What helps people with dementia to live well?

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An evidence summary based on the following systematic review: Martyr A et al. (2018). *Living well with dementia: a systematic review and correlational meta-analysis of factors associated with quality of life, well-being and life satisfaction in people with dementia*. Psychological Medicine 48, 2130–2139.



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Background to the review

Enabling people with dementia to 'live well' is important for patients, carers, policy and practice. If we can identify the factors that influence the ability to live well with dementia, then we can identify potential targets for intervention.

Purpose of the review

This review examined the factors associated with living well in dementia patients. Living well was measured by quality of life (QoL), well-being and life satisfaction scores.

Previous reviews of QoL within the dementia population have used different reporting measures, yielding different results and making it difficult to draw clear conclusions. Furthermore, well-being and life satisfaction measures have not been studied with any depth in people with dementia. This review attempted to address these issues.

- For people with dementia, better quality of life is associated with factors reflecting relationships, social engagement and functional ability.
- Factors associated with poor physical and mental health are associated with a poorer quality of life.
- A patient's age, gender, education level, income, type of dementia and disease duration are not associated with a patient's quality of life.
- Results are the same for patients with Alzheimer's Disease and for those living within a community or residential setting.

What methods did the review use?

Reviewers searched relevant health and social care databases for studies that assessed wellbeing, life satisfaction or QoL in people with a diagnosis of dementia. There were no limits on the type or severity of dementia included in the review and no restrictions on age or living situation.

Studies were included that reported self-rated measures from patients, carers and healthcare professionals (reflecting their appraisal of the patient). Measures were also included by proxy (family or healthcare professional's appraisal of what they think the patient would think). Included studies were 'observational' i.e. patients were observed without intervention.

Data were analysed where comparable from at least 5 studies. The effect size of association between relevant factors and measures of 'living well' were deemed either negligible (<0.09), small (0.10-0.29), moderate (0.30-0.49) or large >0.50.

How good is the review and the quality of included studies?

The review measured the quality of included studies using a checklist adapted from existing assessment tools. Two independent reviewers scored each article and removed studies that were judged to be of poor quality. Differences between studies were accounted for by undertaking a number of sub-group analyses. These had little impact on overall effect sizes.

What are the results of the review?

The review included data from 37,639 people in 198 studies. Within the included studies, there were 45 different measures of QoL reported, seven of wellbeing and four of life satisfaction. The reviewers were only able to compare QoL measures as the well-being or life satisfaction scores reported were not comparable.

Box 1. What improves quality of life for people with dementia?	
Greater social engagement	
Better quality of current relationship with carer	Moderately associated with better quality of life (effect sizes 0.30-0.49 p<0.05)
Religious beliefs and spirituality	олоо олоо от тр тотоо,
White ethnicity	Small associations with better quality of life (effect sizes 0.10-0.29, p<0.05)
Self-rated health and awareness	
Better functional ability	
Having a spouse carer	
Living in the community	
If in a residential setting: -Being cared for in a specialist dementia unit	
-Receiving more patient- centred care	
Carer's self-rated quality of life	
Higher cognitive test scores	
Better self-rated memory functioning	Negligible associations with better quality of life (effect sizes 0-0.09 P<0.27)
Being married	,

How do the authors interpret the results?

Most associations found were small and no factors were strongly associated with quality of life (Boxes 1&2). Factors such as age and gender were largely unrelated to QoL while social, health and carerelated factors were more likely to show associations. The authors summarise: *'Efforts to improve QoL might focus on supporting relationships, social engagement and everyday* functioning, addressing poor physical and mental health, and ensuring high-quality care'.

Box 2. What makes quality of life poorer for people with dementia?	
Depression Neuropsychiatric symptoms Carer burden/stress Carer distress at symptoms	Moderately associated with poorer quality of life (effect sizes 0.30-0.49 p<0.05)
Greater severity of dementia Anxiety Pain Presence of unmet needs Presence of comorbid conditions Living alone Carer depression Carer mental health More time spent caring (by carer) More advanced dementia	Small associations with poorer quality of life (effect sizes 0.10-0.29, p<0.05)
Use of medication Longer duration of stay in residential care	Negligible associations with poorer quality of life (effect sizes 0-0.09 P<0.05)

What are the limitations of the review?

The researchers were unable to measure life satisfaction and wellbeing. These outcomes may be more meaningful and relevant to patients than QoL. They were also unable to separate the results for different dementia types (except for Alzheimer's disease).

More evidence is needed on how to maintain or improve quality of life over-time and to identify those at risk of decline so that preventative measures can be taken.

Who are the authors and where is it published?

The primary authors are from the University of Exeter. The review was published in Psychological Medicine - a peer-reviewed medical journal in the field of psychiatry, psychology and basic sciences. The journal has a 2010 impact factor of 6.159 (which puts it within the top 5% of journals).

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