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To stay or to move: Factors influencing housing choices by people with neurodegenerative disorders who want to continue living in the community

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- Neurodegenerative Disorders Project, 2006 – 2008, was funded by Lotterywest, the official state lottery for Western Australia
- Margaret's attendance at AAG 2008 is funded by Silver Chain



- Four disorders – ALS/MND, MS, PD and HD
- Six components of the project:
 - Client and carer survey (n = 1,080; response rate = 54%)
 - Client and carer interviews (n = 49)
 - Case studies (n = 4)
 - Professionals' interviews (n = 9)
 - Clients and members 1996 to 2006 and data linkage 2006 (n = 2,550, excluding PD)
 - Projections to 2021

Housing Changes



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Level of Dependency	Modified only (%)	Moved only (%)	Both moved and modified (%)	Neither moved nor modified (%)	Total (n)
Independent	10.8	7.1	2.1	80.0	240
Low	24.2	9.3	8.1	58.4	334
Medium	52.5	8.9	14.4	24.3	202
High	59.2	6.8	23.0	11.1	235
All (n)	352	82	115	462	1,011

Housing Moves



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Level of Dependency	Moved (%)	Did not move (%)	Total (n)
Independent	9.1	91.0	241
Low	18.0	82.0	338
Medium	23.3	76.7	202
High	30.1	69.9	236
All (n)	201	816	1,017

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- Reasons for moving include:
 - House size (smaller, bigger)
 - Better bathroom
 - More accessible
 - More wheelchair friendly
 - Closer to family
 - Closer to facilities including health centres
 - Smaller gardens and less home maintenance
 - Temperature control

Moving south to a cooler climate



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Housing Modifications



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Level of Dependency	Made changes (%)	Did not make changes (%)	Total (n)
Independent	12.8	87.2	243
Low	32.4	67.6	339
Medium	66.2	33.8	204
High	82.6	17.4	242
All (n)	476	552	1,028

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- Bedrooms
- Bathrooms
 - Hobless shower
 - Rails
 - Lowering mirror
- Rails
- Ramps
- Leveling floors
 - Access to the home
 - Inside the home
- Lighting
- Temperature control
- Gardens and outdoor areas

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Rails and Hobless Shower



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Fixed Hoist



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Level Access



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Bed rail



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Private entry into lift



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Make-shift threshold



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Shower recess in a new home



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Recessed sliding door



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- Cost
- Energy and expertise
- Living at home during the renovation
- Stigma of the modifications
- Resale value



- People with NDD, in general, have:
 - difficulty with mobility,
 - reduced strength and stamina,
 - reduced vision and hearing, and
 - greater frequency of need to access the toilet.
- For people with declining mobility, including those with NDD, house design and location are important factors involved in enabling them to manage their physical difficulties and remain living in the community.
- Many of the issues concerning the housing experience of people with NDD can be related to the frail elderly.
- Universal design should be considered in the design of all housing. This will benefit not just the 85 in 100,000 with NDD disorders but also up to 23,000 in 100,000 of Australia's ageing population.
- *Note that by 2051, 26 to 28 percent of Australia's population will be aged over 65 years.*