1 S1 <u>Table. Adaptation of caregiver question set</u>

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

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

Sibling	Brother/sister (including half or	
Other relative	step brother or sister)	
Friend	Other relative	
Other (specify)	Friend	
	Other (specify)	
4. What was your most involved	What was your maximum level of	What was your maximum level of
level of care for this person?	personal care for this individual?	personal care for this individual?
[Put responses on show card]	Tick one, and please estimate	INTERVIEWER: By personal care
	how long this was (circle time).	I mean things like helping with
	[Put responses on show card]	washing, dressing, going to the
Day-to-day hands on care	Daily:	toilet, or eating.
Intermittent hands on care	<u>o Days</u>	
Rare hands on care	<u>o Weeks</u>	Show card for options
Didn't provide any care but	<u>o Months</u>	
they were still close to me	o more than a year	Daily
		Occasional/intermittent
	Occasional :	Rare
	<u>o Days</u>	Didn't provide any personal
	<u>o Weeks</u>	care but they were still close to
	<u>o Months</u>	me
	o more than a year	Other (PLEASE SPECIFY)
	Rare:	
	1	1

	<u>o Days</u>	INTERVIEWER: Thinking about
	<u>o Weeks</u>	the time when you were providing
	<u>o Months</u>	help like this, how long was this
	o more than a year	<u>for?</u>
	Didn't provide any personal	Days
	care but they were still close to	U Weeks
	me	<u>Months</u>
		More than a year
	Other (specify):	
	<u>o Days</u>	
	<u>o Weeks</u>	
	<u>o Months</u>	
	o more than a year	
No comparator question this is	Did you look after or give special	Did you look after or give special
replaced by an additional question	help to them in any other way? If	help to them in any other way? If
which now the new question	yes, what was your most	<u>yes, what was your most</u>
shown in the columns to the right	maximum level of help for this	maximum level of help for this
5. Think back to when they were	person? (Interviewer: to have list	person? (Interviewer: to have list
first diagnosed. Was the	of examples: company, errands,	of examples: company, errands,
period after their diagnosis	laundry, shopping, giving lifts,	laundry, shopping, giving lifts,
through to and including their	taking to appointments or out for	taking to appointments or out for
<u>death better or worse than</u>	recreation etc)	recreation etc)
you would have expected?	[Put responses on show card]	

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[Put responses on show card]		Show card for options
	Daily:	
Much better than expected	<u>o Days</u>	Daily
Better than expected	<u>o Weeks</u>	Occasional/intermittent
As expected	<u>o Months</u>	R are
Worse than expected	o more than a year	Didn't provide any personal
Much worse than expected		care but they were still close to
□ I didn't know what to expect	Occasional :	me
	<u>o Days</u>	Other (PLEASE SPECIFY)
	<u>• Weeks</u>	
	<u>o Months</u>	
	\circ more than a year	INTERVIEWER: Thinking about
		the time when you were providing
	Rare:	help like this, how long was this
	<u>o Days</u>	<u>for?</u>
	<u>• Weeks</u>	
	<u>o Months</u>	Days
	o more than a year	U Weeks
		<u>Months</u>
	Didn't provide any personal	More than a year
	care but they were still close to	
	me	
	Other (specify):	
	,	

		<u>o Days</u>	
		<u>o Weeks</u>	
		<u>o Months</u>	
		o more than a year	
<u>6.</u>	Did this person who died of a	Was a palliative care service	Show card for options
	<u>terminal illness use a</u>	used? (Interviewer: "A palliative	No further change
	palliative care service?	care service aims to comfort, not to	
	(Examiner: "A palliative care	cure, to relieve pain and distress for	
	service aims to comfort, not to	people who are dying and to	
	cure, to relieve pain and distress	support patients, families and	
	for people who are dying and to	friends in approaching death and	
	support patients, families and	coping with grief. Typical services	
	friends in approaching death	include; hospice, visits from Marie	
	and coping with grief.")	Curie or/and Macmillan nurses.")	
	Yes	<u>Options – no change</u>	
	No		
	Don't know		
		If no, could you please say why a	
<u>7.</u>	If no, could you please say	palliative care service was not	
	why a palliative care service	used?	
	was not used?		
		<u>Options – no change</u>	
L	l		

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

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

I would definitely take on the	I would definitely take on the	
caring role again	caring role again	
I would probably take on the	I would probably take on the	
caring role again	caring role again	
I would not take on the caring	I would probably not take on	
role again	the caring role again	
	I would not take on the caring	
	role again	
2		