

1 **S1** Table. Adaptation of caregiver question set

<u>Original</u>	<u>Modified Question after focus groups</u>	<u>After field testing and team discussion</u>
<p>1. <u>In the past five years, has anyone close to you died of a terminal illness like cancer, motor neurone disease, or emphysema? If yes, could you say what that illness was?</u> (Interviewer: If more than one person, ask about the most recent person to die of a terminal illness.)</p> <p><input type="checkbox"/> <u>No</u></p> <p><input type="checkbox"/> <u>Emphysema/other lung disease</u></p> <p><input type="checkbox"/> <u>End stage heart failure</u></p> <p><input type="checkbox"/> <u>End stage liver failure</u></p> <p><input type="checkbox"/> <u>Cancer</u></p> <p><input type="checkbox"/> <u>Motor neurone disease/multiple sclerosis</u></p> <p><input type="checkbox"/> <u>End stage kidney failure</u></p> <p><input type="checkbox"/> <u>HIV/AIDS</u></p> <p><input type="checkbox"/> <u>Other (specify)</u></p>	<p><u>In the past five years, has anyone close to you died of a terminal illness? If yes, could you say what that illness was?</u> (Interviewer: If more than one person, ask about the most recent person to die of a terminal illness.)</p> <p><u>Options – no change</u></p>	<p><u>In the past five years, has anyone close to you died of a terminal illness like cancer, motor neurone disease, or emphysema? If yes, could you say what that illness was?</u> (Interviewer: If more than one person, ask about the most recent person to die of a terminal illness.)</p> <p><u>Options – no change</u></p>

<input type="checkbox"/>	<u>Don't know illness</u>		
2.	<u>How long ago did this person die?</u> <u> </u> years <u> </u> months	<u>When did this person die?</u> <u> </u> month <u> </u> year <u>Where did they die?</u> <input type="checkbox"/> <u>Home (theirs)</u> <input type="checkbox"/> <u>Home (yours)</u> <input type="checkbox"/> <u>Home (we lived together)</u> <input type="checkbox"/> <u>hospital</u> <input type="checkbox"/> <u>hospice</u> <input type="checkbox"/> <u>nursing care home</u> <input type="checkbox"/> <u>residential care home</u> <input type="checkbox"/> <u>Other (specify)</u>	<u>This is now two separate questions</u> <u>(when and where)</u> <u>Show card for options</u>
3.	<u>What was your relationship to this person?</u> (Interviewer: If more than one person, ask about the most recent person to die of a terminal illness.) <input type="checkbox"/> <u>Spouse/partner</u> <input type="checkbox"/> <u>Parent</u> <input type="checkbox"/> <u>Child</u>	<u>What was your relationship to this person?</u> <u>This person was my....</u> <input type="checkbox"/> <u>Spouse/partner</u> <input type="checkbox"/> <u>Parent</u> <input type="checkbox"/> <u>Child</u>	<u>What was your relationship to this person?</u> <u>INTERVIEWER: If more than one person, ask about the person who died most recently.</u> <u>Options – no change</u>

<input type="checkbox"/> Sibling <input type="checkbox"/> Other relative <input type="checkbox"/> Friend <input type="checkbox"/> Other (specify)		<input type="checkbox"/> Brother/sister (including half or step brother or sister) <input type="checkbox"/> Other relative <input type="checkbox"/> Friend <input type="checkbox"/> Other (specify)	
4.	<u>What was your most involved level of care for this person?</u> <i>[Put responses on show card]</i> <input type="checkbox"/> Day-to-day hands on care <input type="checkbox"/> Intermittent hands on care <input type="checkbox"/> Rare hands on care <input type="checkbox"/> Didn't provide any care but they were still close to me	<u>What was your maximum level of personal care for this individual?</u> <u>Tick one, and please estimate how long this was (circle time).</u> <i>[Put responses on show card]</i> <input type="checkbox"/> Daily: ○ Days ○ Weeks ○ Months ○ more than a year <input type="checkbox"/> Occasional : _____ ○ Days ○ Weeks ○ Months ○ more than a year <input type="checkbox"/> Rare:	<u>What was your maximum level of personal care for this individual?</u> <u>INTERVIEWER: By personal care</u> <u>I mean things like helping with washing, dressing, going to the toilet, or eating.</u> <u>Show card for options</u> <input type="checkbox"/> Daily _____ <input type="checkbox"/> Occasional/intermittent <input type="checkbox"/> Rare _____ <input type="checkbox"/> Didn't provide any personal care but they were still close to me <input type="checkbox"/> Other (PLEASE SPECIFY)

<input type="checkbox"/> Much better than expected <input type="checkbox"/> Better than expected <input type="checkbox"/> As expected <input type="checkbox"/> Worse than expected <input type="checkbox"/> Much worse than expected <input type="checkbox"/> I didn't know what to expect	<u>[Put responses on show card]</u>	<input type="checkbox"/> <u>Daily:</u> <input type="radio"/> <u>Days</u> <input type="radio"/> <u>Weeks</u> <input type="radio"/> <u>Months</u> <input type="radio"/> <u>more than a year</u> <input type="checkbox"/> <u>Occasional :</u> <input type="radio"/> <u>Days</u> <input type="radio"/> <u>Weeks</u> <input type="radio"/> <u>Months</u> <input type="radio"/> <u>more than a year</u> <input type="checkbox"/> <u>Rare:</u> <input type="radio"/> <u>Days</u> <input type="radio"/> <u>Weeks</u> <input type="radio"/> <u>Months</u> <input type="radio"/> <u>more than a year</u> <input type="checkbox"/> <u>Didn't provide any personal</u> <u>care but they were still close to</u> <u>me</u> <input type="checkbox"/> <u>Other (specify):</u>	<u>Show card for options</u> <input type="checkbox"/> <u>Daily</u> <input type="checkbox"/> <u>Occasional/intermittent</u> <input type="checkbox"/> <u>Rare</u> <input type="checkbox"/> <u>Didn't provide any personal</u> <u>care but they were still close to</u> <u>me</u> <input type="checkbox"/> <u>Other (PLEASE SPECIFY)</u> <u>INTERVIEWER: Thinking about</u> <u>the time when you were providing</u> <u>help like this, how long was this</u> <u>for?</u> <input type="checkbox"/> <u>Days</u> <input type="checkbox"/> <u>Weeks</u> <input type="checkbox"/> <u>Months</u> <input type="checkbox"/> <u>More than a year</u>
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		<ul style="list-style-type: none"> <u>○ Days</u> <u>○ Weeks</u> <u>○ Months</u> <u>○ more than a year</u> 	
6.	<p><u>Did this person who died of a terminal illness use a palliative care service?</u></p> <p>(Examiner: “A palliative care service aims to comfort, not to cure, to relieve pain and distress for people who are dying and to support patients, families and friends in approaching death and coping with grief.”)</p> <p><input type="checkbox"/> <u>Yes</u></p> <p><input type="checkbox"/> <u>No</u></p> <p><input type="checkbox"/> <u>Don’t know</u></p>	<p><u>Was a palliative care service used?</u> (Interviewer: “A palliative care service aims to comfort, not to cure, to relieve pain and distress for people who are dying and to support patients, families and friends in approaching death and coping with grief. Typical services include; hospice, visits from Marie Curie or/and Macmillan nurses.”)</p> <p><u>Options – no change</u></p> <p><u>If no, could you please say why a palliative care service was not used?</u></p> <p><u>Options – no change</u></p>	<p><u>Show card for options</u></p> <p><u>No further change</u></p>
7.	<p><u>If no, could you please say why a palliative care service was not used?</u></p>		

<input type="checkbox"/> <u>A service was not available</u> <input type="checkbox"/> <u>Didn't know about such a service</u> <input type="checkbox"/> <u>Service was not wanted</u> <input type="checkbox"/> <u>Family/friends looked after</u> <input type="checkbox"/> <u>Death was sudden</u> <input type="checkbox"/> <u>The person died in hospital</u> <input type="checkbox"/> <u>Other (specify)</u> <input type="checkbox"/> <u>Don't know</u>			
<u>No comparator</u>		<u>Were any other care services used?</u> (Interviewer: “For example social services, a private care company, meals on wheels, voluntary groups”) <input type="checkbox"/> <u>Yes</u> <input type="checkbox"/> <u>No</u> <input type="checkbox"/> <u>Don't know</u> <u>If no, could you please say why other care services were not used?</u>	<u>Show card for options</u> <u>No further change</u>

		<input type="checkbox"/> <u>A service was not available</u> <input type="checkbox"/> <u>Didn't know about such a service</u> <input type="checkbox"/> <u>Service was not wanted</u> <input type="checkbox"/> <u>Family/friends looked after</u> <input type="checkbox"/> <u>Death was sudden</u> <input type="checkbox"/> <u>The person died in hospital</u> <input type="checkbox"/> <u>Other (specify)</u>	
8.	<u>Since this person died, have you been able to move on with your life?</u> <i>[Put responses on show card]</i> <input type="checkbox"/> <u>I have been able to move on with my life</u> <input type="checkbox"/> <u>I am starting to move on with my life</u> <input type="checkbox"/> <u>I have not been able to move on with my life</u>	<u>Since this person died, have you been able to continue with your life?</u> <i>[Put responses on show card]</i> <input type="checkbox"/> <u>I have been able to continue with my life</u> <input type="checkbox"/> <u>I am starting to continue with my life</u> <input type="checkbox"/> <u>I have not been able to continue with my life</u>	<u>Show card for options</u> <u>No further change</u>
9.	<u>Would you take on the role of caring again in similar circumstances?</u>	<u>Would you take on the role of caring again in similar circumstances?</u>	<u>Show card for options</u> <u>No further change</u>

<input type="checkbox"/> I would definitely take on the caring role again	<input type="checkbox"/> I would definitely take on the caring role again	
<input type="checkbox"/> I would probably take on the caring role again	<input type="checkbox"/> I would probably take on the caring role again	
<input type="checkbox"/> I would not take on the caring role again	<input type="checkbox"/> I would probably not take on the caring role again	
	<input type="checkbox"/> I would not take on the caring role again	

2

3