

Unmet Needs Instrument for Carers of People with Dementia

(UNI-C46)

Your need for help

The following questions ask about your need for help as a result of caring for a person with dementia.

For each item, please tick the response that best describes your need for help **in the last month**.

As everyone will have a different experience with dementia, not all of the items will be relevant to you and your situation. In these cases tick "I didn't need help".

Please answer as honestly as you can to help us understand where support is most needed.

Acknowledgements

Mansfield E, Cameron E, Clapham M, Hall A, Boyes A (2025). Psychometric evaluation of the unmet needs instrument for carers of people with dementia (UNI-C). J Patient Rep Outcomes 9(1): 28.

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Part A: The following items relate to **your own wellbeing**.

In the last month did you need help with:	I <u>didn't</u> need help	I <u>had</u> <u>enough</u> help	I could have used <u>a little</u> <u>more</u> help	I could have used <u>a lot</u> <u>more</u> help
1. Looking after your own health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Getting enough sleep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Balancing your role as a carer with other responsibilities (e.g. family, work)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Asking for help from family and friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Managing stress	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Keeping up your social activities or hobbies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Finding the emotional energy that you need to care for the person you support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Feeling sad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Feeling guilty if you enjoy yourself without the person you support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10 Feeling unsure in your abilities as a carer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11 Worrying about what will happen in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12 Coping with changes in your relationship with the person you support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13 Understanding the perspective of the person you support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14 Explaining to others what you are going through	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15 Dealing with negative reactions of people towards the person you support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16 Coping with thinking for the person you support as well as yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part B: The following items relate to **managing practical needs**.

In the last month did you need help with:	I <u>didn't</u> need help	I <u>had</u> <u>enough</u> help	I could have used <u>a little</u> <u>more</u> help	I could have used <u>a lot</u> <u>more</u> help
17. Being at appointments with the person you support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Helping the person you support with everyday tasks (e.g. bathing or dressing)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Doing tasks which the person you support used to do (e.g. mowing the lawn, doing the laundry)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Preparing meals that the person you support will eat	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Keeping the person you support in touch with family and friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Finding meaningful and enjoyable activities for the person you support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Ensuring the person you support is safe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Keeping the person you support living at home for as long as possible	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Encouraging the person you support to be more independent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Involving the person you support in making decisions about their care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part C: The following items relate to **managing the symptoms of dementia**

In the last month did you need help with:	I <u>didn't</u> need help	I <u>had</u> <u>enough</u> help	I could have used <u>a little</u> <u>more</u> help	I could have used <u>a lot</u> <u>more</u> help
27. The person you support having trouble remembering things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Changes in mood of the person you support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Sleep problems in the person you support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Toileting issues in the person you support (e.g. constipation, getting to the toilet in time)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Aggression from the person you support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. The person you support asking the same questions over and over	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. The person you support following you around	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. The person you support having a lack of understanding about the situation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Part D: The following items relate to **finding information**.

In the last month did you need help with:	I <u>didn't</u> need help	I <u>had</u> <u>enough</u> help	I could have used <u>a little</u> <u>more</u> help	I could have used <u>a lot</u> <u>more</u> help
35. Accessing a home care package with enough help for the person you support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Knowing what care providers to contact for the person you support and when	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Navigating the My Aged Care website	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Accessing respite care (care that you or the person you support can stay in for a short time)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Uncertainty about who will care for the person you support if something happens to you	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. Finding support groups for carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. Understanding how the dementia might change over time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Finding information on possible treatments for dementia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. Being aware of clinical trials and research that we could be involved in	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. Knowing when the person you support should move to a nursing home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. Accessing financial assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46. Knowing what to do when the person you support can no longer make decisions on their own	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>