**Supplementary Material**

Table S1: Search Terms

|  |  |
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| Database | Search terms |
| Medline (OVID\*)(1946 – present)PsycINFO (OVID\*)(1887 – present) Embase (OVID\*)(1947 – present) | 1. (spouse\* or partner\* or carer\* or caregiver\* or family).mp.
2. dementia.mp.
3. dementia/ or alzheimer disease/ or aphasia, primary progressive/ or creutzfeldt-jakob syndrome/ or dementia, vascular/ or diffuse neurofibrillary tangles with calcification/ or frontotemporal lobar degeneration/ or frontotemporal dementia/ or "pick disease of the brain"/ or primary progressive nonfluent aphasia/ or lewy body disease/
4. alzheimer\*.mp.
5. 2 or 3 or 4
6. pre-diagnosis\* or early stage\* or early symptom\* or onset
7. 5 and 6
8. 1 and 7
9. questionnaire\* or survey\* or interview\* or focus group\* or case stud\* or observ\*
10. view\* OR experienc\* OR opinion\* OR attitude\* OR perce\* OR belie\* OR feel\* OR understand\*
11. 9 or 10
12. qualitative.mp. or mixed method\*
13. 11 and 12
14. 8 and 13
 |
| CINAHL (EBSCO)(1961 – present)Web of Science (1900 – present) | ((spouse\* or partner\* or carer\* or caregiver\* or family) AND ((dementia or alzheimer\* or dementia or “alzheimer disease” or “primary progressive aphasia” or “primary progressive nonfluent aphasia” or “creutzfeldt-jakob syndrome” or “vascular dementia” or cadasil or “multi-infarct dementia” or “diffuse neurofibrillary tangles with calcification” or “frontotemporal lobar degeneration” or “frontotemporal dementia” or "pick disease of the brain" or “lewy body disease”) AND (pre-diagnos\* or "early stage\*" or "early symptom\*" or onset ))) AND ((“questionnaire\*” OR “survey\*” OR “interview\*” OR “focus group\*” OR “case stud\*” OR “observ\*” OR “view\*” OR “experienc\*” OR “opinion\*” OR “attitude\*” OR “perce\*” OR “belie\*” OR “feel\*” OR “know\*” OR “understand\*”) AND qualitative OR “mixed method\*”) |

*\*In searches using the OVID platform, terms are added as separate lines each with a corresponding number, rather than repeating the phrases. Hence, terms are searched individually and then added using the Boolean commands ‘and’ or ‘or’. The numbers refer to earlier search terms.*

Table S2: Quality Framework from Walsh and Downe (2006), applied to included studies

|  |  |
| --- | --- |
| **Quality criteria** | **Citation** |
|  | [Allen *et al.* (2009)](#_ENREF_1) | [Bakker *et al.* (2010)](#_ENREF_2) | [Hayes *et al.* (2010)](#_ENREF_3) | [Klink (2013)](#_ENREF_4) | [Krull (2005)](#_ENREF_5) | [Meyer *et al.* (2016)](#_ENREF_6) | [Mukadam *et al.* (2011)](#_ENREF_7) | [Teel and Carson (2003)](#_ENREF_8) | [Valimaki *et al.* (2012)](#_ENREF_9) | [van Vliet *et al.* (2011)](#_ENREF_10) | [Wilson (1989)](#_ENREF_11) |
| Scope and purpose * Clear statement of, and rationale for, research question /aims/purposes
* Study thoroughly contextualised by existing literature
 | S | S | S | S | S | S | S | S | S | S | S |
| Design* Method/design apparent and consistent with research intent
* Data collection strategy apparent and appropriate
 | S | I | I | I | I | S | I | I | S | I | S |
| Sampling strategy* Sample and sampling method appropriate
 | S | I | S | I | I | I | S | I | S | S | S |
| Analysis* Analytic approach appropriate
 | S | S | I | I | I | I | S | S | S | S | S |
| Interpretation * Context described and taken account of in interpretation
* Clear audit trail given
* Data used to support interpretation
 | S | S | S | I | I | S | I | S | S | S | S |
| Reflexivity* Researcher reflexivity demonstrated
 | S | I | S | I | I | S | I | I | S | I | I\* |
| Ethical dimensions* Demonstration of sensitivity to ethical concerns
 | I | I | S | S | I | S | S | I | S | I | I\* |
| Relevance and transferability* Relevance and transferability evident
 | S | S | S | S | S | S | S | I | S | S | S |

*Key: S = sufficient detail provided; I = insufficient detail provided. Sufficient was defined as enough information to answer each of the specific prompts outlined by Walsh and Downe (2006). Insufficient was defined as an absence of or not enough information to answer each of the specific prompts outlined by Walsh and Downe (2006). The reason for choosing ‘sufficient/insufficient’ rather than ‘yes/no’ ratings was because, as expressed by Walsh and Downe (2006) not all of these categories are explicitly stated in a journal article, and some can be assumed based on other information.*

*\* By strict adherence to the quality framework of Walshe and Downe (2006), Wilson’s (1989) study does not meet the criteria relating to reflexivity and ethical dimensions. However, we would add caveat that this is consistent with the tenets of the chosen method. Wilson’s (1989) study adopts a classic grounded theory approach, which does not consider these criteria relevant to determining quality (Glaser and Strauss, 1967).*