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# A Human Rights Based Approach to Dementia Research

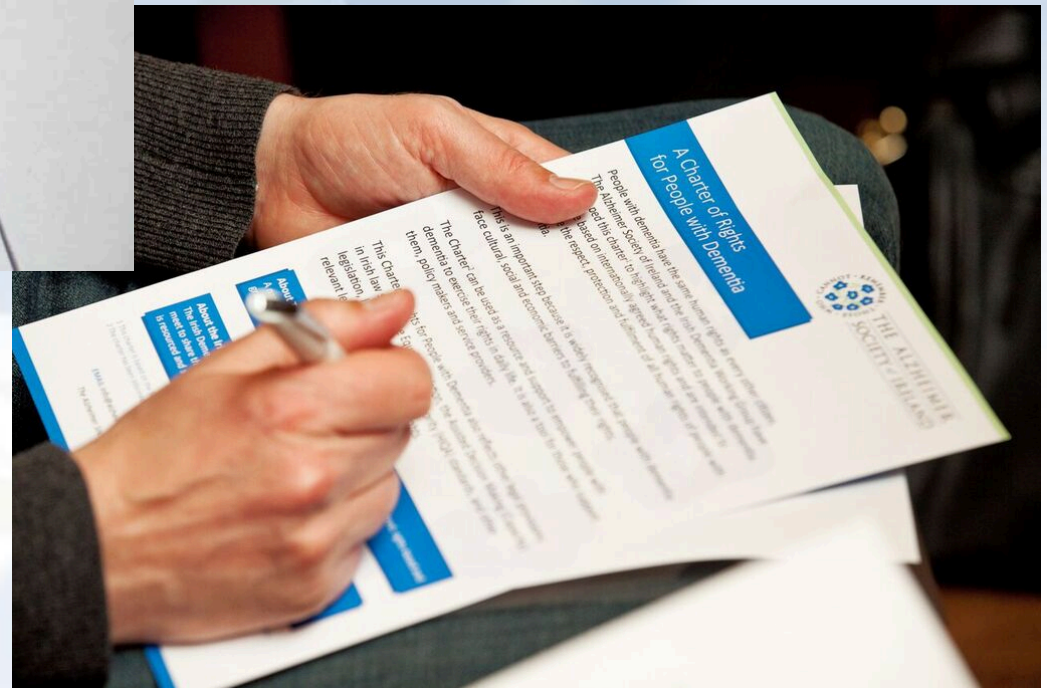
Alzheimer Europe Conference,  
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**Dr Bernadette Rock**  
**Policy & Research Manager, ASI**



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# Human Rights for People Living with Dementia





A Charter of Rights  
for People with Dementia



## Human Rights for People Living with Dementia



“As a person living with dementia this is a momentous day for those of us who are dedicated to fighting for equal rights as citizens,”  
Helen Rochford-Brennan.



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# De-Stress:

A study to assess the health & wellbeing of spousal carers of people with dementia in Ireland.



## PANEL

- Participation
- Accountability
- Non discrimination
- Empowerment
- Legality



# Research Review Committee

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- Person with dementia
- Carer of person with dementia
- Day care centre coordinator/manager
- Advocacy officer



# Participation

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People with dementia have the right to be provided with accessible information and necessary supports to enable them to exercise their right to participate in decisions and policies which affect them.



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# Empowerment

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People with dementia have the right to help to attain and maintain maximum independence, physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.

People with dementia have the right to access opportunities for community education and lifelong learning.



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“I consider that I can offer a unique and valuable perspective representing the greater world outside the Research Community, given my role as Carer for my late husband who lived with Vascular Dementia. What we must remember is the terrifying prospect it must be for a person to receive a diagnosis of dementia. While research for a cure is ongoing, the focus also includes prevention and advocacy, thereby broadening the base for research. It is a privilege to be a member of the Research Review Committee of ASI.”

*Ann Twomey*



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“I am a Chaplain in the Central Mental Hospital and I also organise retreats. This work takes a lot of planning and organisation which I enjoy. I feel my strengths in joining the Research Review Committee would be listening and thinking things through, then giving the necessary feedback and contributing my thoughts where appropriate”,  
*Des, person with dementia.*



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# Person Public Involvement

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- Challenges: late applications
- Non-participative, tokenistic V meaningful
- PPI goal for research strategy
- Over-sampling
- Plan, structure, governance, consolidate



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