

## Some Quality of Life measures for people with dementia and their carers

For additional Quality of Life instruments see: <http://acqol.deakin.edu.au/instruments/instrument.php>

Acronym	Scale Name	Reference	Rating	Admin Time	Comment
	Activity and Affect Indicators of Quality of Life	Albert, S., Castillo-Casteneda, C.D., Sano, M., Jacobs, D.M., Marder, K. et al. (1996). Quality of life in patients with Alzheimer's disease as reported by patient proxies. <i>Journal of the American Geriatrics Society</i> , 44, 1342-1347.	Interview with Carer		<ul style="list-style-type: none"> <li>▪ Domains: activity and affect</li> <li>▪ Useful for mild to severe stages of dementia</li> <li>▪ Narrow measurement of QOL given on two domains</li> <li>▪ 21 items</li> </ul>
ADRQOL	Alzheimer's Disease-Related Quality of Life Scale	Rabins, P.V. Kasper, J.D., Kleinman, L., Black, B.S. (1999). Concepts and methods in the development of the ADRQL: An instrument for assessing health-related quality of life in persons with Alzheimer's disease. <i>Journal of Mental Health and Ageing</i> , 5, 33-48	PwD	Unknown	<ul style="list-style-type: none"> <li>▪ Indications: Measure health-related quality of life in patients with Alzheimer's disease</li> <li>▪ Domains: social interaction, awareness of self, feeling and mood, enjoyment of activities, response to surroundings</li> <li>▪ Copyrighted</li> </ul>

Acronym	Scale Name	Reference	Rating	Admin Time	Comment
BASQID	Bath Assessment of Subjective Quality of Life in Dementia		PwD		
CBS	Cornell-Brown Scale for Quality of Life in Dementia	Ready, R., Ott, B.R., Grace, J., & Fernandez, I. (2002). The Cornell- Brown Scale for Quality of Life in Dementia. <i>Alzheimer Disease and Associated Disorders</i> , 16, 109-115.	Experienced clinician interviews patients and caregivers	10-12 mins	<ul style="list-style-type: none"> <li>▪ Indications: Measure quality of life in patients with dementia</li> <li>▪ Dimensions: mood related signs (anxiety-comfort, sadness-happiness,, lack of reactivity to pleasant events-enjoyment of life's pleasant events, irritability-tolerance), ideational disturbance (suicide-value of life, self-deprecation-self-esteem, pessimism-optimism, mood congruent delusions-secure feelings)</li> <li>▪ Ratings based on symptoms and signs during the week prior to interview</li> <li>▪ Reliability and validity are not adversely affected by degree of patient's cognitive impairment.</li> </ul>
CDQLP	Community Dementia Quality of Life Profile	Salek et a., (1999)	PwD		
CDR	Clinical Dementia Rating		PwD		

Acronym	Scale Name	Reference	Rating	Admin Time	Comment
CILQ	Cognitively Impaired Life Quality Scale	DeLetter, M.C., Tully, C.L., Wilson, J.F., & Rich, E.C. (1995). Nursing staff perceptions of quality of life of cognitively impaired elders: Instrumental development. <i>Journal of Applied Gerontology, 14</i> , 426-443.	Caregiver administered	25 mins long version 10-15 mins short version	<ul style="list-style-type: none"> <li>▪ Indications: To assess QOL in older people with dementia</li> <li>▪ Domains: Social interaction, basic physical care, appearance of patient to others, nutrition, pain</li> </ul>
DCM	Dementia Care Mapping	Bradford Dementia Group (1997)	PwD		<ul style="list-style-type: none"> <li>▪ Observational assessment of dementia patient experiences</li> </ul>
DEMQOL	Dementia Quality of Life	Smith et al (2005)	PwD		
DQOL	Dementia Quality of Life	Brod, M., Stewart, A.L., Sands, L., & Walton, P. Conceptualisation and measurement of quality of life in dementia: The dementia quality of life instrument (DQoL). <i>The Gerontologist, 39</i> , 25-35.	Clinical interview by trained interviewer the PwD (mild to moderate)	30-40 mins	<ul style="list-style-type: none"> <li>▪ Indications: direct assessment of quality of life of people with dementia</li> <li>▪ Domains: physical functioning, daily activities, discretionary activities, mobility, social interaction, interaction capacity, bodily wellbeing, sense of wellbeing, sense of aesthetics</li> </ul>

Acronym	Scale Name	Reference	Rating	Admin Time	Comment
FAST	Functional Assessment Staging	Resiberg, B. (1988). Functional assessment staging (FAST). <i>Psychopharmacology Bulletin</i> , 24, 653-369.	Clinician Rating, after interview with informant	2 mins (once information gathered)	<ul style="list-style-type: none"> <li>▪ Indications: Assessment of functional change in ageing and dementia</li> <li>▪ Rates functional change in 7 major stages with a total of 16 successive stages and substages</li> <li>▪ Adv – identifies a total of 11 substages according to the later stages of the Global Deterioration Scale and useful in detailed staging and substaging of severe Alzheimer's disease</li> </ul>
GAS	Goal Attainment Scaling Interview	Opie, J., & Rosewarne, R. (2006) National Evaluation Dementia Health Priority Initiative	Carer		Asks carer to identify up to 5 areas of concern that affect enjoyment of life and how successful the service will be in improving the situation
HRQOL	Health-Related Quality of Life		PwD		
PDS	Progressive Deterioration Scale	Dejong, R., Osterlund, O.W., Roy, G.W. (1989). Measurement of quality of life changes in patients with Alzheimer's disease. <i>Clinical Therapies</i> , 11, 545-554.	Carer rating	10-15 (based on interview lasting 90 mins)	<ul style="list-style-type: none"> <li>▪ Indications: Assesses changes in quality of life of patients with Alzheimer's disease</li> </ul>

Acronym	Scale Name	Reference	Rating	Admin Time	Comment
PWB-CIP	Psychological Well-Being in Cognitively Impaired Persons	Burgener, S., Twigg, P. & Thorlton, J. (2002). Measuring psychological well-being in cognitive-impaired persons. <i>Gerontological Society of America Boston, Nov</i>	Observer rated		<ul style="list-style-type: none"> <li>▪ Indications: Measure aspects of quality of life related to psychological well-being</li> <li>▪ Domains: positive affect states, negative affect states, and engagement behaviours</li> <li>▪ Used with PwD (mild to moderate severity) being cared for at home</li> <li>▪ Strength – useful with severe D given observer rating</li> <li>▪ Weakness – narrow range of QoL</li> <li>▪ 11 items</li> </ul>
PES-AD	Pleasant Events Schedule – AD	Albert et al., (1996)	PwD		
QUALID	Quality of Life in Late-Stage Dementia Scale	Weiner, M. F. (2000)	PwD		

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QOL-AD	Quality of Life – Alzheimer’s Disease	Logsdon, R.G., Gibbons, L.E., McCurry, S. M., Teri, L. (1999). Quality of life in Alzheimer’s disease: Parent and caregiver reports. <i>Journal of Mental Health and Ageing, 5</i> , 21-32.	Patient and Carer report  Interviewer administered	10 mins	<ul style="list-style-type: none"> <li>▪ Indications: Assessment of quality of life in dementia</li> <li>▪ Domains: physical health, energy, mood, living situation, memory, family, marriage, friends, self as a whole, ability to do chores around the house, ability to do things for fun, money, life as a whole</li> <li>▪ A composite score which weights patient rating more than carer rating can be calculated</li> <li>▪ MMSE scores 10-23</li> <li>▪ 13 items</li> </ul>
QOL-AS	Quality of Life Assessment Schedule	Selai, C.E., Trimble, M. R., Rossor, M., Harvey, R.J. (2001). Assessing quality of life in dementia: Preliminary psychometric testing of the Quality of life Assessment Schedule. <i>Neuropsychological Bulletin, 11</i> , 21-243.	Trained interviewer who will need to prompt answers		<ul style="list-style-type: none"> <li>▪ Indications: Identify relationship between patients current health condition and their quality of life</li> <li>▪ Domains: Physical, psychological, social, daily activities, cognitive function</li> </ul>
QOL-D	Quality of Life in Dementia	Terada et al., (2002)	PwD		

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	Quality of Life in Dementia	B.au, T. H. (1997). Quality of life, social indicators, and criteria of change. <i>Professional Psychology</i> , November, 464-473.	Self-rated	15 mins	<ul style="list-style-type: none"> <li>▪ Indications: Assessment of quality of life</li> <li>▪ Domains: working, leisure, eating, sleeping, social contact, earning, parenting, loving, environment, self-acceptance</li> </ul>
WHO-5	Screening measure for Depression in older adults		PwD		

### Carers of People with Dementia

WHO-5		Screening measure for Depression in older adults
Staff QOL-AD	Interview	Logsdon et al., (2000)
HDQoL-C		Huntington's Disease Quality of Life Battery for Carers