Systematic review summary

Current policy emphasises the importance of ‘living well’ with dementia. Responses to questionnaires about quality of life, well-being and life satisfaction can indicate whether someone is living well and many studies have investigated how different aspects of the experience of people with dementia relate to the ability to live well. We aimed to systematically identify studies and draw together the findings to discover which of these aspects are related to living well with dementia. We did this by searching electronic databases for relevant articles that examined factors related to quality of life, well-being and life satisfaction. To be included articles needed to written in English, present numerical data from samples where at least 75% of participants had dementia, and be published before January 8th 2016.

From the 10,530 unique articles found in the search we identified 307 relevant articles from 213 different studies. This included people with dementia from 36 countries, mostly Europe or North America. Of these 213 studies, there were 205 studies of quality of life, six well-being studies and three life satisfaction studies. Consequently, the review focussed only on quality of life as there were not enough studies to statistically investigate well-being or life satisfaction further. Out of the 205 quality of life studies information could be combined and analysed in a meta-analysis from 198 studies and included nearly 38,000 people with dementia. Findings suggest that many factors have a modest influence on quality of life and that it is likely that to some extent these may be different for each person. However, whether a person with dementia is experiencing a good quality of life is unlikely to depend on personal factors like age, gender, education, marital status or income, or on the type of dementia that s/he has as effect sizes for these factors were very small. There was stronger evidence that people with dementia were more likely to have good quality of life if they were socially active, had good relationships with family and friends, were included and involved in social activities, were able to manage everyday activities, and had religious beliefs. People with dementia who had poor mental or physical health, who had unmet needs, who experienced pain, or whose carer experienced low well-being were more likely to have poor quality of life. We also found that quality of care and support was important. For instance, where a person with dementia is supported by a family member, quality of life is better where the family member feels more positive and better able to cope. For people with dementia in residential care, receiving specialist person-centred care is linked to better quality of life.

Findings suggest that quality of life is linked to many aspects of daily life for people with dementia. This pattern of numerous small associations could reflect individual differences in what people feel is important for their quality of life. Understanding what is important for each individual may help in providing better support. In addition, there may be some things that can be done to ensure people living with dementia can maintain a good quality of life. Focussing on supporting relationships, improving social engagement and everyday functioning, addressing poor physical and mental health, and ensuring high-quality care could improve the quality of life of people with dementia.