

APPENDIX 1

National Dementia Declaration

As part of the Prime Minister's Challenge in relation to dementia working in partnership with organisations supporting people living with the condition, people with dementia and their family carers described seven outcomes they would like to see in their lives. They provide an ambitious and achievable vision of how people with dementia and their families are supported by society. All individuals and organisations, large and small, can play a role in making it a reality.

1. 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.

2. 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 understands 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.

3. 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 needs.

4. 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.

5. 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 feels alone.

6. 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.

7. 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.