

GLOBAL DEMENTIA CHARTER

I CAN LIVE WELL WITH DEMENTIA

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Alzheimer's Disease International



FOREWORD

Dementia, including Alzheimer's disease, is one of the biggest global public health challenges facing our generation. Today, over 35 million people worldwide currently live with the condition and this number is expected to double by 2030 and more than triple by 2050 to 115 million.

We believe that Alzheimer's disease and other forms of dementia must become a national and international public health priority so that countries have adequate care and support systems in place to look after people living with the condition now, and in the future.

Dementia is a degenerative condition with no cure. Symptoms, such as memory loss, difficulty communicating and changes in mood will get worse over time. These experiences are distressing for the individual and upsetting for their loved ones.

But people living with dementia can still have a good quality of life at most stages of the condition, provided the right care and support is in place.

As the largest international provider of specialist dementia care, and the only international federation of Alzheimer associations and global voice on dementia, we intend to revolutionise care and to campaign to ensure people living with dementia live well, and that their family and friends are properly supported.

That's why we have joined forces to outline, for the first time, what we believe are the rights of people living with dementia, wherever they are in the world. Our joint Global Dementia Charter has been written for, and endorsed by, people living with the condition.

Everyone, everywhere, can and must do their bit. That's why our Charter is supported by 'enablers' – a list of actions and accountabilities that outline what families, friends, carers, healthcare professionals, commissioners or purchasers of care, providers, society and governments can do to improve care and support in their country.

We are committed to shaping global dementia care and having people living with dementia lead happier lives, for as long as they can. That is our vision. This is our purpose.



Stuart Fletcher
Chief Executive Officer
Bupa



Marc Wortmann
Executive Director
Alzheimer's Disease International

OUR GLOBAL DEMENTIA CHARTER

'I can live well with dementia'

1. I should have access to a doctor to check if I have dementia.
2. I should have access to information about dementia so I know how it will affect me.
3. I should be helped to live independently for as long as I can.
4. I should have a say in the care and support that I am given.
5. I should have access to high quality care that's right for me.
6. I should be treated as an individual, with those looking after me knowing about my life.
7. I should be respected for who I am.
8. I should have access to medicine and treatment that helps me.
9. My end of life wishes should be discussed with me while I can still make decisions.
10. I want my family and friends to have fond memories of me.

Our Charter has been endorsed by people living with dementia around the world.



1. I SHOULD HAVE ACCESS TO A DOCTOR TO CHECK IF I HAVE DEMENTIA.



“I should have access to a memory assessment to check if my dementia worries are true. A diagnosis will allow my family, friends and I to plan for the years ahead and prepare for when my needs will change.”



Peter Warner Spencer, 89
Australia



2. I SHOULD HAVE ACCESS TO INFORMATION ABOUT DEMENTIA SO I KNOW HOW IT WILL AFFECT ME.



“Dementia will affect me and everyone around me. My family, friends and I should have access to high quality information and advice so we know what to expect as my condition progresses.”



Paco Parejo, 83
Spain



3. I SHOULD BE HELPED TO LIVE INDEPENDENTLY FOR AS LONG AS I CAN.



“I want to be as active as I can, for as long as possible, supported by those around me, in a safe environment.”



Adeleida Cornelia Pojoh-Tulaar, 86
Indonesia



4. I SHOULD HAVE A SAY IN THE CARE AND SUPPORT THAT I AM GIVEN.



“I have a voice and should have a say in the care that I am given, for as long as I can.”



Roger Hamilton King, 75
Zimbabwe



5. I SHOULD HAVE ACCESS TO HIGH QUALITY CARE THAT'S RIGHT FOR ME.



“At all stages of the condition, I should have access to high quality care when I need it, be that in my home, my village, town or community, or in a care home.”



Guang Sun, 84
China



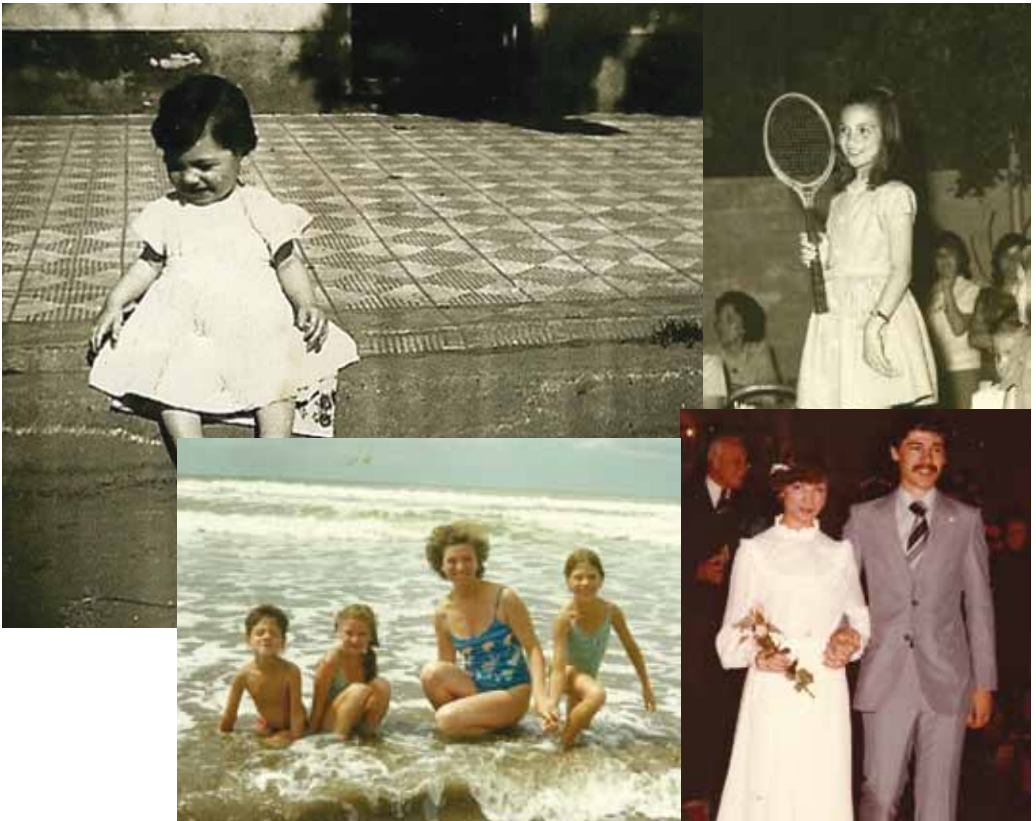
6. I SHOULD BE TREATED AS AN INDIVIDUAL, WITH THOSE LOOKING AFTER ME KNOWING ABOUT MY LIFE.



“People looking after me should know about my life, family and history so they can provide personalised care that’s right for me. My care should be shaped around my personality, preferences and lifestyle.”



Selva Marasco de Luna, 60
Argentina



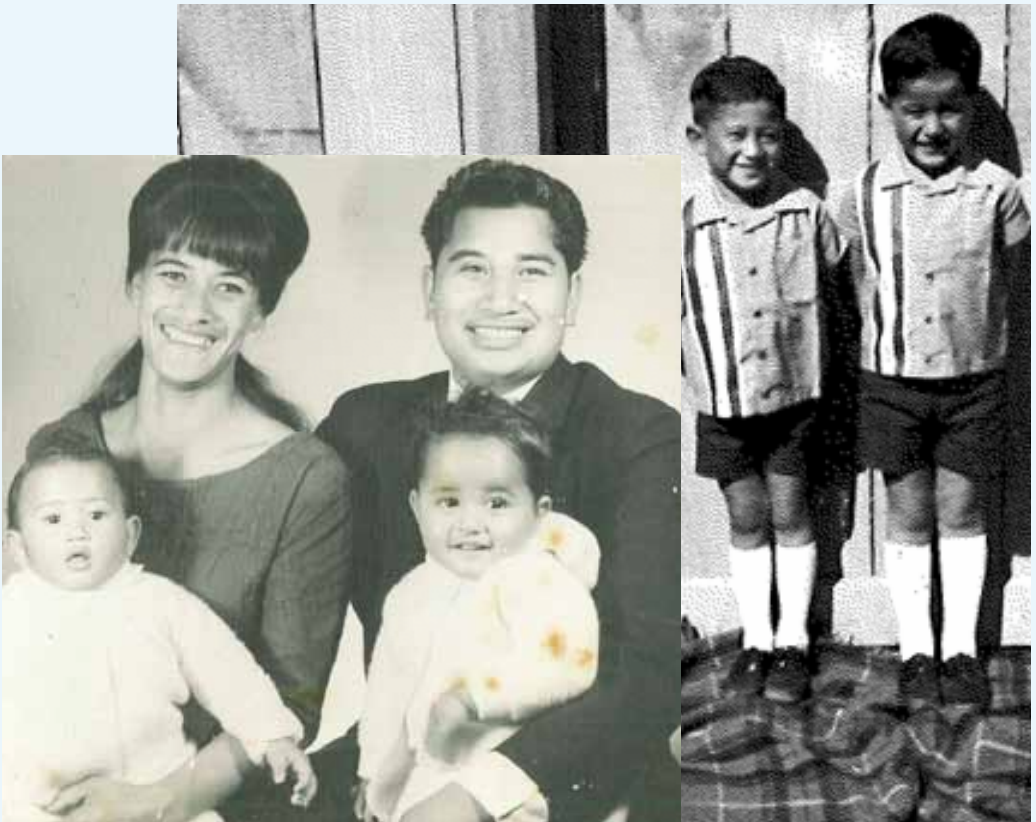
7. I SHOULD BE RESPECTED FOR WHO I AM.



“I should not be discriminated against on any grounds, including age, disability, gender, race, sexual orientation, religious beliefs, social or other status.”



Hemi Wirihana, 71
New Zealand



8. I SHOULD HAVE ACCESS TO MEDICINE AND TREATMENT THAT HELPS ME.



“During all stages of dementia, I should have access to medication and treatment that helps me to live well, and these should be regularly assessed by my doctor.”



Ethel Cannon, 87
United Kingdom



9. MY END OF LIFE WISHES SHOULD BE DISCUSSED WITH ME WHILE I CAN STILL MAKE DECISIONS.



“I should have a say about how I spend my final days, so my end of life care wishes should be discussed with me while I can still make decisions.”



Francis Manavalan, 88
India



10. I WANT MY FAMILY AND FRIENDS TO HAVE FOND MEMORIES OF ME.



“I want to have peace of mind that my family and friends will have adequate support to cope with my death and be comforted in their grief, to help them remember me for the person I was.”



Nancy Molina, 52
Dominican Republic



THE 'ENABLERS'

Families, friends, their carers, healthcare professionals, commissioners or purchasers of care, healthcare providers, society and governments have a responsibility to ensure people with dementia can live well. We have outlined what can be done to achieve this.

General

- Governments should develop a National Dementia Plan to make dementia a public health priority. This should be developed in consultation with all interested parties.
- Best practice dementia care should be shared around the world.
- National dementia charities should be set up to champion the needs of those living with dementia.

Enabling access to a doctor to check for dementia (point 1)

- Governments should ensure that health systems are adequately funded and structured to be able to test for the condition, for example via general practitioners or community nurses.
- Healthcare professionals should have adequate training in how to identify for possible dementia.
- Social care workers should have training to alert them to the possible presence of dementia.
- Civil society should call for recommended screening for dementia for older people.
- Families and friends should be supported to seek advice on how to broach the issue with a loved one if they think they might have dementia.



Enabling access to information about dementia (point 2)

- Governments, commissioners or purchasers of care, providers and charities should work together to create accessible literature and online content. This should be condition and age specific so it is appropriate and easy to understand.
- Governments, commissioners or purchasers of care, providers and charities should identify and reach 'at risk' individuals.
- Providers should reach out to local communities to help people learn more about the condition.

Enabling the person to live independently for as long as possible (point 3)

- Governments should ensure that there are local services that enable an individual to live as long as possible in their own home.
- Governments should ensure there is adequate funding to support families, friends and carers to help them look after a loved one as long as they can.
- Dementia friendly societies should provide support to family, friends and carers who support a loved one.

Enabling people to have a say in their care and support (point 4)

- Healthcare professionals and providers should make sure there are effective systems in place to ensure that an individual living with dementia is thoroughly involved and empowered in any decision about their care, while they still can be.
- Families, friends and carers should make sure they involve a loved one in decisions about their care.

Enabling access to high quality care and support (point 5)

- Governments should make sure there is adequate funding in the healthcare system to ensure appropriate dementia care and support is available when people need it.
- Governments and providers should make sure there is adequate capacity for provision by tracking trends and planning for future demand.
- Governments should have a health and social care workforce development plan to cover training and education so there is a competent and informed system of care.

Enabling the person to be treated as an individual (point 6)

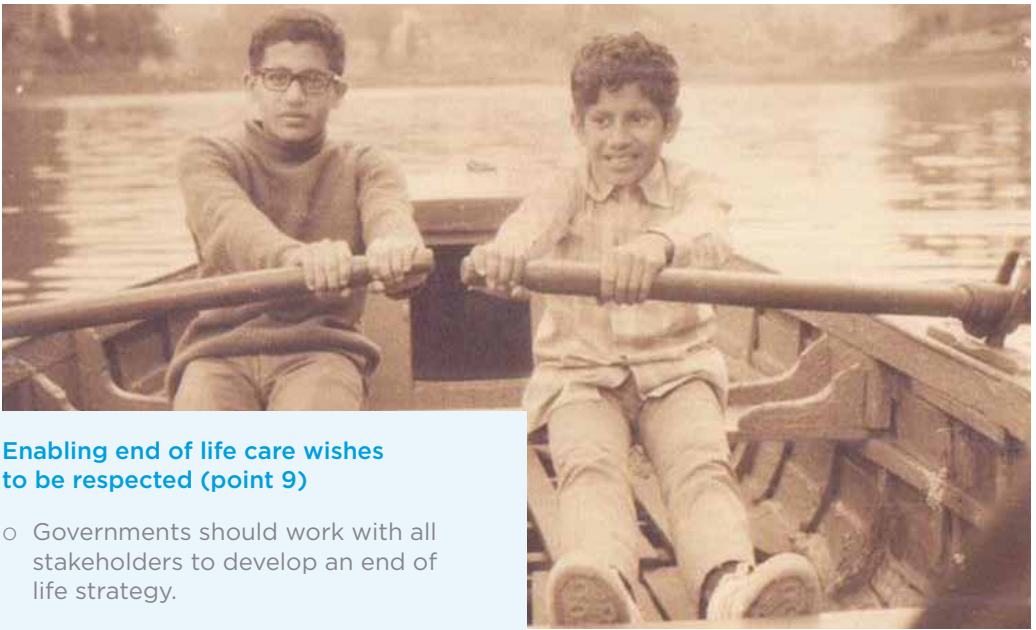
- Providers should ensure that anyone caring for someone with dementia has specialist training in person centred care.
- Family, friends and carers should support a loved one to capture their memories and preferences, and be helped to stay closely involved in their loved one's care.

Enabling respect (point 7)

- Discrimination, of any sort, should be made illegal by governments.
- Providers should acknowledge and act upon the human rights of people living with dementia.
- Healthcare professionals and providers should ensure there are adequate systems and processes that highlight when care falls below standard.

Enabling access to medication and treatment that helps an individual (point 8)

- Public/private partnerships should be established to fund long term research into risks, disease modifying drugs and psychosocial interventions for dementia.
- Governments should ensure that the drugs that slow down the progression of dementia are accessible.
- Healthcare professionals and providers should work together to make sure anti-psychotic drugs are used appropriately.



Enabling end of life care wishes to be respected (point 9)

- Governments should work with all stakeholders to develop an end of life strategy.
- Providers should do all they can to uphold the person's wishes in their final days.
- Families, friends and carers should discuss the issue with a loved one while they can still make decisions, and respect their final wishes.

Enabling family and friends to have fond memories of their loved one (point 10)

- Healthcare professionals and providers should have specialist training to make sure families and friends are supported to deal with grief when a loved one passes away.
- Everyone should support families and friends to celebrate the life of a loved one once they have passed away so they, as a person, can be remembered for who they were.

About Bupa

- Bupa's purpose is longer, healthier, happier lives.
- A leading international healthcare group, Bupa offers personal and company-financed health insurance, runs hospitals, and provides workplace health services, home healthcare, health assessments and chronic disease management services. Bupa is also a major international provider of nursing and residential care for elderly people.
- With no shareholders, Bupa invests its profits to provide more and better healthcare and fulfil its purpose.
- Bupa employs more than 54,000 people, principally in the UK, Australia, Spain, New Zealand and the USA, as well as Saudi Arabia, Hong Kong, India, Thailand, China and across Latin America.

About Bupa's social care services around the world

- Bupa cares for more than 30,000 people in 467 care homes and retirement villages in the UK, Spain, Australia and New Zealand.
- Bupa is the largest international provider of specialist dementia care, caring for more than 19,000 residents with dementia.
- In the UK, Bupa Care Services looks after more than 17,900 residents in almost 300 care homes.
- In Australia, Bupa Care Services Australia currently operates 60 care homes caring for more than 5,100 residents.
- In New Zealand, Bupa Care Services New Zealand cares for more than 3,800 people in 47 homes, 20 retirement villages and seven rehabilitation sites and also provides telecare services via a personal alarm network.
- In Spain, Bupa (Sanitas Residencial) cares for around 4,000 residents in 40 care homes.



About Alzheimer's Disease International

- ADI is the international federation of more than 75 Alzheimer associations around the world.
- It is in official relations with the World Health Organization and has consultative status with the United Nations.
- ADI's vision is an improved quality of life for people with dementia and their families throughout the world.
- ADI believes that the key to winning the fight against dementia lies in a unique combination of global solutions and local knowledge. As such, it works locally, by empowering Alzheimer associations to promote and offer care and support for people with dementia and their carers, while working globally to focus attention on dementia and campaign for policy change from governments.
- Alzheimer's Disease International: The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc. is incorporated in Illinois, USA, and is a 501(c)(3) not-for-profit organisation.



For more information, visit www.alz.co.uk

