

SIDECAR

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

SIDECAR is a questionnaire to assess the quality of life of friends and family caring for someone living with dementia. SIDECAR comprises three separate scales. All items within the scales are scored using a binary Agree/Disagree response format. The time frame reference for the questions is TODAY.

- If you wish to use SIDECAR please register with the University of Leeds Fast Licensing Platform. A link to this may be found at the DECIDE website <https://licensing.leeds.ac.uk/> .
- Please include the copyright statement when administering SIDECAR.
- Please reference the relevant papers in any dissemination (papers and presentations).

SIDECAR D Direct Impact.
 This is the primary quality of life scale of 18 items.

SIDECAR I Indirect Impact.
 This is made up of 10 items.

SIDECAR S Support and Information.
 This has 11 items and is reverse scored.

Scoring information is provided at the end of this document.

SIDECAR D Direct Impact

Please put an **X** to indicate if you agree or disagree with these statements.
Please complete the questions on how things are for you **today**.

	Agree	Disagree
1 I regularly have to do things as a carer that I am not comfortable with	<input type="checkbox"/>	<input type="checkbox"/>
2 Almost all of my conversations are about dementia or caring	<input type="checkbox"/>	<input type="checkbox"/>
3 People see me only as a carer rather than a person in my own right	<input type="checkbox"/>	<input type="checkbox"/>
4 It is hard to find anyone else to spend time looking after the person I care for	<input type="checkbox"/>	<input type="checkbox"/>
5 I dread the future	<input type="checkbox"/>	<input type="checkbox"/>
6 I can only get through one day at a time	<input type="checkbox"/>	<input type="checkbox"/>
7 My role in our relationship has changed	<input type="checkbox"/>	<input type="checkbox"/>
8 Receiving help is more hassle than it's worth	<input type="checkbox"/>	<input type="checkbox"/>
9 I have to cope with a lot of opinions about what I should and shouldn't do	<input type="checkbox"/>	<input type="checkbox"/>
10 There is always something new to deal with when providing care	<input type="checkbox"/>	<input type="checkbox"/>
11 Little things add up to make caring difficult	<input type="checkbox"/>	<input type="checkbox"/>
12 I don't take very good care of myself	<input type="checkbox"/>	<input type="checkbox"/>
13 I often feel I want to escape my caring responsibilities	<input type="checkbox"/>	<input type="checkbox"/>
14 Caring prevents me from fulfilling my other responsibilities (e.g. working, being a parent, volunteering)	<input type="checkbox"/>	<input type="checkbox"/>
15 I feel guilty if I do something for myself	<input type="checkbox"/>	<input type="checkbox"/>
16 I would like it if others tried harder to understand the situation I am in	<input type="checkbox"/>	<input type="checkbox"/>
17 Everything I do has to be planned in advance now	<input type="checkbox"/>	<input type="checkbox"/>
18 I spend a lot of time trying to sort out services	<input type="checkbox"/>	<input type="checkbox"/>

SIDECAR I Indirect Impact

Please put an **X** to indicate if you agree or disagree with these statements.
Please complete the questions on how things are for you **today**.

	Agree	Disagree
1 I worry about what people think of the behaviour of the person I care for	<input type="checkbox"/>	<input type="checkbox"/>
2 It is hard to decide what to tell others about the person's dementia	<input type="checkbox"/>	<input type="checkbox"/>
3 I have distressing arguments with the person I care for	<input type="checkbox"/>	<input type="checkbox"/>
4 I worry about what will happen if I can no longer provide care	<input type="checkbox"/>	<input type="checkbox"/>
5 It is hard to know when to help the person I care for and when to let them do things on their own	<input type="checkbox"/>	<input type="checkbox"/>
6 It is distressing when I have to upset the person I care for to do the right thing for them	<input type="checkbox"/>	<input type="checkbox"/>
7 I find it hard to understand how dementia affects the person I care for	<input type="checkbox"/>	<input type="checkbox"/>
8 It is distressing to see the person I care for changing	<input type="checkbox"/>	<input type="checkbox"/>
9 I feel the good things we have won't last	<input type="checkbox"/>	<input type="checkbox"/>
10 I worry about the safety of the person I care for	<input type="checkbox"/>	<input type="checkbox"/>

SIDECAR S Support and Information

Please put an **X** to indicate if you agree or disagree with these statements.
Please complete the questions on how things are for you **today**.

	Agree	Disagree
1 I get help from people who know a lot about how to care for someone with dementia	<input type="checkbox"/>	<input type="checkbox"/>
2 I have been given clear information about finances (e.g. benefits, financial planning)	<input type="checkbox"/>	<input type="checkbox"/>
3 I receive all the support I need to help me provide care	<input type="checkbox"/>	<input type="checkbox"/>
4 I have planned for when things get worse	<input type="checkbox"/>	<input type="checkbox"/>
5 I have been given clear information about medical issues (e.g. diagnosis, managing medications)	<input type="checkbox"/>	<input type="checkbox"/>
6 I have been given clear information about how to make future plans (e.g. care arrangements if circumstances changed, power of attorney)	<input type="checkbox"/>	<input type="checkbox"/>
7 I have been given clear information about social care for the person I care for (e.g. adult social care services)	<input type="checkbox"/>	<input type="checkbox"/>
8 I am willing to ask for help if I need it	<input type="checkbox"/>	<input type="checkbox"/>
9 I feel other people care about me	<input type="checkbox"/>	<input type="checkbox"/>
10 I am well supported by medical professionals (e.g. GPs, psychiatrists)	<input type="checkbox"/>	<input type="checkbox"/>
11 I have enough guidance to know how to provide care (e.g. managing difficult behaviours, providing activities)	<input type="checkbox"/>	<input type="checkbox"/>

SCORING

SIDECAR D – Simply add the number of ‘**Agree**’ responses. This scale is made up of 18 items, consequently the score range is 0-18, where a higher score reflects a worse quality of life.

SIDECAR I – Simply add the number of ‘**Agree**’ responses. This scale is made up of 10 items, consequently the score range is 0-10, where a higher score reflects a worse quality of life.

SIDECAR S – Simply add the number of ‘**Disagree**’ responses. This scale is made up of 11 items, consequently the score range is 0-11, where a higher score reflects a worse quality of life.

In the case of COMPLETE data, a 0-100 linear score transformation is available for each of the SIDECAR scales, as below.

*Please note that this transformation is only valid when ALL items within a scale have responses

SIDECAR D	
Raw Score	0-100 Score
0	0
1	11
2	19
3	25
4	30
5	34
6	38
7	42
8	46
9	49
10	53
11	56
12	60
13	64
14	68
15	73
16	79
17	88
18	100

SIDECAR I	
Raw Score	0-100 Score
0	0
1	19
2	32
3	41
4	49
5	56
6	63
7	70
8	78
9	88
10	100

SIDECAR S	
Raw Score	0-100 Score
0	0
1	14
2	24
3	32
4	39
5	45
6	52
7	58
8	65
9	74
10	85
11	100