

Living alone with mild-to-moderate dementia over a two-year period: longitudinal findings from the IDEAL cohort

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Supplemental digital content

Supplemental digital content 1. Measures

Supplemental digital content 2. Comparison of those who remained in the study and those who dropped out

Supplemental digital content 3. Statistical analyses

Supplemental digital content 4. Tables and Figures

Supplemental digital content 5. References

Supplemental digital content 1. Measures

Person with dementia - demographic characteristics

Age was classified into five groups for purposes of analysis: <65, 65-59, 70-74, 75-79, 80+.

Education was classified into four groups: no qualifications, school leaving certificate at age 16, school leaving certificate at age 18, and University level education.

Socioeconomic status was grouped into three categories based on the Office for National Statistics¹ three-level National Statistics Socio-Economic Classification: 1 (Higher managerial, administrative, and professional occupations), 2 (Intermediate occupations) and 3 (Routine and manual occupations). People who never worked were coded as missing.

Person with dementia - clinical characteristics

Dementia diagnosis was taken from medical records and recorded by researchers under one of seven categories: Alzheimer's disease, vascular dementia, mixed Alzheimer's disease and vascular dementia, frontotemporal dementia, Parkinson's disease dementia, dementia with Lewy bodies, and other/unspecified.

Co-morbidity was a count of the number of conditions, excluding dementia, endorsed in the Charlson Comorbidity Index.^{2,3} Scores range between 0 and 22. At T1, the Charlson Comorbidity Index was administered as a joint interview involving the person with dementia and caregiver where there was a caregiver participating, and was completed by the person with dementia where there was no caregiver participating. At T2 and T3 the Charlson Comorbidity Index used informant ratings where a caregiver was available, and self-ratings by the person with dementia where there was no caregiver participating.

Self-rated health was assessed using a single-item;⁴ scores range from 1 (very poor) to 6 (excellent) with higher scores indicating better subjective health.

Person with dementia – service use

Questions from the Client Services Receipt Inventory⁵ were used to gather information about use of health and social care services over the previous three months and current use of assistive technologies. Services covered were hospital, primary, community health and mental health care, mental health medications, and community-based long-term care (e.g., in-home care, day centers, meals on wheels). Methods of collecting data on use of services have been described previously in full detail.⁶ At T1, the Client Services Receipt Inventory was administered as a joint interview involving the person with dementia and caregiver where there was a caregiver participating, and was completed by the person with dementia where there was no caregiver participating. At T2 and T3 the Client Services Receipt Inventory used informant ratings where a caregiver was available, and self-ratings by the person with dementia where there was no caregiver participating.

Person with dementia - cognitive tests

Cognition was assessed using the Mini-Mental State Examination⁷ and the Addenbrooke's Cognitive Examination-III.⁸ Scores for the Mini-Mental State Examination range between 0 and 30. Scores for the Addenbrooke's Cognitive Examination-III range between 0 and 100. The Addenbrooke's

Cognitive Examination-III also provides scores for five cognitive subdomains (Attention, Verbal fluency, Language, Memory, Visuospatial). For both measures, a higher score indicates better cognition. At T2 and T3 if a person with dementia scored below 10 on the MMSE, the ACE-III was not administered, as described previously.⁹

Person with dementia - self-report measures

Functional ability was assessed with an 11-item modified Functional Activities Questionnaire,¹⁰ amended to include a question about telephone use as described in detail previously.^{11,12} Scores range from 0 to 33, with higher scores indicating more functional difficulties. Measure reliability was acceptable; Cronbach's alpha: T1 - 0.861, T2 - 0.872, T3 - 0.890.

Mood was assessed using the 10-item Geriatric Depression Scale.¹³ Scores range from 0 to 10, with scores over 4 indicating the presence of depressive symptoms. Measure reliability was acceptable; Cronbach's alpha: T1 - 0.756, T2 - 0.761, T3 - 0.732.

Loneliness was assessed using the six-item De Jong Gierveld Loneliness Scale.¹⁴ Scores range from 0 to 6, with scores of 0 or 1 indicating not lonely, scores between 2 and 4 indicating moderate loneliness, and scores of 5 or 6 indicating severe loneliness. Measure reliability was acceptable; Cronbach's alpha: T1 - 0.698, T3 - 0.691 (this question was not asked at T2).

Stigma was assessed with four items from the Stigma Impact Scale¹⁵ for people with dementia,¹⁶ one item from each of the subscales. The stigma questions were only administered where participants showed awareness of dementia when responding to the Representations and Adjustment to Dementia Index.¹⁷ Scores range from 1 to 16, with higher scores indicating more perceived stigma relating to dementia. Measure reliability was acceptable; Cronbach's alpha: T1 - 0.722, T2 - 0.692, T3 - 0.753.

The six-item Lubben Social Network Scale¹⁸ assessed social isolation. Scores range from 0 to 30, with scores between 0 and 11 indicating social isolation, whereas scores over 12 indicate no social isolation. Measure reliability was acceptable; Cronbach's alpha: T1 - 0.722, T2 - 0.804, T3 - 0.765.

Social capital was assessed with the Office for National Statistics core social capital items.¹⁹ These core questions covered neighborhood reciprocity and trust, neighborhood social problems, civic participation, social participation, and frequency of social contact with people not living in the same household.

- Neighborhood reciprocity and trust was assessed with the question: "If you lost your purse or wallet how likely would it be that you get it back with nothing missing". Responses are rated on a 5-point scale. Scores of 4 - 5 were coded as 'likely' and scores of 1 - 3 were coded as 'other'.
- Neighborhood social problems were assessed through seven questions concerning local problems such as people being drunk or rowdy, litter lying around, vandalism, graffiti, and other deliberate damage. Each question was rated on a 5-point scale and scores from all seven questions were added to give a total score, with a maximum possible score of 35. Higher scores indicate fewer local problems. Scores of 35 were coded as 'no problems' and scores below 35 as 'some problems'.
- Civic participation was assessed by asking about seven ways in which participants could have attempted to solve a problem affecting people in their local area. Scores range from 0 to 7, with higher scores indicating more active engagement with solving local problems.

- Social participation was assessed by asking about 12 different ways in which participants could have given any unpaid help to any groups, clubs, or organizations in the previous 12 months. Scores range from 0 to 12, with higher scores indicating more active engagement with groups or clubs.
- Frequency of social contact with people not living in the same household was assessed through five questions concerning speaking to friends or family on the telephone, speaking to neighbors, and meeting with friends or family. Scores were summed to give a total score between 0 and 20, with higher scores indicating more frequent social contact. Measure reliability was acceptable; Cronbach's alpha: T1 – 0.625, T2 – 0.665, T3 – 0.672.

Cultural capital reflects the sociological understanding of capital as not solely economic but rather in terms of the relations between economic, social, and cultural assets. The measure used here, the Cultural Capital and Social Exclusion Survey,²⁰ was developed for a study on cultural capital and social exclusion in the UK, which explored cultural participation, cultural tastes and cultural knowledge across age-groups, social classes, genders, and ethnicities. The measure examines cultural participation by asking about frequency of engagement in 13 cultural practices – the kinds of activities typically available to people within their culture, from what might be considered 'high' culture such as going to the opera or visiting a museum to more widespread activities such as going to the cinema or pub or eating out. Scores range from 13 to 65, with higher scores indicating more frequent participation in these cultural practices. Greater participation is considered to indicate greater cultural capital and concomitantly less social exclusion. Data from this measure have been described previously in detail.²¹ Measure reliability was acceptable; Cronbach's alpha: T1 - 0.743, T2 – 0.743, T3 – 0.753.

Capability to live well with dementia was assessed using three measures:

- The Quality of Life in Alzheimer's Disease scale²² is a widely-used measure²³ that asks about aspects of everyday life such as current memory, mood, and energy levels. Scores range from 13 to 52, with higher scores indicating better quality of life. Measure reliability was acceptable; Cronbach's alpha: T1 - 0.832, T2 – 0.840, T3 – 0.825.
- The Satisfaction with Life Scale²⁴ is a widely-used measure²⁵ designed to measure global judgments of satisfaction with life. Scores range from 5 to 35, with higher scores indicating greater satisfaction with life. Measure reliability was acceptable; Cronbach's alpha: T1 - 0.823, T2 – 0.838, T3 – 0.861.
- The World Health Organization-Five Well-Being Index²⁶ is a widely-used measure²⁵ designed to cover aspects such as positive mood, being active, and general interest in things. Scores range from 0 to 25, with higher scores indicating greater well-being. Scores can also be converted to a percentage score by multiplying raw scores by 4, and it is the percentage score that is used in the present study. Measure reliability was acceptable; Cronbach's alpha: T1 - 0.800, T2 – 0.803, T3 – 0.808.

Informant-rated measures completed by the caregiver

Functional ability was assessed with the 11-item modified Functional Activities Questionnaire described above. Measure reliability was acceptable; Cronbach's alpha: T1 - 0.916, T2 – 0.917, T3 – 0.927.

Social isolation was assessed with the six-item Lubben Social Network Scale described above. Measure reliability was acceptable; Cronbach's alpha: T1 - 0.787, T2 – 0.799, T3 – 0.777.

Dependence was assessed with the 13-item Dependence Scale.^{27,28} Scores range from 0 to 15, with higher scores indicating greater dependence. Measure reliability was acceptable; Cronbach's alpha: T1 - 0.765, T2 - 0.811, T3 - 0.835.

Neuropsychiatric symptoms were assessed using the 12-item Neuropsychiatric Inventory-Questionnaire.²⁹ Item wording was adapted from the 2008 version used in the US National Alzheimer's Coordinating Center³⁰ to facilitate self-completion by the caregiver. Scores range from 0 to 12. If a symptom was present two sub-questions were asked concerning severity of the symptom (scores range from 0 to 36) and how distressing the caregiver found that symptom (scores range from 0 to 72). Higher scores indicate more symptoms, higher symptom severity, or greater distress at the symptom, respectively.

Supplemental digital content 2. Comparison of those who remained in the study and those who dropped out

Demographic characteristics and scores on study measures were compared for those who remained in the study and those who dropped out at the next timepoint. Responses at Time 1 were compared for those who remained in the study and those who left at Time 2, and responses at Time 2 were compared for those who remained in the study and those who left at Time 3. Unpaired two-sample t-tests were used to compare continuous study measures and Chi-squared tests were used to compare categorical study measures.

As shown in Supplementary Table 1A, measures associated with dropout included older age, being more cognitively or functionally impaired, being more depressed, having less social contact and less involvement in the community, experiencing more or more severe neuropsychiatric symptoms, and having lower quality of life.

Resource use is summarised in Supplementary Table 1B. At either timepoint, more people who dropped out were receiving home care visits compared to those who remained. At T2, more of those who dropped out had emergency department visits recorded, and at T3 more of those who dropped out had GP home visits, physiotherapy or occupational therapy visits, social worker visits, or sitting service visits recorded.

Supplemental digital content 3. Statistical analysis

Data on service use and categories of assistive technology devices were summarized in terms of numbers and proportions using the service. Data on study measures were summarized in terms of numbers and proportions within each category or means and standard deviations for continuous measures.

Mixed effects models^{31,32} were used to investigate change in outcomes measured over the three timepoints of data collection (T1-T3) using Stata 17.³³ Conditional (covariate-adjusted) random coefficient models, with a random intercept and a random slope³⁴ were fitted initially and tested against a random intercept model to see if adding the random slope improved model fit. In cases where the model fit was not improved, a random intercept model was used. All models had unstructured covariance allowing subject-specific random slopes to vary freely over time.

For continuous measures, residuals were examined for normality and either linear models or generalized linear models with a gamma distribution and a log link were fitted. A logistic mixed effects model was fitted for binary study measures including use of each service or assistive technology.

Count measures comprised Neuropsychiatric Inventory Questionnaire symptoms, social participation, and civic participation. A Poisson model was fitted for analysis using the number of Neuropsychiatric Inventory-Questionnaire symptoms. A negative binomial model, to account for overdispersion, was fitted for social participation and civic participation. As the severity and distress sub-questions from the Neuropsychiatric Inventory-Questionnaire were answered where symptoms were present a two-part model for semi-continuous data was conducted in R using the *GLMMadaptive* package.³⁵ This model specifies a logistic regression for the dichotomous indicator (did or did not have symptoms) and a linear model for the logarithmic transformation of non-zero responses. A two-part model was also conducted for stigma, as only people who were aware of their condition answered this question.

Models were adjusted for age, sex, and dementia diagnosis. Missing data on outcome measures was handled using full information maximum likelihood estimation. Main effects of living alone at baseline (vs living with others) and change over time for those not living alone were reported for longitudinal outcomes, in addition to the interaction between living alone and the slope (indicating the expected difference in slope between those living alone and those living with others). Population-averaged predicted probabilities were estimated from models where the interaction effects were significant.

Supplemental digital content 4: Tables and Figures

Supplementary Table 1. Characteristics of people with dementia stratified by remaining or withdrawing at the next timepoint

A) Demographics and study measures

	T1 (baseline)				T2			
	Total (n=1525)	Remained in study at T2 (n=1177)	Did not remain in study at T2 (n=348)	P-value	Total (n=1177)	Remained in study at T3 (n=840)	Did not remain in study at T3 (n=337)	P-value
Lives alone status (N, %)								
Lives alone	281 (18.4%)	205 (17.4%)	76 (21.8%)	0.062	205 (17.4%)	144 (17.1%)	61 (18.1%)	0.695
Does not live alone	1244 (81.6%)	972 (82.6%)	272 (78.2%)		972 (82.6%)	696 (82.9%)	276 (81.9%)	
Age years (mean, sd; N)	76.4 (8.5), 1525	76.1 (8.35), 1177	77.4 (9.0), 348	0.014	76.1 (8.4), 1177	75.5 (8.4), 840	77.7 (7.9), 337	<0.001
Sex (n, %)								
Male	861 (57.2%)	668 (56.8%)	193 (55.5%)	0.183	668 (56.8%)	472 (56.2%)	196 (58.2%)	0.537
Female	664 (42.8%)	509 (43.2%)	155 (44.5%)		509 (43.2%)	368 (43.8%)	141 (41.8%)	
Education (N, %)				0.119				0.558
No qualifications	423 (24.6%)	317 (26.9%)	106 (31.0%)		317 (26.9%)	229 (27.3%)	88 (26.1%)	
School certificate age 16	272 (15.8%)	202 (17.2%)	70 (20.5%)		202 (17.2%)	136 (16.2%)	66 (19.6%)	
School certificate age 18	514 (29.9%)	410 (34.8%)	104 (30.4%)		410 (34.8%)	294 (35.0%)	116 (34.4%)	
Higher education	510 (29.7%)	248 (21.1%)	62 (18.1%)		248 (21.1%)	181 (21.5%)	67 (19.9%)	
Socio-economic status (N, %)				0.489				0.496
1. Higher managerial, administrative, and professional occupations	630 (42.1%)	492 (42.8%)	138 (40.0%)		492 (42.8%)	353 (43.0%)	139 (42.1%)	
2. Intermediate occupations	444 (29.7%)	333 (29.0%)	111 (32.2%)		333 (29.0%)	243 (29.6%)	90 (27.3%)	

3. Routine and manual occupations	421 (28.2%)	325 (28.3%)	96 (27.8%)		325 (28.3%)	224 (27.3%)	101 (30.6%)	
Marital status (N, %)				0.006				0.027
Single	26 (1.7%)	15 (1.3%)	11 (3.2%)		15 (1.3%)	13 (1.5%)	2 (0.6%)	
Married/Partnership/ Cohabiting	1151 (75.5%)	904 (76.8%)	247 (71.0%)		904 (76.8%)	653 (77.7%)	251 (74.5%)	
Divorced/Separated	88 (5.8%)	72 (6.1%)	16 (4.6%)		72 (6.1%)	56 (6.7%)	16 (4.7%)	
Widowed	260 (17.0%)	186 (15.8%)	74 (21.3%)		186 (15.8%)	118 (14.0%)	68 (20.2%)	
Dementia diagnosis (N, %)				0.056				0.006
Alzheimer's disease (AD)	845 (55.4%)	663 (56.3%)	182 (52.3%)		654 (55.6%)	484 (57.6%)	170 (50.4%)	
Vascular dementia	167 (11.0%)	120 (10.2%)	47 (13.5%)		118 (10.0%)	81 (9.6%)	37 (11.0%)	
Mixed AD/vascular dementia	323 (21.2%)	259 (22.0%)	64 (18.4%)		265 (22.5%)	185 (22.0%)	80 (23.7%)	
Frontotemporal dementia	54 (3.5%)	36 (3.1%)	18 (5.2%)		39 (3.3%)	31 (3.7%)	8 (2.4%)	
Parkinson's disease dementia	44 (2.9%)	34 (2.9%)	10 (2.9%)		35 (3.0%)	16 (1.9%)	19 (5.6%)	
Dementia with Lewy bodies	53 (3.5%)	35 (3.0%)	18 (5.2%)		40 (3.4%)	26 (3.1%)	14 (4.2%)	
Other/Unspecified	39 (2.6%)	30 (2.5%)	9 (2.6%)		26 (2.2%)	17 (2.0%)	9 (2.7%)	
<i>Study measures</i>								
Charlson Comorbidity Index^ (mean, sd; N)	1.8 (1.6), 1460	1.8 (1.6), 1154	1.8 (1.7), 306	0.701	2.2 (1.8), 1177	2.3 (1.8), 814	2.2 (1.9), 303	0.958
Self-rated health (mean, sd; N)	3.8 (1.2), 1520	3.8 (1.2), 1174	3.8 (1.1), 346	0.438	3.8 (1.1), 1153	3.9 (1.1), 823	3.6 (1.1), 330	<0.001
Mini-Mental State Examination (mean, sd; N)	23.2 (3.6), 1524	23.5 (3.5), 1176	22.3 (3.7), 348	<0.001	21.6 (5.1), 1155	22.4 (4.7), 822	19.5 (5.4), 333	<0.001

Addenbrooke's Cognitive Examination-III Total Score (mean, sd; N)	68.5 (13.5), 1487	69.9 (13.2), 1163	63.5 (13.4), 324	<0.001	66.3 (15.9), 1068	68.5 (15.1), 796	60.0 (16.3), 272	<0.001
Functional Activities Questionnaire (mean, sd; N)	9.6 (7.7), 1473	9.1 (7.4), 1136	11.3 (8.1), 337	<0.001	11.1 (8.4), 989	10.3 (8.0), 722	13.3 (9.0), 267	<0.001
Geriatric Depression Scale-10 (mean, sd; N)	2.7 (2.9), 1358	2.5 (2.2), 1054	3.1 (2.5), 304	<0.001	2.4 (2.3), 1058	2.3 (2.2), 761	2.7 (2.4), 297	0.007
Loneliness (mean, sd; N)	1.4 (1.5), 1423	1.3 (1.5), 1113	1.5 (1.5), 310	0.087	1.3 (1.5), 1113^	1.3 (1.5), 800^	1.4 (1.6), 313^	0.476^
Stigma (mean, sd; N)	7.6 (1.8), 1293	7.6 (1.9), 1014	7.9 (1.7), 279	0.019	7.7 (1.8), 965	7.6 (1.8), 710	8.0 (1.8), 255	0.004
Lubben Social Network Scale (mean, sd; N)	15.1 (6.2), 1440	15.4 (6.2), 1110	14.2 (5.9), 330	0.002	14.9 (6.2), 1078	15.1 (6.1), 791	14.2 (6.5), 287	0.037
Frequency of social contact (mean, sd; N)	12.1 (3.6), 1413	12.2 (3.6), 1115	11.6 (3.7), 298	0.011	11.8 (3.8), 1022	12.0 (3.7), 766	11.2 (4.1), 256	0.005
Neighborhood reciprocity and trust (N, %)								
Likely	1118 (75.7%)	885 (76.1%)	233 (74.4%)	0.544	870 (79.4%)	645 (79.7%)	225 (78.4%)	0.632
Other	358 (24.3%)	278 (23.9%)	80 (25.6%)		226 (20.6%)	164 (20.3%)	62 (21.6%)	
Social problems in neighborhood (N, %)								
No local problems	557 (40.1%)	434 (39.6%)	123 (41.8%)	0.494	453 (44.3%)	320 (42.5%)	133 (49.4%)	0.149
Some local problems	832 (59.9%)	661 (60.4%)	171 (58.2%)		569 (55.7%)	433 (57.5%)	136 (50.6%)	
Civic participation (mean, sd; N)	0.3 (0.8), 1483	0.3 (0.8), 1165	0.2 (0.6), 318	0.011	0.2 (0.7), 1097	0.1 (0.5), 810	0.1 (0.5), 287	0.034
Social participation (mean, sd; N)	0.8 (1.6), 1481	0.9 (1.7), 1164	0.4 (1.3), 317	<0.001	0.7 (1.6), 1097	0.8 (1.8), 810	0.3 (0.7), 287	<0.001
Cultural Capital (mean, sd; N)	22.9 (5.6), 1439	23.2 (5.6), 1131	21.6 (5.5), 308	<0.001	22.2 (5.5), 1060	22.5 (5.4), 785	21.5 (5.9), 275	0.009
QoL-AD (mean, sd; N)	36.8 (5.9), 1362	37.1 (5.9), 1057	35.8 (6.1), 305	0.001	37.0 (5.9), 1027	37.5 (5.7), 751	35.5 (6.0), 276	<0.001

Satisfaction with Life Scale (mean, sd; N)	26.1 (6.1), 1483	26.3 (6.0), 1142	25.4 (6.1), 341	0.013	26.3 (6.1), 1091	26.5 (6.2), 794	25.9 (5.8), 297	0.148
WHO-5 Well-Being Index (mean, sd; N)	61.0 (20.5), 1499	61.6 (20.5), 1156	59.1 (20.4), 343	0.053	60.8 (20.7), 1111	61.8 (21.0), 804	58.1 (19.7), 307	0.008
<i>Informant-rated measures</i>								
Functional Activities Questionnaire (mean, sd; N)	17.9 (8.6), 1173	17.1 (8.5), 928	20.9 (8.3), 245	<0.001	20.7 (8.5), 914	19.6 (8.6), 662	23.7 (7.5), 252	<0.001
Neuropsychiatric Inventory Questionnaire (mean, sd; N)								
Symptoms	3.6 (2.5), 1199	3.4 (2.4), 948	4.1 (2.5), 251	<0.001	3.7 (2.5), 937	3.6 (2.4), 677	4.2 (2.8), 260	0.001
Severity	5.8 (4.9), 1157	5.4 (4.7), 914	7.1 (5.4), 243	<0.001	6.1 (5.1), 903	5.8 (4.8), 653	7.1 (5.6), 250	<0.001
Caregiver distress	6.2 (6.4), 1050	8.1 (7.2), 833	8.1 (7.2), 217	<0.001	6.7 (6.6), 839	6.3 (6.2), 602	7.9 (7.4), 237	0.001
Lubben Social Network Scale (mean, sd; N)	14.7 (5.7), 1081	14.7 (5.7), 854	14.5 (5.6), 227	0.587	14.3 (5.8), 866	14.7 (5.7), 624	13.4 (5.8), 242	0.004

A) Resource use

	T1 (baseline)				T2			
	Total (n=1525)	Remained in study at T2 (n=1177)	Did not remain in study at T2 (n=348)	P-value	Total (n=1177)	Remained in study at T3 (n=840)	Did not remain in study at T3 (n=337)	P-value
General practitioner – office visits (N, %)								
Yes	948 (64.8%)	749 (65.3%)	199 (63.2%)	0.484	747 (67.8%)	544 (68.2%)	203 (66.8%)	0.658
No	514 (35.2%)	398 (34.7%)	116 (36.8%)		355 (32.2%)	254 (31.8%)	101 (33.2%)	

	T1 (baseline)				T2			
	Total (n=1525)	Remained in study at T2 (n=1177)	Did not remain in study at T2 (n=348)	P-value	Total (n=1177)	Remained in study at T3 (n=840)	Did not remain in study at T3 (n=337)	P-value
General practitioner – home visits (N, %)								
Yes	75 (5.1%)	54 (4.7%)	21 (6.7%)	0.160	102 (9.1%)	61 (7.5%)	41 (13.4%)	0.002
No	1390 (94.9%)	1096 (95.3%)	294 (93.3%)		1015 (90.9%)	750 (92.5%)	265 (86.6%)	
General practitioner – telephone calls (N, %)								
Yes	255 (17.5%)	200 (17.5%)	55 (17.6%)	0.966	191 (17.4%)	134 (16.9%)	57 (18.7%)	0.494
No	1203 (82.5%)	945 (82.5%)	258 (82.4%)		905 (82.6%)	657 (83.1%)	248 (81.3%)	
Practice nurse office visits (N, %)								
Yes	684 (47.2%)	553 (48.7%)	131 (41.9%)	0.031	573 (51.9%)	422 (52.9%)	151 (49.3%)	0.284
No	764 (52.8%)	582 (51.3%)	182 (58.1%)		530 (48.1%)	375 (47.1%)	155 (50.7%)	
Community nurse visits (N, %)								
Yes	121 (8.3%)	92 (8.1%)	29 (9.4%)	0.466	150 (13.6%)	95 (11.9%)	55 (18.2%)	0.007
No	1330 (91.7%)	1049 (91.9%)	281 (90.6%)		952 (86.4%)	704 (88.1%)	248 (81.8%)	
Physio/Occupational therapy visits (N, %)								
Yes	164 (11.2%)	130 (11.3%)	34 (10.8%)	0.805	138 (12.6%)	89 (11.3%)	49 (16.0%)	0.035
No	1298 (88.8%)	1018 (88.7%)	280 (89.2%)		960 (87.4%)	702 (88.7%)	258 (84.0%)	
Specialist nurse visits (N, %)								
Yes	114 (7.8%)	91 (7.9%)	23 (7.3%)	0.732	57 (5.2%)	37 (4.7%)	20 (6.5%)	0.219
No	1346 (92.2%)	1056 (92.1%)	290 (92.7%)		1044 (94.8%)	756 (95.3%)	288 (93.5%)	

	T1 (baseline)				T2			
	Total (n=1525)	Remained in study at T2 (n=1177)	Did not remain in study at T2 (n=348)	P-value	Total (n=1177)	Remained in study at T3 (n=840)	Did not remain in study at T3 (n=337)	P-value
Community mental health nurse visits (N, %)								
Yes	236 (16.2%)	185 (16.2%)	51 (16.5%)	0.906	128 (11.7%)	85 (10.7%)	43 (14.2%)	0.101
No	1218 (83.8%)	959 (83.8%)	259 (83.5%)		970 (88.3%)	711 (89.3%)	259 (85.8%)	
Psychiatrist visits (N, %)								
Yes	225 (15.5%)	179 (15.7%)	46 (14.7%)	0.683	75 (6.8%)	53 (6.7%)	22 (7.2%)	0.781
No	1228 (84.5%)	962 (84.3%)	266 (85.3%)		1020 (93.2%)	736 (93.3%)	284 (92.8%)	
Psychologist visits (N, %)								
Yes	49 (3.4%)	43 (3.8%)	6 (1.9%)	0.116	16 (1.5%)	13 (1.6%)	3 (1.0%)	0.417
No	1407 (96.6%)	1103 (96.2%)	304 (98.1%)		1079 (98.5%)	778 (98.4%)	301 (99.0%)	
Social work visits (N, %)								
Yes	68 (4.7%)	49 (4.3%)	19 (6.1%)	0.173	99 (9.1%)	59 (7.5%)	40 (13.2%)	0.004
No	1385 (95.3%)	1094 (95.7%)	291 (93.9%)		992 (90.9%)	728 (92.5%)	264 (86.8%)	
In-home care visits (N, %)								
Yes	163 (11.1%)	118 (10.2%)	45 (14.3%)	0.040	183 (16.4%)	106 (13.2%)	77 (24.8%)	<0.000
No	1309 (88.9%)	1039 (89.8%)	270 (85.7%)		933 (83.6%)	700 (86.8%)	233 (75.2%)	
Meals on wheels visits (N, %)								
Yes	23 (1.6%)	15 (1.3%)	8 (2.5%)	0.117	47 (4.2%)	37 (4.6%)	10 (3.2%)	0.311
No	1453 (98.4%)	1144 (98.7%)	309 (97.5%)		1063 (95.8%)	765 (95.4%)	298 (96.8%)	
Cleaner visits (N, %)								
Yes	339 (23.1%)	273 (23.7%)	66 (21.1%)	0.335	300 (26.8%)	211 (26.0%)	89 (28.6%)	0.385
No	1127 (76.9%)	880 (76.3%)	247 (78.9%)		821 (73.2%)	599 (74.0%)	222 (71.4%)	

	T1 (baseline)				T2			
	Total (n=1525)	Remained in study at T2 (n=1177)	Did not remain in study at T2 (n=348)	P-value	Total (n=1177)	Remained in study at T3 (n=840)	Did not remain in study at T3 (n=337)	P-value
Laundry service visits (N, %)								
Yes	41 (2.8%)	33 (2.9%)	8 (2.5%)	0.761	6 (0.5%)	1 (0.1%)	5 (1.6%)	0.002
No	1424 (97.2%)	1118 (97.1%)	306 (97.5%)		1118 (99.5%)	812 (99.9%)	306 (98.4%)	
Sitting service visits (N, %)								
Yes	34 (2.3%)	24 (2.1%)	10 (3.1%)	0.260	55 (4.9%)	33 (4.1%)	22 (7.1%)	0.040
No	1441 (97.7%)	1133 (97.9%)	308 (96.9%)		1061 (95.1%)	772 (95.9%)	289 (92.9%)	
Caregiver support visits (N, %)								
Yes	42 (2.9%)	30 (2.6%)	12 (3.8%)	0.269	39 (3.5%)	23 (2.9%)	16 (5.2%)	0.063
No	1408 (97.1%)	1106 (97.4%)	302 (96.2%)		1071 (96.5%)	777 (97.1%)	294 (94.8%)	
Day center days (N, %)								
Yes	182 (12.3%)	137 (11.8%)	45 (14.1%)	0.271	175 (15.5%)	120 (14.7%)	55 (17.4%)	0.260
No	1296 (87.7%)	1022 (88.2%)	274 (85.9%)		957 (84.5%)	696 (85.3%)	261 (82.6%)	
Lunch club visits (N, %)								
Yes	133 (9.0%)	105 (9.1%)	28 (8.8%)	0.901	105 (9.3%)	74 (9.1%)	31 (9.9%)	0.677
No	1343 (91.0%)	1054 (90.9%)	289 (91.2%)		1025 (90.7%)	742 (90.9%)	283 (90.1%)	
Emergency Department visits (N, %)								
Yes	73 (5.0%)	49 (4.3%)	24 (7.7%)	0.015	86 (7.7%)	58 (7.2%)	28 (8.9%)	0.335
No	1379 (95.0%)	1091 (95.7%)	288 (92.3%)		1029 (92.3%)	744 (92.8%)	285 (91.1%)	
Inpatient days (N, %)								
Yes	82 (5.6%)	65 (5.7%)	17 (5.4%)	0.872	97 (8.7%)	66 (8.2%)	31 (9.9%)	0.368
No	1373 (94.4%)	1078 (94.3%)	295 (94.6%)		1016 (91.3%)	735 (91.8%)	281 (90.1%)	

	T1 (baseline)				T2			
	Total (n=1525)	Remained in study at T2 (n=1177)	Did not remain in study at T2 (n=348)	P-value	Total (n=1177)	Remained in study at T3 (n=840)	Did not remain in study at T3 (n=337)	P-value
Outpatient appointments (N, %)								
Yes	753 (51.1%)	600 (51.9%)	153 (48.1%)	0.231	352 (31.5%)	261 (32.5%)	91 (29.1%)	0.274
No	721 (48.9%)	556 (48.1%)	165 (51.9%)		765 (68.5%)	543 (67.5%)	222 (70.9%)	
Central nervous system medications (N, %)								
Yes	330 (22.8%)	248 (21.8%)	82 (26.6%)	0.073	264 (24.4%)	186 (23.4%)	78 (27.4%)	0.177
No	1116 (77.2%)	890 (78.2%)	226 (73.4%)		817 (75.6%)	610 (76.6%)	207 (72.6%)	
Dementia medications (N, %)								
Yes	1041 (71.4%)	827 (72.2%)	214 (68.6%)	0.207	816 (73.9%)	611 (75.2%)	205 (70.2%)	0.093
No	416 (28.6%)	318 (27.8%)	98 (31.4%)		288 (26.1%)	201 (24.8%)	87 (29.8%)	

Note. There are 12 people who did not participate at T2 but returned at T3. Unpaired t-tests were used to compare continuous study measures, and Chi-squared tests to compare categorical study measures, with the aim of examining differences between those who remained in the study and those who dropped out at the next timepoint.

^Loneliness was not recorded at T2, so the comparison for those who dropped out or remained at T3 are based on T1 data.

Supplementary Table 2. Sensitivity analysis: mixed effects models showing associations of living alone at baseline with the intercept and slope of scores on longitudinal measures including only those who remained living alone or living with others for all timepoints at which they participated

(a) Self-report measures completed by the person with dementia

Outcome	Baseline: Lives alone	Slope: Lives with others	Interaction: Lives Alone x Slope
Linear model	Estimate (95% CI)	Estimate (95% CI)	Estimate (95% CI)
Quality of Life in Alzheimer's Disease Scale	-1.25 (-2.09, -0.42)*	0.12 (-0.27, 0.52)	-0.50 (-0.98, -0.02)*
Satisfaction with Life Scale	-2.86 (-3.69, -2.05)*	0.10 (-0.34, 0.53)	0.18 (-0.34, 0.69)
World Health Organization-Five Well-Being Index	-4.15 (-6.95, -1.36)*	-1.02 (-2.51, 0.48)	-0.48 (-2.26, 1.30)
Addenbrooke's Cognitive Examination-III	3.15 (1.17, 5.14)*	-5.70 (-6.70, -4.69)*	2.15 (0.95, 3.35)*
Lubben Social Network Scale	-0.50 (-1.37, 0.38)	-0.50 (-0.96, -0.04)*	-0.07 (-0.62, 0.47)
Self-rated health	-0.18 (-0.33, -0.02)*	-0.03 (-0.11, 0.06)	0.10 (0.00, 0.20)
Non-linear model: continuous	Rate ratio (95% CI)	Rate ratio (95% CI)	Rate ratio (95% CI)
Mini-Mental State Examination	1.04 (1.02, 1.07)*	0.90 (0.85, 0.90)*	1.07 (1.04, 1.11)*
Functional Activities Questionnaire	0.73 (0.64, 0.82)*	1.22 (1.14, 1.31)*	0.92 (0.85, 0.99)*
Frequency of social contact	1.14 (1.08, 1.19)*	0.94 (0.91, 0.96)*	1.04 (1.01, 1.08)*
Cultural capital	0.96 (0.93, 1.00)	0.96 (0.95, 0.98)*	1.01 (0.99, 1.03)
Depression	1.11 (1.01, 1.22)*	0.99 (0.95, 1.04)	0.96 (0.38, 1.02)
Loneliness	1.30 (1.19, 1.41)*	1.00 (0.95, 1.05)	0.97 (0.91, 1.03)
Non-linear model: binomial	Odds ratio (95% CI)	Odds ratio (95% CI)	Odds ratio (95% CI)
Neighborhood reciprocity and trust	1.24 (0.73, 2.11)	0.95 (0.66, 1.36)	1.32 (0.89, 1.95)
Neighborhood social problems	0.67 (0.42, 1.09)	0.73 (0.54, 1.00)	1.36 (0.95, 1.96)
Non-linear model: count	Rate ratio (95% CI)	Rate ratio (95% CI)	Rate ratio (95% CI)
Social participation	1.42 (0.99, 2.06)	0.78 (0.64, 0.95)*	1.14 (0.94, 1.39)
Civic participation	0.91 (0.55, 1.53)	0.64 (0.44, 0.93)*	1.80 (1.24, 2.59)*
Number of health conditions	1.15 (1.00, 1.31)*	1.21 (1.12, 1.30)*	0.99 (0.91, 1.07)
Two-part model	Rate ratio (95% CI)	Rate ratio (95% CI)	Rate ratio (95% CI)
Stigma: conditional on awareness of condition	1.01 (0.98, 1.07)	1.03 (0.97, 1.12)	0.97 (0.93, 1.02)

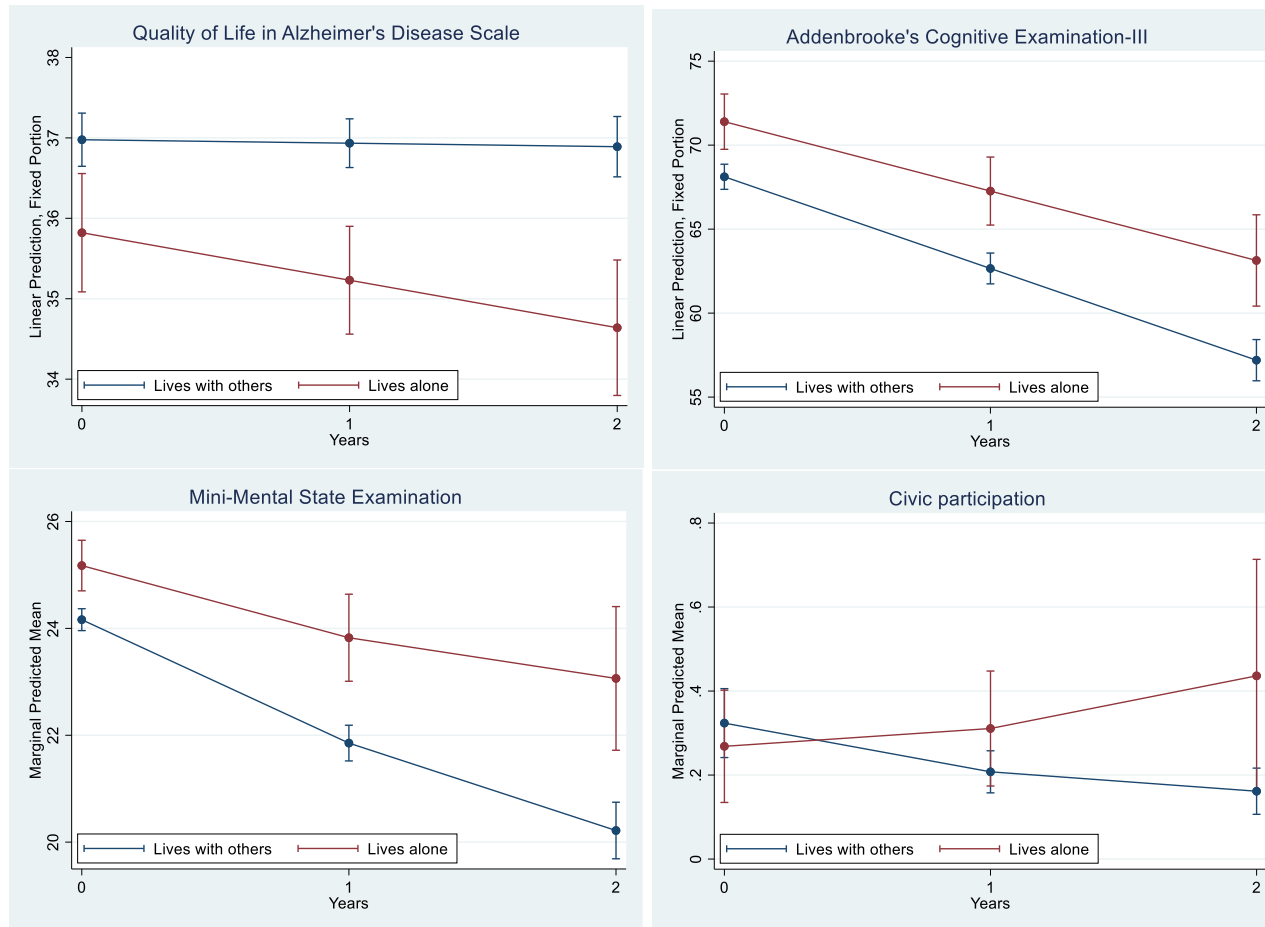
(b) Informant-rated measures completed by the caregiver

Outcome	Baseline: Lives alone	Slope: Lives with others	Interaction: Lives Alone x Slope
Linear model	Estimate (95% CI)	Estimate (95% CI)	Estimate (95% CI)
Dependence scale	-0.83 (-1.36, -0.30)*	0.96 (0.75, 1.17)	0.04 (-0.29, 0.37)
Lubben Social Network Scale	-1.74 (-2.93, -0.55)*	-0.70 (-1.13, -0.27)*	-0.03 (-0.72, 0.66)
Non-linear model: continuous	Rate ratio (95% CI)	Rate ratio (95% CI)	Rate ratio (95% CI)
Functional Activities Questionnaire	0.83 (0.73, 0.95)*	1.18 (1.14, 1.23)*	1.03 (0.97, 1.10)
Non-linear model: count	Rate ratio (95% CI)	Rate ratio (95% CI)	Rate ratio (95% CI)
NPI-Q symptoms	1.05 (0.90, 1.23)	1.11 (1.04, 1.19)*	1.02 (0.92, 1.12)
Two-part model	Rate ratio (95% CI)	Rate ratio (95% CI)	Rate ratio (95% CI)
NPI-Q severity: conditional on having symptoms	1.08 (0.90, 1.30)	1.09 (1.01, 1.17)*	1.00 (0.90, 1.12)
NPI-Q distress: conditional on having symptoms	1.16 (0.93, 1.44)	1.11 (1.00, 1.22)*	1.00 (0.88, 1.14)

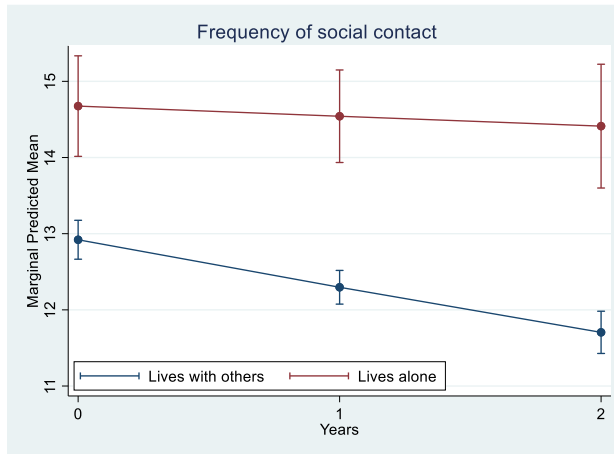
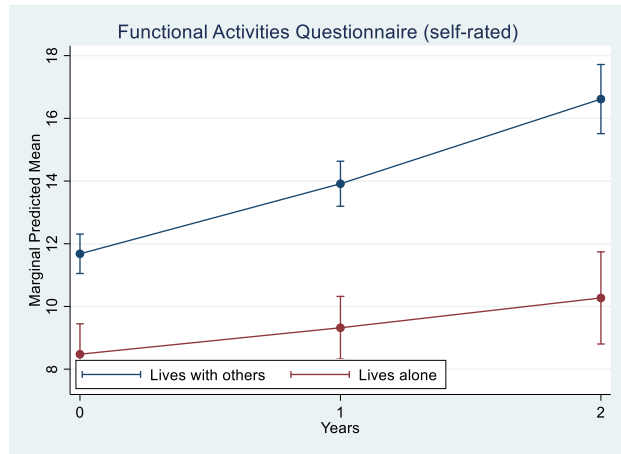
* For linear models, 95% CI do not cross 0. For non-linear models 95% CI does not cross 1. The interaction is the difference in slope compared to the slope for 'Lives with others'. Models were adjusted for age, sex, and dementia diagnosis. CI, confidence intervals, NPI-Q, Neuropsychiatric Inventory Questionnaire.

Supplementary Figure 1. Predictive margins for (a) Quality of Life in Alzheimer's Disease Scale, Addenbrooke's Cognitive Examination-III, Mini-Mental State Examination, and civic participation from the main analysis, and (b) self-rated Functional Activities Questionnaire and frequency of social contact from the sensitivity analysis, showing the differences in trajectories for those living alone and those living with others

(a) Main analyses in Table 3



(b) Sensitivity analysis in Supplementary Table 1



Supplementary Table 3. Resource use by living situation

(a) Use of services

Item	Living with others		Living alone	
	Numbers of users/Valid N (%)	Mean frequency of use (SE)	Numbers of users/Valid N (%)	Mean frequency of use (SE)
Time 1	Expected N=1244		Expected N=281	
General practitioner – office visits	793/1197 (66%)	1.35 (0.05)	155/265 (58%)	1.39 (0.13)
General practitioner – home visits	50/1196 (4%)	0.07 (0.01)	25/269 (9%)	0.16 (0.03)
General practitioner – telephone calls	200/1193 (17%)	0.31 (0.03)	55/265 (21%)	0.35 (0.06)
Practice nurse office visits ¹	586/1190 (49%)	0.93 (0.05)	98/258 (38%)	0.90 (0.14)
Community nurse visits	84/1188 (7%)	0.31 (0.09)	37/263 (14%)	1.72 (0.62)
Physio/Occupational therapy visits	140/1196 (12%)	0.33 (0.04)	24/266 (9%)	0.17 (0.04)
Specialist nurse visits	101/1196 (8%)	0.14 (0.02)	13/264 (5%)	0.09 (0.04)
Community mental health nurse visits	193/1188 (16%)	0.28 (0.02)	43/266 (16%)	0.39 (0.09)
Psychiatrist visits	190/1191 (16%)	0.19 (0.01)	35/262 (13%)	0.16 (0.03)
Psychologist visits	43/1193 (4%)	0.09 (0.02)	6/263 (2%)	0.09 (0.05)
Social work visits	48/1191 (4%)	0.07 (0.02)	20/262 (8%)	0.21 (0.06)
In-home care visits	84/1206 (7%)	3.77 (0.62)	79/266 (30%)	24.65 (3.47)
Meals on wheels visits	7/1207 (1%)	0.18 (0.10)	16/269 (6%)	2.57 (0.81)
Cleaner visits	248/1199 (21%)	2.28 (0.17)	91/267 (34%)	3.73 (0.49)
Laundry service visits	29/1197 (2%)	0.25 (0.06)	12/268 (4%)	0.54 (0.17)
Sitting service visits	31/1206 (3%)	0.25 (0.06)	-	-
Caregiver support visits	36/1185 (3%)	0.25 (0.07)	6/265 (2%)	0.24 (0.11)
Day center days	139/1209 (11%)	2.15 (0.23)	43/269 (16%)	2.46 (0.41)
Lunch club visits	100/1206 (8%)	0.99 (0.14)	33/270 (12%)	2.28 (0.52)
Emergency Department visits	57/1185 (5%)	0.06 (0.01)	16/267 (6%)	0.10 (0.03)
Inpatient days	65/1186 (5%)	0.33 (0.09)	17/269 (6%)	0.18 (0.06)
Outpatient appointments	626/1206 (52%)	1.47 (0.08)	127/268 (47%)	1.34 (0.18)
Central nervous system medications	267/1182 (23%)	0.28 (0.02)	63/264 (24%)	0.26 (0.03)
Dementia medications	852/1191 (72%)	0.75 (0.01)	189/266 (71%)	0.73 (0.03)

Time 2	Expected N=965		Expected N=200	
General practitioner – office visits ²	640/920 (70%)	1.40 (0.05)	106/181 (59%)	1.28 (0.12)
General practitioner – home visits ³	74/932 (8%)	0.14 (0.02)	28/184 (15%)	0.34 (0.07)
General practitioner – telephone calls ⁴	156/922 (17%)	0.32 (0.03)	35/173 (20%)	0.47 (0.10)
Practice nurse office visits ⁵	498/928 (54%)	1.05 (0.06)	74/174 (43%)	0.76 (0.11)
Community nurse visits ⁶	109/922 (12%)	0.43 (0.11)	41/179 (23%)	1.52 (0.60)
Physio/Occupational therapy visits	115/912 (13%)	0.36 (0.05)	23/185 (12%)	0.24 (0.06)
Specialist nurse visits	53/916 (6%)	0.13 (0.03)	-	-
Community mental health nurse visits	108/912 (12%)	0.20 (0.02)	20/185 (11%)	0.31 (0.08)
Psychiatrist visits	58/905 (6%)	0.08 (0.01)	17/189 (9%)	0.11 (0.03)
Psychologist visits	14/909 (2%)	0.04 (0.02)	-	-
Social work visits	75/908 (8%)	0.15 (0.02)	24/182 (13%)	0.30 (0.09)
In-home care visits	120/925 (13%)	6.87 (0.91)	63/190 (33%)	34.47 (5.66)
Meals on wheels visits	23/917 (3%)	0.66 (0.18)	24/192 (13%)	6.55 (1.54)
Cleaner visits	229/929 (25%)	2.68 (0.22)	71/191 (37%)	5.25 (1.00)
Laundry service visits	-	-	-	-
Sitting service visits	49/925 (5%)	0.49 (0.08)	6/190 (3%)	0.86 (0.53)
Caregiver support visits	31/920 (3%)	0.30 (0.07)	8/189 (4%)	1.20 (0.98)
Day center days	148/940 (16%)	2.76 (0.27)	27/191 (14%)	2.59 (0.56)
Lunch club visits	80/938 (9%)	0.84 (0.16)	25/191 (13%)	1.71 (0.58)
Emergency Department visits	65/924 (7%)	0.09 (0.01)	21/190 (11%)	0.20 (0.05)
Inpatient days	80/923 (9%)	0.43 (0.11)	17/189 (9%)	0.39 (0.14)
Outpatient appointments	289/926 (31%)	0.86 (0.09)	62/190 (33%)	0.80 (0.14)
Central nervous system medications	221/900 (25%)	0.33 (0.02)	43/181 (24%)	0.28 (0.04)
Dementia medications	685/920 (74%)	0.78 (0.02)	131/184 (71%)	0.73 (0.04)
Time 3	Expected N=696		Expected N=144	
General practitioner – office visits ⁷	423/663 (64%)	1.29 (0.06)	70/131 (53%)	1.10 (0.14)
General practitioner – home visits ⁸	54/676 (8%)	0.12 (0.02)	25/133 (19%)	0.35 (0.08)
General practitioner – telephone calls ⁹	109/667 (16%)	0.29 (0.03)	25/132 (19%)	0.41 (0.09)
Practice nurse office visits	319/661 (48%)	0.95 (0.07)	51/132 (39%)	0.54 (0.07)
Community nurse visits	94/663 (14%)	0.31 (0.04)	28/129 (22%)	4.91 (2.21)

Physio/Occupational therapy visits	71/662 (11%)	0.31 (0.06)	23/137 (17%)	0.78 (0.28)
Specialist nurse visits	30/661 (5%)	0.07 (0.02)	-	-
Community mental health nurse visits	74/662 (11%)	0.19 (0.03)	12/135 (9%)	0.18 (0.06)
Psychiatrist visits	41/665 (6%)	0.08 (0.01)	6/137 (4%)	0.04 (0.02)
Psychologist visits	14/662 (2%)	0.04 (0.01)	-	-
Social work visits	64/656 (10%)	0.16 (0.02)	20/133 (15%)	0.28 (0.07)
In-home care visits	114/674 (17%)	10.78 (1.52)	49/140 (35%)	33.44 (6.95)
Meals on wheels visits	16/671 (2%)	0.87 (0.32)	16/138 (12%)	7.05 (2.49)
Cleaner visits	184/671 (27%)	3.20 (0.27)	46/138 (33%)	4.15 (0.85)
Laundry service visits	-	-	-	-
Sitting service visits	55/672 (8%)	0.83 (0.15)	-	-
Caregiver support visits	25/664 (4%)	0.25 (0.07)	7/138 (5%)	0.51 (0.22)
Day center days	133/678 (20%)	3.63 (0.38)	18/139 (13%)	2.69 (0.72)
Lunch club visits	58/677 (9%)	0.69 (0.14)	14/139 (10%)	1.12 (0.37)
Emergency Department visits	44/673 (7%)	0.08 (0.01)	17/140 (12%)	0.17 (0.04)
Inpatient days	43/671 (6%)	0.36 (0.12)	13/139 (9%)	1.20 (0.53)
Outpatient appointments	195/678 (29%)	0.68 (0.06)	38/139 (27%)	0.50 (0.08)
Central nervous system medications	212/686 (31%)	0.33 (0.03)	44/139 (32%)	0.31 (0.05)
Dementia medications	518/686 (76%)	0.80 (0.02)	99/140 (71%)	0.71 (0.04)

Note: (-) denotes low numbers of 5 or fewer cases. These have been censored.

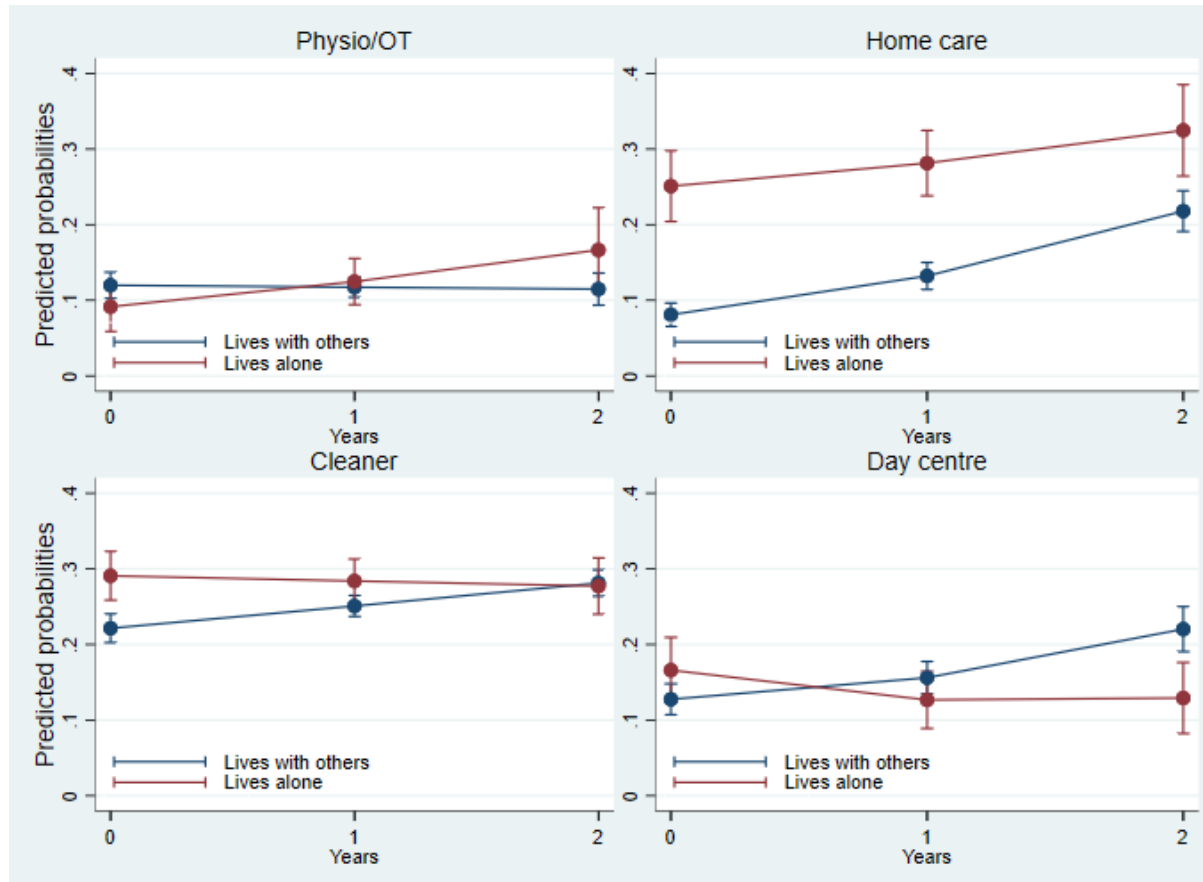
1. difference in missingness: 5% vs.10%, $t=-2.74$, $p<0.05$
2. difference in missingness: 5% vs.9%, $t=-2.06$, $p<0.05$
3. difference in missingness: 3% vs.8%, $t=-2.95$, $p<0.001$
4. difference in missingness: 3% vs.8%, $t=-2.77$, $p<0.05$
5. difference in missingness: 4% vs.14%, $t=-4.95$, $p<0.001$
6. difference in missingness: 4% vs.8%, $t=-2.12$, $p<0.05$
7. difference in missingness: 4% vs.8%, $t=-2.66$, $p<0.05$
8. difference in missingness: 4% vs.13%, $t=-5.27$, $p<0.001$
9. difference in missingness: 4% vs.10%, $t=-3.43$, $p<0.001$
10. difference in missingness: 5% vs.10%, $t=-2.68$, $p<0.05$

(b) Use of aids and adaptations

Item	Living with others						Living alone					
	Time 1		Time 2		Time 3		Time 1		Time 2		Time 3	
	Expected N=1256		Expected N=144		Expected N=696		Expected N=285		Expected N=144		Expected N=696	
	N users/ valid N	%	N users/ valid N	%	N users/ valid N	%	N users/ valid N	%	N users/ valid N	%	N users/ valid N	%
Any use												
Yes ¹	738/1162	64%	581/893	65%	461/658	70%	218/268	81%	158/187	84%	115/138	83%
Uses equipment for												
Memory ²	125/1160	11%	125/884	14%	113/656	17%	75/268	28%	56/187	30%	45/136	33%
Falls prevention ³	121/1160	10%	119/886	13%	98/656	15%	107/268	40%	82/187	44%	67/136	49%
Activities of daily living ⁴	578/1159	50%	447/891	50%	352/657	54%	171/268	64%	116/187	62%	86/138	62%
Mobility ⁵	524/1160	45%	416/887	47%	327/657	50%	163/268	61%	117/187	63%	90/138	65%

1. Any use of equipment
2. calendar clocks, medication dispenser reminders
3. falls detectors, pendant alarms
4. bath seats, bed rails, commodes, over bath showers, incontinence pads, walk-in showers, toilet seats, perching stools
5. grab/stair rails, outdoor rails, sticks, frames

Supplementary Figure 2. Predicted probabilities of service receipt over the prior three months



Supplemental digital content 5. References

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