

1 **Residential respite care use is associated with fewer overall days in residential aged care**

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19 **Brief summary**

20 Residential respite care was associated with fewer overall days in residential care if people  
21 went home after using respite. Residential respite care may help older people stay living at  
22 home longer.

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32 **Abstract**

33 Objectives: To examine the use of residential respite care and determine associations between  
34 respite care and total days spent in residential care (respite days plus long-term care days).

35 Design: A retrospective cohort study of individuals accessing aged care services in Australia  
36 was conducted as part of the National Historical cohort of the Registry of Older South  
37 Australians.

38 Setting: Residential respite care (short stays in residential aged care homes) and long-term  
39 residential care accessed in all government-subsidised residential aged care homes in  
40 Australia.

41 Participants: This study included people who were approved for government-subsidised  
42 residential respite care between January 2005 and June 2012 (n=480,862) and included a two-  
43 year follow-up period.

44 Methods: Poisson regression models were used to examine associations between use of  
45 residential respite care and number of days spent in residential care.

46 Results: Of people approved for residential respite care, 36.9% used their approval within 12  
47 months (32.0% used respite once and went directly to long-term care without returning home,  
48 40.7% used respite once and did not go directly to long-term care and 27.3% used respite  $\geq 2$   
49 times). Compared to people who did not use respite care, using respite care once and not  
50 going directly to long-term care was associated with less total days in residential care  
51 (Incidence Rate Ratio, 95% Confidence Interval: 0.68, 0.67-0.69,  $p < 0.001$ ) and using respite  
52 care  $\geq 2$  times was also associated with less days (0.86, 0.84-0.87,  $p < 0.001$ ). Using respite  
53 care once and going directly to long-term care was associated with more days in residential  
54 care (1.11, 1.10-1.12,  $p < 0.001$ ).

55 Conclusions and Implications: Using residential respite care reduces the number of days  
56 people spend in residential care when people return home after using respite. The findings

- 57 suggest that using residential respite as intended by returning home after use achieves the
- 58 goal to help people stay living at home longer.

59 **Introduction**

60 Residential respite care services involve short stays in residential aged care homes (nursing  
61 homes) with the aim of providing planned or emergency care to people who have been  
62 assessed and approved to receive it and to give a carer or care recipient a break from their  
63 usual care arrangements.<sup>1</sup> In Australia there are over 75,000 admissions annually to  
64 residential respite care at a cost of approximately AUD\$313 million to the Australian  
65 Government.<sup>2</sup> Residential respite care is considered a key aged care service to support carers  
66 and delay entry of older people to long-term residential aged care for as long as is practical<sup>3</sup>.  
67 Yet, the evidence regarding the benefits of respite care in terms of delaying entry to long-  
68 term residential care is lacking.<sup>4, 5</sup>

69 Informal carers (family or friends who provide unpaid care) are an invaluable resource to  
70 support older people to stay living in the community in their own homes for as long as is  
71 possible<sup>6</sup>, which is the general preference for the clear majority of people.<sup>7</sup> Living with a  
72 carer reduces the risk that people will start long-term residential aged care.<sup>8</sup> Residential  
73 respite care is an option that may help temporarily reduce carer burden, carer stress-related  
74 outcomes and behavioural changes for people with dementia.<sup>9</sup> Some qualitative research has  
75 suggested that carers have found respite services beneficial in terms of reporting high levels  
76 of satisfaction with the respite care, but there is a lack of high-quality research internationally  
77 to demonstrate the benefits or unintended consequences associated with respite care.<sup>4, 10, 11</sup>

78 There is a lack of consensus regarding what defines effective respite care, but the impact of  
79 respite care on rates of entry to long-term care and days spent in residential care is of high  
80 interest due to the preference of people to stay living at home and the high financial costs  
81 associated with residential care.<sup>4, 7, 10, 12</sup> Therefore, the current study was performed to  
82 determine if respite care reduces the total number of days someone spends in residential care,  
83 inclusive of residential respite and residential long-term care days. We combined residential

84 respite and residential long-term days as an outcome of interest because of the high financial  
85 cost associated with days spent in residential care and as a proxy for number of days spent  
86 living at home e.g. fewer days in respite and long-term care may suggest more days spent at  
87 home.

88 Specifically, the primary objectives of this study were to examine associations between the  
89 use of residential respite care and (1) entry into long term care and (2) number of days spent  
90 in residential care (respite days plus long-term care days).

91 **Materials and Methods**

92 *Study design, setting and participants*

93 A retrospective study was conducted using the National Historical cohort of the Registry of  
94 Older South Australians (ROSA).<sup>13</sup> In brief, ROSA captures all people who accessed  
95 government-subsidised aged care services between 1997 and June 2014 in Australia. In  
96 ROSA, de-identified data collected during aged care eligibility assessments were linked to  
97 information on mortality and information on the aged care services the person received  
98 (including the date the person started using the service and the date the person stopped using  
99 the service).

100 Starting in 2003, aged care eligibility assessments have been conducted by a team of medical  
101 and allied health professionals who collect information in an interview about the person's  
102 sociodemographic characteristics, carer information and physical and psychological health  
103 using a standardised questionnaire to determine which aged care services are appropriate for  
104 the individual.<sup>14</sup> Approval for residential respite care in Australia is based on the information  
105 collected at the time of the aged care eligibility assessment. There are no set eligibility  
106 criteria for residential respite, but the aged care assessment team use the information  
107 collected in the assessments to determine which aged care services the person should be  
108 approved for, including home care, residential respite care and long-term residential care.  
109 The current study includes all people aged 65 years or older or aged 50 years or older if they  
110 identified as Aboriginal or Torres Strait Islander, who had aged care assessments between  
111 January 2005 and June 2012 and had a subsequent approval for residential respite care.

112 *Residential respite care use*

113 We determined all respite use within a 12-month period after the participant's aged care  
114 eligibility assessment and categorised respite use as: one use with entry directly to long-term  
115 care, one use but did not go directly to long-term care or multiple respite uses ( $\geq 2$  separate  
116 stays in residential respite) within this period. This categorisation was chosen because respite

117 care can be used multiple times and at times be used immediately before entry into long-term  
118 care. In Australia, after aged care eligibility approval, an individual is eligible to access  
119 residential respite care for up to 63 days per financial year, which can be divided several  
120 times as required. Furthermore, the person can apply to extend their respite care in portions of  
121 21 extra days if an eligibility assessment confirms this extra time is necessary and this can be  
122 applied for multiple times.<sup>1</sup> The purpose of residential respite care is for an individual to have  
123 short stays in an aged care home with the intention of returning home after the stay.

#### 124 *Outcome of interest*

125 The main outcomes of interest were 1) entry to long-term care (dichotomous variable yes/no)  
126 and 2) total days in residential care including residential respite care days plus long-term  
127 residential care days within two years following aged care eligibility assessment. The number  
128 of days in residential care was determined by totalling the number of days in residential  
129 respite care and the number of days in long-term residential care by examining the dates in to  
130 and out of care or date of death within the two-year time period. To ensure each person has  
131 two years follow-up, only people who had an aged care assessment between 2005 and June  
132 2012 and had follow up until June 2014 were included in this analysis. We limited all  
133 analyses to two years following the date of aged care eligibility assessment, so all participants  
134 had the same follow-up time, unless they died within two years of their eligibility assessment  
135 then the follow-up period will have been until date of death.

#### 136 *Covariates*

137 Covariates were chosen from examining existing literature and were obtained from aged care  
138 eligibility assessments. Recent studies on predictors of admission to residential care have  
139 reported consistently that age, ethnicity, whether the person has a partner, activity limitations,  
140 physical illness, depression scores, dementia and cognitive function scores are associated  
141 with care home admission.<sup>15-18</sup> Therefore, the following available variables were included in

142 this analysis: 1) demographic information: age, sex, location (state), country of birth  
143 (Australia or overseas); 2) whether the person had a carer (yes/no); 3) health conditions  
144 (including depression) and 4) activity limitations.

145 The aged care eligibility assessments can record up to 10 health conditions, which are  
146 mapped to equivalent health condition codes in the International Statistical Classification of  
147 Disease and Related Health Problems-Tenth Revision-Australian Modification (ICD-10-  
148 AM). In this analysis we examined health conditions that are included in commonly used co-  
149 morbidity indices: the Charlson, Elixhauser and Rx-Risk-V<sup>19-21</sup>. Activity limitations included  
150 moving around, self-care, social and community participation, transport, communication,  
151 domestic assistance, health care tasks, home maintenance, meals, movement activities and  
152 other.

### 153 *Statistical analyses*

154 Descriptive statistics by whether the participants used their approval for residential respite  
155 within 12 months are presented. Cox proportional hazard models were used to examine  
156 associations between use of residential respite care and use of long-term residential care.  
157 Hazard ratios (HR) with 95% confidence intervals (95%CI) are presented. Proportional  
158 hazard assumptions were tested based on Schoenfeld residuals after fitting a model. Poisson  
159 regression models were used to examine associations between use of residential respite care  
160 and number of days in residential care. The number of days in residential care was examined  
161 as a rate of the number of days in the study (to the end of the two-year follow-up period or  
162 until date of death). Incidence Rate Ratios (IRR) with 95%CIs are presented. Models were  
163 adjusted for all covariates. Statistical analyses were performed using Stata v.15.0 (Stata Corp  
164 LP, College Station, TX, USA).

### 165 *Sensitivity Analysis*

166 Previous research has suggested that people living with dementia are more likely to use their  
167 approval for residential respite care.<sup>22</sup> Carers of people with dementia are at a high risk of  
168 carer stress and have identified respite care as a key support service to help them continue  
169 with their caregiving role.<sup>3, 23-25</sup> Therefore, due to the high interest in the effectiveness of  
170 respite services for people living with dementia, results were stratified by whether people  
171 were identified as having dementia at the time of their aged care assessment.

172 *Ethical Approval*

173 The study received ethical approval from Details removed for double-blind review process.

174 **Results**

175 *Participant characteristics*

176 Between January 2005 and June 2012, 480,862 people had a first-time approval for  
177 residential respite care services. Table 1 shows the characteristics of people by whether they  
178 accessed residential respite care within one year of their aged care assessment. Of people who  
179 were approved for residential respite care 37.7% did not have a concurrent approval for home  
180 care or long-term care. The mean (standard deviation (SD)) age of people approved for  
181 residential respite care was 83.0 (7.0), the majority were female (61.1%) and were born in  
182 Australia (70.0%). In this cohort 23.6% of people approved for residential respite care had  
183 their assessment in a hospital. Most people had a carer (86.9%), over half had a female carer  
184 (56.2%) and 45.1% of people approved for respite had a carer who was a son or daughter.  
185 Hypertension (43.7%), gout (36.3%) and dementia (28.3%) were the most common health  
186 conditions reported for people who were approved for residential respite care at the time of  
187 the assessment (see Supplementary Table 1 for the full list of health conditions). Of those  
188 approved for residential respite care, 27.4% died within one year of their assessment.

189 *Use of residential respite care services 2005-2012*

190 Of those approved for residential respite care, 36.9% (n=177,596) used their approval to  
191 access residential respite care services at least once in the 12 months following their aged  
192 care eligibility assessment (Supplementary Figure 1). Of those people who accessed  
193 residential respite care services within 12 months, 32.0% used residential respite care once  
194 and went directly to long-term residential care (within 2 weeks of respite care), 40.7% used  
195 respite care once within 12 months and did not go directly to long-term care and 27.3% used  
196 respite  $\geq 2$  times within 12 months (Supplementary Figure 2).

197 *Use of residential respite care and use of long-term care*

198 Of those approved for residential respite care, 55.8% started long-term residential care within  
199 two years of their aged care eligibility assessment (Table 2). This was lower for people who  
200 used respite once and did not go directly to long-term care (40.4%), compared to people who  
201 did not use residential respite care (48.8%), but this was higher for people who used respite  
202  $\geq 2$  times (71.2%).

203 After adjustment for covariates, using respite care once and not going directly to long-term  
204 care was associated with a lower risk of using long-term care (HR (95%CI): 0.58 (0.57,  
205 0.59)) but using respite care  $\geq 2$  times was associated with a higher risk of using long-term  
206 care (1.07 (1.06, 1.08)) (Table 3). For people with dementia, using respite care once and not  
207 going directly to long-term care was associated with a lower risk of using long-term care  
208 (0.52 (0.51, 0.53)) and using respite care  $\geq 2$  times was also associated with a lower risk of  
209 using long-term care (0.85 (0.83, 0.87)).

#### 210 *Use of residential respite care and number of days in residential care*

211 When including only those who did go on to access long-term care, the total number of days  
212 in residential care (respite days plus long-term care days) was lower for people who accessed  
213 respite once and did not go directly to long-term care (median (IQR) 323 (159-509)) or used  
214 respite  $\geq 2$  times (435 (254-582)) compared to people who did not use respite care (507 (184-  
215 676)). The total number of days in residential care was higher for people who accessed  
216 respite care once and went directly to long-term care (598 (366-701)).

217 Accessing respite care once and not going directly to long-term care was associated with  
218 fewer days spent in residential care (residential respite days plus long-term care days)  
219 compared to those who did not use respite care (IRR (95% CI) 0.68 (0.67, 0.69),  $p < 0.001$ )  
220 when only including those who accessed long-term care in the two-year period (Table 4).

221 Accessing respite care  $\geq 2$  times was also associated with fewer days spent in residential care

222 compared to those who did not use respite care (0.86 (0.84, 0.87),  $p < 0.001$ ). Using respite  
223 once and going directly to long-term care was associated with significantly more days in  
224 residential care compared to those who did not use respite care (1.11 (1.10, 1.12),  $p < 0.001$ )  
225 (Table 4), and this was similar when stratifying by whether people were living with dementia.

226 **Discussion**

227 This study utilises data from the largest study of older people accessing aged care services in  
228 Australia and is the first study to examine associations between use of residential respite care  
229 and use of long-term residential care in a nationally representative cohort. This study showed  
230 that using residential respite care once and not going directly to long-term care was  
231 associated with both a lower risk of going into long-term care and fewer overall days in  
232 residential care. For people using residential respite care two or more times, while they were  
233 more likely to go into long-term residential care, they used overall less days in care compared  
234 to people who did not access respite care. However, for people with dementia using  
235 residential respite care two or more times continued to be associated with a lower risk of  
236 using long-term residential care.

237 The findings suggest that the use of residential respite care delayed people's entry to long-  
238 term care if people returned home after their first stay in respite. Prior to this study there was  
239 little evidence to support the effectiveness of residential respite care to delay entry to long-  
240 term care for older people. One controlled trial from 1989 reported that respite care for  
241 people with Alzheimer's disease compared to no respite led to people living 22 extra days in  
242 the community before starting long-term residential care.<sup>26</sup> Multiple uses of residential respite  
243 care in this study were associated with fewer overall days in residential care but the amount  
244 of days reduced was not as high as for those who only used residential respite care once. The  
245 results suggest the utilisation of residential respite care could lead to a cost saving for the  
246 government in terms of a reduction in the number of days spent in residential care. In  
247 addition, delaying entry to long-term residential care for people with and without dementia is  
248 the preference for the majority of people who access aged care services and their carers<sup>7</sup> and  
249 this study suggests the use of residential respite care may help them to stay at home for as  
250 long as is feasible.

251 In this study a high proportion of people went directly to long-term care from their first  
252 respite use, it has been suggested that residential respite care is being utilised as a method of  
253 transitioning to long-term care. Residential respite may be preferred by some consumers and  
254 aged care providers as a first step before becoming a long-term resident while financial  
255 arrangements are processed or people using residential respite care as a “trial” before starting  
256 long-term care.<sup>27</sup> We also found that only 37% of those approved for residential respite care  
257 used their approval and accessed respite. We could not explore the underlying reasons for this  
258 further in this study, but there are likely to be multiple reasons including barriers to access  
259 such as availability of places,<sup>27</sup> people choosing to use only home services or enter long-term  
260 care or people may die before they are able to use the service as we showed 27% of people  
261 approved for residential respite died within 12 months of their aged care assessment.

262 Most people with dementia live in the community (83% of men and 71% of women living  
263 with dementia) and 91% of these individuals rely on an informal carer to support them (either  
264 with or without additional formal care services).<sup>6, 28</sup>

265 Informal carers help people to stay living in their homes and delays the need for older people  
266 to start long-term residential care.<sup>3, 7</sup> Previous qualitative research has suggested that respite  
267 care provided in a residential aged care home on a planned or emergency basis is more than  
268 just a “short break” and can positively impact the person receiving care and their carer by  
269 reducing carer burden, carer stress-related outcomes and improving mood.<sup>9</sup> Some research  
270 has also suggested that respite care may improve quality of life for the person and their  
271 carer.<sup>3</sup> However, research is lacking to gain a clear understanding if residential respite care  
272 improves carer well-being.<sup>10</sup> In this study we found for people with dementia using  
273 residential respite multiple times was associated with a lower risk of using long-term care,  
274 which may suggest that residential respite is more effective for people with dementia in terms  
275 of supporting the carer and care recipient to stay living at home. We could not explore the

276 reasons for this further, but a systematic review has suggested day respite care in a residential  
277 aged care home may help to reduce behavioural changes for people living with dementia, but  
278 there is a lack of evidence regarding respite provided as short stays in a residential aged care  
279 home.<sup>9</sup> Longitudinal studies are needed to examine behavioural changes and other outcomes  
280 for people with and without dementia before and after using residential respite services.  
281 Moving from living at home to a long-term residential aged care home is not only financially  
282 costly for the individual and the government but the experience can be daunting for the  
283 individual and their family and can negatively impact the health and the well-being of the  
284 individual and their carer.<sup>29</sup> Therefore, the effectiveness of interventions to help people live at  
285 home for longer, such as residential respite care, is critical for the individuals receiving care,  
286 their families, aged care providers and policy makers.

#### 287 *Strengths and limitations*

288 This is a large-scale, nationally representative study of all people who accessed or were  
289 approved for government-subsidised residential respite care services in Australia over an  
290 eight-year period with two years follow-up for all participants. We were able to determine  
291 whether the participants accessed long-term residential care, how many days they accessed  
292 residential respite and long-term residential care for and when they died.

293 With the comprehensive data collected we were able to adjust for many health conditions that  
294 may have contributed to differences in how participants used respite care. However, the aged  
295 care eligibility assessments can only list up to ten health conditions and conditions that affect  
296 the person's need for aged care services are more likely to be reported; therefore, we may not  
297 have a complete capture of the range of co-morbidities that people have. We did not have  
298 information detailing the reasons for why people chose to use residential respite care or long-  
299 term care, so the underlying reasons could not be further explored. There is also the potential  
300 for residual confounding for factors that are not captured in the aged care assessments. This

301 study is limited to exploring the use of residential respite care but the full portfolio of respite  
302 care in Australia includes both community-based respite and residential respite care.

### 303 **Conclusions and Implications**

304 By utilising the largest study of people accessing aged care services in Australia, we showed  
305 that using residential respite care was associated with fewer days spent in residential care  
306 overall when people did not go directly to long-term care from their first residential respite  
307 stay. Going directly to long-term care after first use of residential respite care was associated  
308 with a greater number of days spent in residential care. These findings are critical in Australia  
309 and internationally to the planning of future aged care services. This research supports the use  
310 of residential respite care services being optimised for the future ageing population as a  
311 means of delaying entry to long-term residential care. Methods to improve residential aged  
312 care may include methods to improve access such as increasing the availability of residential  
313 respite care places and long-term care places. Increases in long-term care places may reduce  
314 the need for people using respite care while waiting for a long-term care place to become  
315 available. An additional care program may be needed for people currently using residential  
316 respite as a way of entering long-term care or as a trial of long-term care. In addition,  
317 variation in quality of care provided in residential respite services should be further examined  
318 to determine optimal models of care.

319

320 **Conflicts of Interest**

321 The authors do not declare any conflicts of interest.

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## **Appendix 1**

**Supplementary Table 1. Health conditions for people who had approval for residential respite care, January 2005 to June 2012.**

**Supplementary Figure 1. Proportion of people who used residential respite care within 12 months of their aged care eligibility assessment (N=480,862).**

**Supplementary Figure 2. Proportion of people who used residential respite care once or multiple times within 12 months of their aged care eligibility assessment (N=177,596).**