to the commissioners to be able to develop more interventions and tailor our support on psychological issues.”

Dementia Support Manager

Using SIDECAR in your organisation

If you would like to use SIDECAR in your organisation or as part of your role in supporting carers of people living with dementia, there are a number of issues you will need to consider. To make the planning process more straightforward, we have developed an implementation plan. You can download the template [here](#).

Here are ten steps we recommend for the effective implementation of SIDECAR in your organisation:

1

Set up a SIDECAR leadership team tasked with overseeing the implementation of SIDECAR. This SIDECAR team does not need to be larger than five or six members (including carers of people living with dementia).



2

Include at least two carers in your SIDECAR leadership team. A number of organisations told us that while implementing SIDECAR, staff were guided by the experience of carers.



3

Identify a SIDECAR “champion” among your staff who will take day-to-day responsibility for ensuring that colleagues are engaged with SIDECAR. This person will need time and resources allocated to carry out the role.

4

As a team, decide what you want to achieve when using SIDECAR and the way you will reach your goals. One example might be:

“We want to identify the key needs of carers recently referred to our organisation with a view to signposting them to the most appropriate support.”



5

Consider how prepared your organisation and team are to implement SIDECAR. Do you have the time, resources and support you need?



6

Organise a meeting with staff members who will use SIDECAR. Discuss barriers they foresee and come up with ideas about how you might overcome them. For example:

Barrier: Staff do not feel confident in using SIDECAR.

Solution: Host a training session where staff can practice completing SIDECAR with each other.

OR ...

Barrier: Staff don't understand the purpose of SIDECAR.

Solution: Create a leaflet explaining what SIDECAR is and why your organisation wishes to use it. Highlight potential benefits for both staff and carers of people living with dementia.

7

Plan the process. How will you complete SIDECAR with carers? Will it be in person or over the phone? Will carers complete SIDECAR on their own or with staff support?



8

Using information from staff meetings and discussions in the leadership team, complete your implementation plan.



9

Start using SIDECAR! This may involve adapting existing staff routines and organisational procedures (many tips and recommendations are included at the end of this toolkit to help). Be prepared to learn as you go along. Be flexible.



10

Assuming your implementation is successful, you need to think ahead about how you can continue using SIDECAR. Can you foresee any barriers in sustaining it? Put together a plan for its continuing use!

Making sense of SIDECAR data

You can download a copy of the SIDECAR survey [here](#). There are a number of ways that its scores can help your organisation, depending on your purpose for using it. In this section, we go through the steps on how the survey scores can be used for different purposes.

There is no complicated maths involved! Basically, the carers' responses just need entering into a simple spreadsheet. You can access and download 'Scoring SIDECAR' [here](#).

Assessing the individual carer's needs

The simplest way to identify areas where a carer of someone living with dementia may need further support is to pay attention to their responses to individual statements.

For example, while completing SIDECAR D (direct impact of care), you might notice that, while the carer has disagreed with most statements, they have agreed with 'I spend a lot of time trying to sort out services'. This indicates that the carer needs support with this aspect of their role.

You can go a step further by adding up total scores for each scale. To do this, add all "agrees" for SIDECAR D (direct impact of care) and SIDECAR I (indirect impact), and add all the "disagrees" for SIDECAR S (support and information needs). This will give three "raw scores".

Instead of adding it up yourself, you can obtain the "raw scores" using the Scoring SIDECAR spreadsheet [here](#). Completing it is straightforward:

1. In the columns for First Assessment enter "agree" or "disagree" for each statement using the dropdown menu.

2. The Scoring SIDECAR sheet will automatically give you totals for each SIDECAR section.

As well as the raw scores, the Scoring SIDECAR sheet gives you a converted 0-100 score. This allows you to easily compare the totals of each scale.

The totals for each scale will indicate in which area/s the carer needs the most support. For example, if you completed the whole SIDECAR survey with a carer and added up the raw scores, you might get the following raw score totals and converted 0-100 scores:

$$\text{SIDECAR D} = 17/18 = 88/100$$

$$\text{SIDECAR I} = 8/10 = 78/100$$

$$\text{SIDECAR S} = 3/11 = 32/100$$

The higher the score, the worse we consider the carer's quality of life. The high scores on SIDECAR D and I therefore suggest that the carer would benefit from support prioritising the direct impact of caring and their psychological wellbeing.

If you need to convert the raw scores to 0-100 scores without the Scoring SIDECAR sheet, you can convert each raw score into a converted 0- 100 by consulting the following table (also included on the final page of the SIDECAR survey).

SIDECAR D		SIDECAR I		SIDECAR S	
<i>Raw score</i>	<i>0-100 score</i>	<i>Raw score</i>	<i>0-100 score</i>	<i>Raw score</i>	<i>0-100 score</i>
0	0	0	0	0	0
1	11	1	19	1	14
2	19	2	32	2	24
3	25	3	41	3	32
4	30	4	49	4	39
5	34	5	56	5	45
6	38	6	63	6	52
7	42	7	70	7	58
8	46	8	78	8	65
9	49	9	88	9	74
10	53	10	100	10	85
11	56			11	100
12	60				
13	64				
14	68				
15	73				
16	79				
17	88				
18	100				

Using this table, we might find that one carer has recorded the following:

SIDECAR D		SIDECAR I		SIDECAR S	
<i>Raw score</i>	<i>Standardised score</i>	<i>Raw score</i>	<i>Standardised score</i>	<i>Raw score</i>	<i>Standardised score</i>
6	38	10	100	3	32

The higher the score the worse the carer's quality of life. This person's standardised score for SIDECAR I is 100, so they have poor quality of life for this aspect.

Measuring changes in a carer's quality of life

You may have asked carers to complete SIDECAR more than once with a view to identifying meaningful changes over time. In this case, you will need to compare the “before” and “after” scores to see whether there have been any changes, either positive or negative.

The Scoring SIDECAR spreadsheet (you can download it [here](#)) will do this for you. In the columns for Follow-up, enter “agree” or “disagree” for each statement using the dropdown menu.

The Scoring SIDECAR sheet will automatically tell you the “score change” and indicate if the carer's quality of life is an improvement, is worse, or if there is no meaningful change.

For meaningful change at an individual level, there needs to be the following difference in points:

SIDECAR D – a change by 9 points.

SIDECAR I – a change of 10 points.

SIDECAR S – a change of 11 points.

A lower score the second time means *improving* quality of life, and higher score on the second time indicates *worsening* quality of life.

Please be aware that if the carer's quality of life is shown to have become worse, it might be due to their changing circumstances rather than as a result of your service being ineffective.

Assessing the collective needs of carers

You may have chosen to implement SIDECAR into your organisation with a view to getting an overview of carers' needs in order to help you decide what services to offer in the future and which to request funding for. In this case, you can collate SIDECAR scores for a whole group.

We have created a second Excel spreadsheet (Collating SIDECAR data) to help you with this and you can download it [here](#).

The Collating SIDECAR sheet will help you to see at a glance the range of SIDECAR scores of carers in your organisation. You will then be able to say if carers you support generally have a high or a low quality of life when they are referred to you for support.

You will be able to see from the total scores if the main needs of carers in your service are connected with direct effects of caring (SIDECAR D), psychological consequences (SIDECAR I) or lack of support and information (SIDECAR S). This could help you target your service development – for example, towards psychological support.

You may have decided to use SIDECAR to evaluate your support service by asking carers to complete SIDECAR before and after they have accessed it. The collated scores will show you whether the quality of life of the carers you support improves over time or not. You could use this to adjust your services or to show commissioners your effectiveness.

Here is an example comparing scores at two time points for five carers. Remember: a higher score shows more needs and lower quality of life. If scores go down over time, this is good.

Carer	SIDE CAR D				SIDE CAR I				SIDE CAR I			
	First assessment		Follow up		First assessment		Follow up		First assessment		Follow up	
	Raw score	Standardised score	Raw score	Standardised score	Raw score	Standardised score	Raw score	Standardised score	Raw score	Standardised score	Raw score	Standardised score
1	14	68	10	53	8	78	8	78	4	39	8	65
2	13	64	15	73	6	63	6	63	4	39	3	32
3	12	60	15	73	9	88	9	88	9	74	7	58
4	9	49	10	53	6	63	7	70	8	65	2	24
5	12	60	12	60	6	63	6	63	0	0	5	45

- Carer 1's practical needs *decreased* over time (score indicated in green) but their support needs *increased* (score in red).
- Carer 3's practical needs *increased* over time but their support needs *decreased*.
- For all five carers, there was no change in psychological needs.

Tips and recommendations for using SIDECAR

This section draws on insights gained from research with the voluntary sector groups that took part in the SIDECAR study on which this toolkit is based. It is hoped that they will provide guidance as you seek to implement the survey within your own organisational practices.

<p>Getting started</p>	<ul style="list-style-type: none"> • Management should communicate the purpose of SIDECAR very clearly and explain why the organisation has chosen to use it (for example, to demonstrate to commissioners how effective their services are). • Identify the survey’s benefits to staff, carers, and the people living with dementia they support. • Consider how SIDECAR can work alongside existing carer assessment processes. How can the survey be best incorporated into existing practices?
<p>Preparing to use SIDECAR</p>	<ul style="list-style-type: none"> • Encourage staff to practice using SIDECAR by completing the survey themselves, perhaps with a colleague asking them the questions. In-house training enhances confidence and familiarity with the survey. • Decide at what stage in the caring role you plan to use SIDECAR. It might be better to avoid the very earliest stages, when carers are dealing with significant changes, and yet not use it so late that any issues identified by the survey will benefit less from targeted support.
<p>Using SIDECAR with carers</p>	<ul style="list-style-type: none"> • Encourage carers not to “overthink” responses when completing SIDECAR. Too much reflection can make it difficult to decide whether to answer agree or disagree. It is best to go on first instincts. • Be aware that SIDECAR can raise emotional issues for carers, so it is important for staff to provide appropriate support.

	<ul style="list-style-type: none"> • Be aware that not all statements in SIDECAR are relevant to all carers, so some degree of flexibility is required when using the survey. • Don't worry if staff initially find it takes a long time to complete SIDECAR. Our research showed that the process becomes quicker with staff familiarity and practice. • Although SIDECAR can be completed quickly, staff should set aside sufficient time to complete it with carers, as each statement can lead to useful discussions, resulting in detailed understandings of their situations. • Allow carers to decide where they prefer to complete SIDECAR. Some might like to do it alone at home and others in a public venue with a member of support staff. Survey responses are more likely to be accurate if carers feel comfortable when providing them. • Be careful not to raise carers' expectations unrealistically when using SIDECAR. The survey is designed to identify specific needs for support but solutions depend on the availability of suitable services. • Be aware that carers might consider some SIDECAR statements intrusive and may refuse to respond to them. Reassure carers that it is fine to skip these parts and that all responses will be treated confidentially.
<p>Other considerations while using SIDECAR</p>	<ul style="list-style-type: none"> • Decide when it is best to use SIDECAR for a second time with carers in order to explore the impact of your services on their quality of life. How long will any support put in place take to help them? • Encourage your SIDECAR "champion" and other staff to arrange weekly or monthly get-togethers. How are things going? Have any unanticipated challenges arisen? How can these be overcome?

Further information

If you would like to enquire further into any aspect of our SIDECAR research, please contact a member of the team:

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