

End of Life Impact

THINKING ABOUT YOUR EXPERIENCE, PLEASE TICK (✓) ONE BOX FOR EACH GROUP WHICH BEST DESCRIBES YOUR SITUATION

1. Communication with those providing care services (e.g. doctors, nurses and carers). This includes things like:

- being able to get information about the person's health and care;
- having been able to have a say in the care that the person receives;
- being able to ask questions, have them answered and have views respected;
- being at ease with those providing care.

A. I have been able to have good communication all of the time.....	<input type="checkbox"/>	5
B. I have been able to have good communication most of the time....	<input type="checkbox"/>	4
C. I have been able to have good communication some of the time....	<input type="checkbox"/>	3
D. I have been able to have good communication a little of the time..	<input type="checkbox"/>	2
E. I have been able to have good communication none of the time....	<input type="checkbox"/>	1

2. Privacy and Space. This includes things like:

- having been able to have time with the person in private (e.g. a private room in hospital);
- having been able to be in a peaceful location with pleasant facilities;
- having been able to be with the dying person at the end of their life.

A. I have been able to have privacy and space all of the time.....	<input type="checkbox"/>	5
B. I have been able to have privacy and space most of the time.....	<input type="checkbox"/>	4
C. I have been able to have privacy and space some of the time.....	<input type="checkbox"/>	3
D. I have been able to have privacy and space a little of the time.....	<input type="checkbox"/>	2
E. I have been able to have privacy and space none of the time.....	<input type="checkbox"/>	1

3. Practical Support. This includes things like:

- having been able to get practical support and help with the care of the person, such as nursing help, help from social services or help from family;
- being able to get practical support from employers such as time off when needed;
- being able to get practical support with bereavement processes and dealing with the person's affairs.

A. I have been fully able to get practical support.....	<input type="checkbox"/>	5
B. I have been mostly able to get practical support.....	<input type="checkbox"/>	4
C. I have been somewhat able to get practical support.....	<input type="checkbox"/>	3
D. I have been mostly unable to get practical support.....	<input type="checkbox"/>	2
E. I have been completely unable to get practical support.....	<input type="checkbox"/>	1

4. Emotional Support. This includes things like:

- being able to get emotional support through family, friends or colleagues;
- being able to get emotional support through other services including charities and religion if applicable.

A. I have been fully able to get emotional support.....	5
B. I have been mostly able to get emotional support.....	4
C. I have been somewhat able to get emotional support.....	3
D. I have been mostly unable to get emotional support.....	2
E. I have been completely unable to get emotional support.....	1

5. Preparing and Coping. This includes things like:

- being prepared for the person’s death;
- having the person’s post-bereavement affairs and funeral arrangements in order;
- being free from guilt and regrets.

A. I have been fully able to prepare for and cope with, the person’s death.....	5
B. I have been mostly able to prepare for, and cope with, the person’s death.....	4
C. I have been somewhat able to prepare for, and cope with, the person’s death.....	3
D. I have been mostly unable to prepare for, and cope with, the person’s death.....	2
E. I have been completely unable to prepare for, and cope with, the person’s death.....	1

6. Emotional Distress to you, related to the condition of the person. This includes things like being free from emotional distress resulting from:

- seeing the person in pain and discomfort;
- seeing the loss of dignity, or a lack of respect given to the person;
- seeing a lack of care and attention given to the person.

A. I have been fully able to be free from emotional distress.....	5
B. I have been mostly able to be free from emotional distress.....	4
C. I have been somewhat able to be free from emotional distress.....	3
D. I have been mostly unable to be free from emotional distress.....	2
E. I have been completely unable to be free from emotional distress.....	1

Thank you for your help with this research