



1. Introduction

1.1 What are the 'I' Statements and why are they being reviewed?

In 2010 many organisations interested in Dementia came together to form the Dementia Action Alliance. The key document, which they all agreed to base their action plans around was the National Dementia Declaration, a series of 'I' statements which described an ambitious and achievable vision for how society could support people with dementia and their carers. The idea was that the statements would encapsulate what someone with dementia could say about their life if they were properly supported. There are 7 "I statements" with 35 sub-statements. A list of the 'I' statements are included at the end of this document in section 5.3.

There is a lot that has changed since 2010. We have had two Prime Minister's Challenges on Dementia. The Dementia 2020 Challenge Implementation Plan published in March 2016 commits to listening to the voices of people with dementia and their carers by a new Citizens' Panel, their first action being to contribute to

a review of the Declaration

Alzheimer's Society is leading this review on behalf of the Dementia Action Alliance, but input from people with dementia, carers and the other organisations who use the statements is essential in order to make the review a success.

1.2 Who is this toolkit for?

This toolkit is to help people (staff working with people with dementia or carers) who want to guide a discussion with people with dementia on the 'I' Statements, in order to contribute to the review of the 'I' statements which is currently going on. This might be a group discussion, or a discussion with one individual.

If you are a carer of someone with dementia and would like to contribute your own opinion on the statements, or work with carers and would like them to be involved, please contact ppa@alzheimers.org.uk.

If you are an organisation that uses the 'I' statements and would like to contribute the organisation's point of view, please email ppa@alzheimers.org.uk, or go to the DAA website at www.dementiaaction.org.uk

2. Engaging people with dementia

2.1 One-to-one conversations

One-to-one conversations are useful for exploring the views and attitudes of the person living with dementia and their carer/s in detail and enable greater insight into their lived experience. They are also useful if individuals do not engage well in group settings. Section 3.2 is a discussion guide you can use with people with dementia. You can also use this as a form to write down what the person says.

Because of the detailed nature of one-to-one conversations, the process can be lengthy and time-consuming. Therefore, always check with the individuals the amount of time that they have available and ensure this is valued and respected. Make sure they know they can stop at any time if they don't want to continue.

2.2 Group discussions

Group discussions (or focus groups) should consist of 2 to 8 people with a facilitator helping the group to talk to each other. They can be particularly useful for exploring views and attitudes on broad subject areas. A group will often produce a greater range of opinions as people build on each other's ideas or challenge them. Section 3.1 is a discussion guide you can use for a discussion in a group and as a form to write down what the people with dementia say.

We hope that many existing groups of people living with dementia will choose to discuss the 'I' Statements. These groups may have individual ways of working and needs and we are happy for facilitators to find a way which works for the individuals in the group. If you need support in working out how to do this, please email ppa@alzheimers.org.uk and we can help and advise.

Group discussions can be highly flexible – both in terms of number of participants, groups, costs and duration, but also in that the group discussion format can sometimes uncover related but unanticipated topics.

As focus groups lend themselves to broad discussion, only a limited number of questions can be used during each session for it to generate any useful insight. The facilitator must keep the conversation on track, and must also be mindful of any dominant personalities coming to the fore. It is for this reason that we suggest limiting the number of participants to 8, so that everyone can have a say.

2.3 Individual surveys

If individuals with dementia or carers want to participate in a paper questionnaire rather than in a one-to-one conversation, please contact ppa@alzheimers.org.uk.

2.4 Consent

You must gain informed consent from all people with dementia and carers who you engage with face-to-face. If it is helpful for you to use a form to talk this through with someone, a consent form is included in section 5.2 to support this.

To gain consent, you should be clear about what we will ask them to do, and what their contributions will be used for.. You are responsible for making it clear that their contributions will be anonymised, we will not be collecting any personal details, but if we use material that they say, we will attribute it to 'a person with dementia'.

Local dementia groups and networks should ensure that their systems and processes for collecting and holding any data or information obtained as a result of engaging with people with dementia and carers are compliant with guidance provided by the Office of the Information Commissioner at: <https://ico.org.uk/for-organisations/guide-to-data-protection/>

2.5 Be clear on influence

It is important to ensure that you manage the expectations of the people you speak to. Be clear from the outset how their engagement will affect the outcome of the work, and how decisions are made.

Here is some text which will help to explain how people affected by dementia are influencing the review of the 'I' statements:

The team at Alzheimer's Society will look at everything that people with dementia and carers have said. They will also look at what organisations have said about how they use the statements and any other information which is relevant. We will then come up with suggested changes to the statements. Organisations who use the statements, the DAA board and a group of people with dementia and carers will be asked to agree these. If agreed by the DAA Board we will launch the reviewed statements in Dementia Awareness Week next year. We will feed back to the person running the discussion about how we have taken on board your contribution.

2.6 Submitting your feedback

Whether you are submitting an individual survey response or comments from a one to one or group discussion please send the completed discussion guides (sections 3.1 and 3.2) to the address below by email or post:

All feedback should be sent to ppa@alzheimers.org.uk or by post to:

Martina Kane
Alzheimer's Society
43-44 Crutched Friars,

LONDON, EC3N 2AE.

Thank you for supporting this important activity. We welcome any feedback on this toolkit so that it can be constantly improved so please send us any improvements you'd like to see made.

3. Discussion guides

3.1 Discussion guide and data capture form for groups

Date of group and name (if applicable)

Number of participants with dementia

Co-ordinator name and contact details:

1) What is the most important thing to you in life right now?

capture key themes and areas of discussion

2) If you could change one thing in your life right now, what would it be?

capture key themes and areas of discussion

3) Of these words and phrases, which is the most important to you:

choice and control

designed around me

support

knowledge and knowhow

supportive environment

belonging and being valued

research

Please record which are most important, if there is agreement/disagreement and any important points said about the words

4) These statements were written to help organisations understand what people with dementia and carers want and help them to work out what to do.

(Either provide a sheet of the statements, or have them displayed and available to reference)

(It may be helpful to focus on the ones that people identified as most important in the previous question – if some are focused on then please indicate which. We are also interested in feedback about the statements as a whole (eg. They are too long, the words aren't how I would speak))

What is good about them?

What is bad about them?

What is missing?

5) If you could tell the people reviewing these statements one thing, what would it be?

Please send this sheet to Martina Kane, Alzheimer's Society, 43-44 Crutched Friars, LONDON, EC3N 2AE. Please include your contact details, so we can raise any queries, and keep in touch about the progress of the project.

3.2 Individual response discussion guide and data capture form

Name of person supporting completion of this form:

Contact details of person supporting completion (so we can raise any queries and keep in touch about progress)

If you are helping someone with dementia in a one to one conversation, write down their answers in the spaces below.

1) What is the most important thing to you in life right now?

2) If you could change one thing in your life right now, what would it be?

3) Of these words and phrases, which is the most important to you:

choice and control

designed around me

support

knowledge and knowhow

supportive environment

belonging and being valued

research

Please record any that participants feel to be most important, plus if there is agreement/disagreement and any important points in the discussion about the words

4) Provide the person with a sheet of the current 'I' statements

It may be helpful to focus on the ones that people identified as most important in the previous question – if some are focused on then please indicate which. We are also interested in feedback about the statements as a whole (eg. They are too long, the words aren't how I would speak)

These statements were written to help organisations understand what people with dementia want and help them to work out what to do.

What is good about them?

What is bad about them?

What is missing?

5) If you could tell the people reviewing these statements one thing, what would it be?

Please send this sheet to Martina Kane, Alzheimer's Society, 43-44 Crutched Friars, LONDON, EC3N 2AE. Please include your contact details, so we can raise any queries, and keep in touch about the progress of the project.

4. Facilitation Hints and Tips

4.1 Organising one to one discussions

- The conversations should not last more than one hour. This may be too long for some people and it is important to be aware of the on-going capabilities of the person. Let the person with dementia know that they can stop any time that they want to.
- Let the person with dementia and/or carer decide on the venue- the home setting may be best. Ensure that you have an ID badge to ensure authenticity.
- It may help to have a second person to observe and take notes, or to use a voice recorder with permission. Part of an interviewer's task is to make sure that the participant feels listened-to throughout the conversation, so try to maintain eye contact and put the participant at ease.
- Do not forget refreshments and a comfortable, preferably light and airy room. You should also ensure there will be no interruptions.
- Some people with dementia may wish for a family member or a friend to join the conversation. This is fine, provided that the person with dementia is able to speak openly for themselves, without the other person speaking for them. This may require tactful facilitation. To help us understand your data please ensure it is clear whose views (the person with dementia or their supporter) are being expressed on which statement.

How to lead the conversation

- Introduce yourself (if required). Explain the purpose of the conversation (that is to find out their views about the 'I' Statements in order to help them better reflect the views of people with dementia).
- Emphasise that we need their help and encourage them to speak openly. "We want to know what you really think!", "I am here to learn from your experience", etc.
- Reassure them that, although you will be taking notes/ recording, what they say will remain anonymous and confidential, and comments will not be attributed to them, although they may be attributed to 'a person with dementia'.
- If taking notes, you need to record the person's words as far as possible - this kind of qualitative data is much more useful and real. If you do not have another member of staff to assist you, keep writing as you talk and keep as much eye contact as possible.
- At the end thank the person for their time, explain what will happen next, and reaffirm confidentiality
- Write up your notes as soon as possible after the event.

Interview questions: some guidance

- The questions should be taken from the discussion guide so that they are kept consistent with the other discussions taking place. Use these questions as conversation prompts, and be sure to follow up on any questions that lead on from the discussion.
- Often the conversation will take off in a different direction from the one you had planned, but try to steer it so that all of the things you would like to discover are discussed in one way or another!
- Try to check as you go along what you think you are hearing them saying - especially if you are finishing off a long discussion on a single topic, e.g. ask 'Am I hearing what you are saying correctly?'
- Probe if they give you vague answers.

Remember: The main aim is to obtain information, not to offer your own views, though sometimes people will ask.

Be as encouraging/neutral as possible, even if you do not agree.

Do not let your tone betray your views. You can share your views at the end of the conversation, if you wish. It is always acceptable to offer information.

Be sensitive to communication problems or fear of expressing views.

Do not forget posture - gesture, facial expressions - you need to communicate warmth, interest, encouragement and caring

4.2 Organising group discussions

- Provide clear, straightforward information about the purpose of the meeting beforehand. Use the information sheet provided if appropriate
- Think about providing a photograph of yourself so the group know who you are, where you work, and what your job is (DEEP Guide: Collecting the views of people with dementia)
- Think about the location of the session – is it accessible by public transport? Is there parking? Is the room easily accessible to a person with dementia? Will someone be available to greet them, show the way and escort out at the end?
- Think about any other adjustments that you need to make for your participants to participate, including differing languages, signing or culturally appropriate refreshments.
- Do not forget refreshments and ensuring that the room is comfortable and accessible.
- Think ahead of how you would support someone who may feel upset or distressed during the conversation- is there a quiet space available for someone to go?

The discussion should not last more than two hours. This may be too long for some people and it is important to be aware of the on-going capabilities of the group. Make sure that people know that they can stop at any time. We recommend having a comfort break in the middle of the discussion.

It helps to have more than one facilitator at each session

We recommend a maximum of 8 participants per session to ensure that everyone can participate.

Facilitating group discussions

- Introduce yourself. Explain the purpose of the group meeting.
- Ask the others to introduce themselves. Ask for names and how they heard about the session. Name badges or cards may be useful.
- Emphasise that we need their help and encourage them to speak openly, for example: "we want to know what you really think!", "I am here to learn from your experience - you are the experts here." "I want to hear as many different experiences and views as possible."
- Reassure that, although you will be taking notes/ recording, what they say will remain anonymous and confidential, and comments will not be attributed to them.
- When taking notes, record people's exact words as far as possible - this kind of qualitative data is much more useful and real. Keep writing as you talk and keep as

much eye contact as possible – this is where it helps to have a second facilitator, even in smaller group sessions.

- It is useful to have a set of cards for participants to raise if they want to speak; for the facilitator to slow down; or if they need help.
- Try not to offer your own views, though sometimes people will ask. You need to be as encouraging/neutral as possible, even if their views are not what you would wish.
- Be sensitive to communication problems or fear of expressing views. Do not forget posture, gesture and facial expressions. You need to communicate warmth, interest, encouragement and caring.
- Given the potential emotive nature of the experiences of people living with dementia and their family carers, it is important to ensure that there is an appropriate supervision/debriefing process available after the event should the facilitator or volunteer require this.
- At the end thank the participants for their time, explain what will happen next, and affirm confidentiality.

DEEP recommendations on facilitating focus groups for people with dementia

- Have a clear timetable for your session, with refreshments available at set times
- Take your lead from the group. Be prepared to join in other group discussions or activities before it is time for your discussion
- Take it slowly, don't overwhelm people with too much information at the beginning
- Use visual aids where possible to help people connect with the discussion topics
- Think about different ways that people can be supported to express their views, eg:
 - Small group discussions: very helpful for people who are quieter or who struggle to speak in a large group
 - Questions to help people begin to talk about a particular issue
 - Visual aids to help people recall discussions
- Let people know about these beforehand

Group discussion questions: some guidance

- 'Am I hearing what you are saying correctly?' - check as you go along what you think you are hearing them saying - especially if you are finishing off a long discussion
- If a lot of people are silent, break the groups into 2s or 3s and get them to feed back - or ask people direct questions.

4.3 Useful links

Alzheimer's Society Factsheet on communicating with someone with dementia and on how to encourage the person to communicate in whichever way works best for them:

https://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1128

DEEP guides are a great place to start <http://dementivoices.org.uk/resources/deep-guides/>

DEEP guide: Involving people with dementia as members of steering or advisory groups

http://dementivoices.org.uk/wp-content/uploads/2016/03/DEEPGuidance_involvingpeoplewithdementiainadvisorygroups.pdf

DEEP guide: Tips for organisations wanting to consult people with dementia about written

documents <http://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Consulting-about-written-documents.pdf>

DEEP guide: Choosing a dementia-friendly meeting space <http://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Choosing-a-meeting-space.pdf>

DEEP guide: Dementia words matter: Guidelines on language about dementia

<http://dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>

DEEP guide: Collecting the views of people with dementia <http://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Collecting-views.pdf>

5. Project resources

5.1 Information sheet on Reviewing the 'I' Statements for people affected by dementia

Background

In 2010 many organisations interested in dementia came together to form the Dementia Action Alliance. The key document, which they all agreed to base their action plans around was the '[National Dementia Declaration](#)', a series of 'I' statements which described an ambitious and achievable vision for how society could support people with dementia. The idea was that the statements would encapsulate what someone with dementia could say about their life if they were properly supported. There are 7 "I statements" and 35 sub-statements. The "I statements" are:

- I have personal choice and control or influence over decisions about me.
- I know that services are designed around me and my needs.
- I have support that helps me live my life.
- I have the knowledge and know-how to get what I need.
- I live in an enabling and supportive environment where I feel valued and understood.
- I have a sense of belonging and of being a valued part of family, community and civic life.
- I know there is research going on which delivers a better life for me now and hope for the future.

The full set of statements are available on the DAA website, or ask the person who gave you this sheet.

Why are we reviewing them? Why now?

There is a lot that has changed since 2010. We have had two Prime Minister's Challenges on dementia since then and the Dementia 2020 Challenge Implementation Plan published in March 2016 commits to a review of the statements, which will recognise the progress which has been made.

Alzheimer's Society is leading this review on behalf of the Dementia Action Alliance, but we need input from people with dementia, carers and the other organisations who use the statements.

What we would like you to do?

We would like to ask you some questions relating to the 'I' statements, and some other questions about the topics that the 'I' statement cover.

Taking part is completely up to you. If at any point you don't want to take part any more, just let the person running the discussion know.

We won't keep any of your personal details and you won't be identified personally in any of the work. We may use a quotation from you and attribute it to "a person with dementia".

What happens next?

The team at Alzheimer's Society will look at everything that people with dementia have said. They will also look at what organisations have said about how they use the statements and any other information which is relevant. We will then come up with suggested changes to the statements. Organisations who use the statements, the DAA board and a group of people with dementia will be asked to agree these. We will feedback to everyone who has contributed on how we have taken on board what they have said. We will launch the reviewed statements in Dementia Awareness Week in May next year.

If you would like more information:

Ask: for more information from the person who gave you this sheet

Email: ppa@alzheimers.org.uk

Phone: Martina Kane on 020 7423 7361

If you have concerns about Alzheimer's disease or about any other form of dementia, Alzheimer's Society National Dementia Helpline on [0300 222 1122](tel:03002221122) can provide information, support, guidance and signposting to other appropriate organisations.

The Helpline is usually open from:

9am - 8pm Monday to Wednesday

9am - 5pm on Thursday and Friday

10am - 4pm on Saturday and Sunday

5.2 Consent Form – Review of the 'I' Statements project

Please read out these statements to the person/group;

I understand why I am being asked about the 'I' Statements and what will happen next I know I can ask questions about this I know that if I become uncomfortable, or don't want to keep going I can stop I know that my name won't be used, but that things I say might be used and attributed to 'a person with dementia'

I agree to participate in the study as outlined to me.

Yes/No

I am happy for my comments to be used

Yes/No

5.3 List of current 'I' statements

I have personal choice and control or influence over decisions about me.

I have control over my life and support to do the things that matter to me.

I have received an early diagnosis which was sensitively communicated.

I have access to adequate resources (private and public) that enable me to choose where and how I live.

I can make decisions now about the care I want in my later life.

I will die free from pain, fear and with dignity, cared for by people who are trained and supported in high quality palliative care

I know that services are designed around me and my needs.

I feel supported and understood by my GP and get a physical checkup regularly without asking for it.

There are a range of services that support me with any aspect of daily living and enable me to stay at home and in my community, enjoying the best quality of life for as long as possible.

I am treated with dignity and respect whenever I need support from services.

I only go into hospital when I need to and when I get there staff understand how I can receive the best treatment so that I can leave as soon as possible.

Care home staff understand a lot about me and my disability and know what helps me cope and enjoy the best quality of life every day.

My carer can access respite care if and when they want it, along with other services that can help support them in their role.

I have support that helps me live my life.

I can choose what support suits me best, so that I don't feel a burden.

I can access a wide range of options and opportunities for support that suits me and my needs.

I know how to get this support and I am confident it will help me.

I have information and support and I can have fun with a network of others, including people in a similar position to me.

My carer also has their own support network that suits their own needs

I have the knowledge and know-how to get what I need.

It's not a problem getting information and advice, including information about the range of benefits I can access to help me afford and cope with living at home.

I know where I can get the information I need when I need it, and I can digest and re-digest it in a way that suits me.

I have enough information and advice to make decisions about managing, now and in the future, as my dementia progresses.

My carer has access to further information relevant to them, and understands which benefits they are also entitled to.

I live in an enabling and supportive environment where I feel valued and understood.

I had a diagnosis very early on and, if I work, an understanding employer which means I can still work and stay connected to people in my life.

I am making a contribution which makes me feel valued and valuable.

My neighbours, friends, family and GP keep in touch and are pleased to see me.

I am listened to and have my views considered, from the point I was first worried about my memory.

The importance of helping me to sustain relationships with others is well recognised.

If I develop behaviour that challenges others, people will take time to understand why I am acting in this way and help me to try to avoid it.

My carer's role is respected and supported. They also feel valued and valuable, and neither of us feel alone.

I have a sense of belonging and of being a valued part of family, community and civic life.

I feel safe and supported in my home and in my community, which includes shops and pubs, sporting and cultural opportunities.

Neither I nor my family feel ashamed or discriminated against because I have dementia.

People with whom we come into contact are helpful and supportive.

My carer and I continue to have the opportunity to develop new interests and new social networks.

It is easy for me to continue to live in my own home and I and my carer will both have the support needed for me to do this.

I know there is research going on which delivers a better life for me now and hope for the future.

I regularly read and hear about new developments in research.

I am confident that there is an increasing investment in dementia research in the UK.

I understand the growing evidence about prevention and risk reduction of dementia.

As a person living with dementia, I am asked if I want to take part in suitable clinical trials or participate in research in other ways.

I believe that research is key to improving the care I'm receiving now.

I believe that more research will mean that my children and I can look forward to a range of treatments when I need it and there will be more treatments available for their generation.

I know that with a diagnosis of dementia comes support to live well through assistive technologies as well as more traditional treatment types

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We would also like to thank the people with dementia who read and suggested changes to this document.