



THE ALZHEIMER
SOCIETY *of* IRELAND

**Submission on the *Think Ahead* Consultation to
the Irish Hospice Foundation**

January 2015



1. Introduction

The Alzheimer Society of Ireland welcomes the opportunity to input into the *Think Ahead* consultation.

The Alzheimer Society of Ireland is the leading dementia specific service provider in Ireland. The Alzheimer Society of Ireland works across the country in the heart of local communities providing dementia specific services and supports and advocating for the rights and needs of all people living with dementia and their carers.

Our vision is an Ireland where no one goes through dementia alone and where policies and services respond appropriately to the person with dementia and their carers, at the times they need support.

A national non-profit organisation, The Alzheimer Society of Ireland is person centred, rights-based and grassroots led with the voice of the person with dementia and their carer at its core.

The Alzheimer Society of Ireland also operates the Alzheimer National Helpline offering information and support to anyone affected by dementia at 1800 341 341.

2. General comments

This consultation feedback was drafted in collaboration with the Chairperson of the Irish Dementia Working Group, Helen Rochford-Brennan. The questions are answered in her capacity as a person living with dementia.

3. Specific feedback on consultation questions

About you:

1. Tell us a bit about yourself. Only share the information that you are happy to share with us. The consultation process is completely confidential and we will not share your information with anyone

Name (optional): Helen Rochford-Brennan

Age: 60+

Job (optional): Voluntary Chairperson of the Irish Dementia Working Group

2. Are you completing this as someone who has difficulties reading, remembering or understanding some things?

Yes ✓

No

Or

3. Are you a staff member who works with and supports people with these difficulties?

Yes

No ✓

General questions

1. Is the information about what 'Think Ahead' is easy to understand?

Yes ✓

No

Comments:

Although the wording is clear, there is a lot of information. Any sentences that can be shortened should be edited or deleted. The less text there is in a document, then the better it is for understanding. The colour coding is clear. Colours, text and images should be kept minimal; it is easier to understand when the page is least 'busy'.

Also, the number of questions should be reduced. Try to ask questions with clarity and leave out additional questions, which cover the same topic. Some examples are given below relative to sections.

2. Layout and design – Do you like the layout?

Yes ✓

No

3. Is it easy to find the different sections?

Yes ✓

No

Comments:

The sections are clear. The emergency section, which has a perforated side image, should be at the end of the form rather than mid-way through the form.

The financial section should be removed. The information requested is too sensitive to be put in writing. A person's EPA should have this information or a person's will should contain such data.

4. Are the words easy to understand?

Yes ✓

No

If you answered 'no', tell us which words are difficult to understand:

Again, use fewer words in the document whenever possible.

5. Does the form provide enough information for people who are filling in the form?

Yes ✓

No

If not, what is missing?

6. Does the form provide enough information for staff who have been asked by someone to assist them to complete the form?

Yes ✓

No

If not, what is missing?

7. Is there anything that you think should be in the form that is not there now?

No comments.

8. General comments – do you have anything else to say about the form?

Generally a very useful document and one which people will find valuable.

4. Feedback on each section

4.1 Section 1: Key Information

1. Is this section easy to understand?

Yes ✓

No

2. If you answered, 'no', what is difficult to understand?

3. What would help?

Too many review lines. Two is enough.

4.2 Section 2: Care Preferences

1. Is this section easy to understand?

Yes ✓

No

2. If you answered, 'no', what is difficult to understand?

3. What would help?

Here are some suggestions to improve this section:

- Reduce the number of options of who the information can be shared with.
- Remove the question 'what I would not like' (page 10) as it is confusing. The other two questions are enough to gather preferences and likes.
- A line should be put in at the start of page 12/13 that specifies a person only needs to complete this information if they do not already have an Advanced Healthcare Directive.
- Ensure that information on advanced healthcare directives is up to date with current Assisted Decision Making (Capacity) Act 2015.

4.3 Section 3: Legal

1. Is this section easy to understand?

Yes ✓

No

2. If you answered, 'no', what is difficult to understand?

3. What would help?

Here are some suggestions to improve this section:

- New legislation on Assisted Decision Making will mean that people have other decision making options in addition to EPAs. It is important to include a question about whether a person has any decision making agreements registered with Decision Support Service.

4.4 Section 4: Financial

1. Is this section easy to understand?

Yes

No ✓

2. If you answered, 'no', what is difficult to understand?

3. What would help?

This section should not be in the form or should be qualified with a statement advising not to complete if you have an EPA. There is too much sensitive information asked for in writing.

Financial matters could be integrated into the Legal section and once a person ticks EPA then it can be assumed that he/ she is supporting financial arrangements. A supplementary question could exist for anyone who does not have an EPA and it could ask 'Have you arrangements in place for someone to manage financial arrangements such as closing bank accounts?' This question could prompt someone to think about an EPA or some other arrangement regarding their financial matters.

4.5 Section 5: When I die

1. Is this section easy to understand?

Yes ✓

No

2. If you answered, 'no', what is difficult to understand?

3. What would help?

The organ donation option should include an option for brain as there is a Dublin Brain Bank.