

Appendix: Expenditure method

The 20 questions from the residential classification scale questionnaire were mapped to questions from the ABS Survey of Disability Ageing and Carers. From this mapping an estimate was made of the likely response of each SDAC person to the RCS questions. A proxy RCS score (SDAC-RCS score) is calculated by applying a response weight to the likely response and summing the response weights for the mapped SDAC questions. The distribution of the SDAC-RCS score was adjusted to fit as closely as possible the distribution of the RCS scores from the RCS file. This provided the cut-off points for the SDAC-RCS between each level on the RCS scale – e.g. the highest scoring 20% allocated to category 1, the next 25% to category 2 and so on in line with the distribution from the RCS.

The conditions¹⁴ recorded in the SDAC were allocated across eight categories grouped according to similarities in the likely need for assistance for the condition. These eight groups are listed in Table 8.6 (and Table A8.1 for a list of conditions). Each group was only counted once, which means that someone who has two conditions that are allocated to the same group only has one of them counted (i.e. the disease group is an on/off variable and does not count multiple conditions within each group). For each record, each condition group is given either a '1' or a '0' and an 8-digit condition list is generated which depends on the value for each condition group. Figure A8.1 shows the derivation of the 'condition list' from the 'condition groups 1–8' for a person with dementia or Alzheimer's disease, one or more mental health problems, one or more communication problems and one or more other conditions.

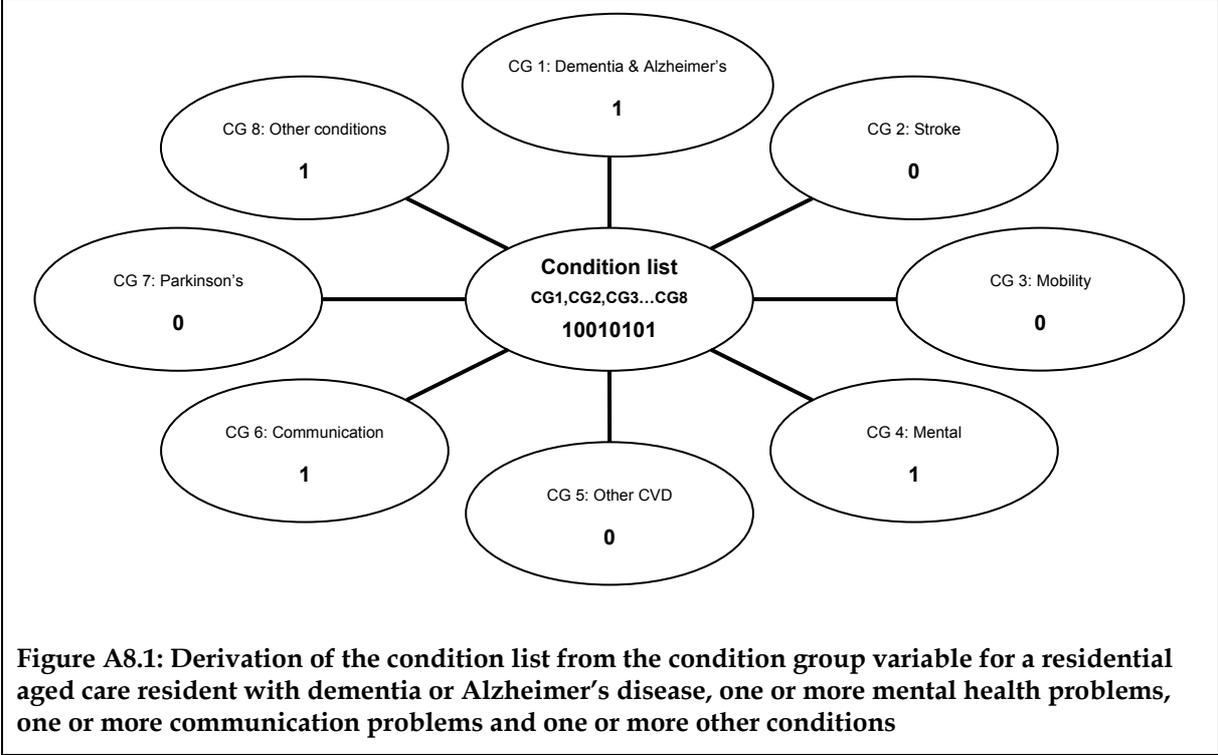
A regression model was established using all possible combinations of the condition list variable. In this model the dependent variable is the RCS score and there are 239 independent variables representing the combinations of conditions. The model has 207 degrees of freedom, an F value of 13.36 ($Pr > F = 0.0001$) and an adjusted R^2 of 0.39.

From the model a predicted RCS score is generated for each combination of the condition groups which provides an average RCS score and hence level of funding for each independent variable within the model.

Comparisons were then made between sets of conditions with dementia and the same set of conditions without dementia and the impact of the dementia on that set of conditions in terms of change in RCS score and associated level of funding ascertained. For example, the result for dementia, stroke, mobility and communication is compared to the result for stroke, mobility and communication. If the group of conditions with which to compare does not feature in the data set, then the last (eighth) digit of the condition list is changed and a comparison is made with the new condition list. If this does not reveal a match, then the second last (seventh) digit is changed. For example, the condition list '10001010' needs to be compared with condition list '00001010'. If this does not exist in the data set, then the eighth digit is changed and the comparison is made with the condition list '00001011'. In turn if this does not exist in the data set, then the seventh digit is changed and the comparison with '00001000' is used to determine the impact of dementia.

¹⁴ High cholesterol and hypertension have been left out of this analysis since they do not add significantly to the need for care.

The level of funding for dementia is the difference between the level of funding for the group of conditions without dementia and the level of funding for the group of conditions plus dementia. Using this method, a cost of each disease group is allocated to each record in the SDAC according to the conditions listed for that record. The total allocated cost is scaled to the total basic funding for each RCS group.



Appendix tables

Table A5.1: Summary of published Australian studies: age and sex distribution of care recipients

Study	Age		Other details	Sex	
	Range	Mean (std dev)		% female	% male
Victorian Carers' Program					
Schofield et al. (1998b)			Includes recipients >50		
Dementia			93% >70	77	23
Undiagnosed memory loss			76% >70	60	40
Physical impairment			77% >70	68	32
Brody et al. (2005)			30% 53–73, 45% 74–82 & 25% >83		
Dementia caregivers' training programme	49–79	70.2 (6.5)	Eligible patients <80	48	52
Brody & Hadzi-Pavlovic (1990)	51–91	72.2 (8.3)	Numbers are for patients who were alive at survey	54	46
Bindoff et al. (1997)					
Dementia		76.2 (12.5)			
Intellectual disability		23.5 (7.8)			
Physical disability		54.2 (25.4)			
Luscombe et al. (1998)			Eligible recipients <65		
Alzheimer's disease		56.5 (5.8)		51	49
Huntington's disease		46.3 (10.5)		39	61
Other dementias		54.5 (8.4)		24	76
LoGiudice et al. (1999)				57	43
Control		77.5 (8.6)		61	39
Memory clinic		72.9 (7.9)		52	48
Bruce & Paterson (2000)	57–93	79		46	54
Leong et al. (2001)					
Schofield (2001)					
Bruce et al. (2002)					
Low et al. (2002)	49–95	82.9 (7.8)		74	26
Ward et al. (2003)	62–93	79.7		48	52
Bruce et al. (2005)					
Helmes et al. (2005)	55–96	78.49 (8.56)		63	37

Table A6.1: Summary of published Australian studies: methodology

Study	Year data collected	Recruitment	Carer identification & eligibility criteria	Care recipient eligibility criteria	Living arrangements	Number of carers & care recipients
Victorian Carers' Program	1993	94% of 26,000 randomly selected Victorian households agreed to answer the screening question	Do you or does anyone in your household take the main responsibility in caring for someone who is aged or has a long-term illness, disability or other problem?		Included both co-resident & non-resident carers & carers of people in residential care	Of the self-identified carers, 976 (78%) participated in an extensive telephone interview
Schofield et al. (1998b): <i>Carers of people aged over 50 with physical impairment, memory loss & dementia: a comparative study</i>				Subsample included caregivers of people aged over 50 years with physical impairment, memory loss or dementia		Subsample included 196 carers of those with physical impairment, 182 carers of those with memory loss & 117 carers of those with dementia
Brodaty et al. (2005): <i>Why caregivers of people with dementia & memory loss don't use services</i>			Principal carers	Subsample included caregivers of people with dementia or memory loss	Subsample included caregivers of people living in the community	109 carers
Dementia caregivers' training programme Brodaty & Gresham (1989): <i>Effect of a training programme to reduce stress in carers of patients with dementia</i> Brodaty & Peters (1991): <i>Cost effectiveness of a training program for dementia carers</i> Brodaty et al. (1997): <i>The Prince Henry Hospital dementia caregivers' training programme</i>		Subjects were recruited by referral or publicity & the programs were conducted in a Sydney hospital		Mild to moderate dementia Aged less than 80 years old Could understand English Did not wander & were not aggressive	Eligible patients lived at home with their carer	96 patient-carer pairs—33 in the dementia carers' program, 31 in the memory retraining group & 33 in the wait list group

(continued)

Table A6.1 (continued): Summary of published Australian studies: methodology

Study	Year data collected	Recruitment	Carer identification & eligibility criteria	Care recipient eligibility criteria	Living arrangements	Number of carers & care recipients
Brodsky & Hadzi-Pavlovic (1990): <i>Psychosocial effects on carers of living with persons with dementia</i>		Sampled from list of NSW Alzheimer's Disease & Related Disorders Society members			Included both co-resident & non-resident carers as well as carers of people in institutions—Only co-resident carers completed all 3 sections of the survey	146 usable questionnaires—112 were carers of a person with dementia who was still alive & 53 carers lived with the person with dementia
Cahill & Shapiro (1993): <i>'I think he might have hit me once': aggression towards caregivers in dementia care</i>	September 1990 – March 1991	Recruited in the Brisbane metropolitan area	Female, primary caregivers	Dementia	Retrospective study while carers were providing care in the community	39 caregivers
Bindoff et al. (1997): <i>Caregivers of family members with dementia & disability: a comparative study of wellbeing</i>		Tasmania			Dependent was co-resident	72 family caregivers: 20 of physically disabled & 19 of intellectually disabled dependants & 22 of a dependant with a dementia-related disorder
Luscombe et al. (1998): <i>Younger people with dementia: diagnostic issues, effects on carers & use of services</i>		Recruited through support groups of the Alzheimer's Association & Huntington's Disease Association of Australia & clinician referrals		Dementia, excluding AIDS-related dementia Less than 65 years of age when surveyed		102 eligible carers
LoGiudice et al. (1999): <i>Do memory clinics improve the quality of life of carers? A randomized pilot trial</i>		Recruited through various sources: local GPs, local community services including district nursing service; council services & ACATs; & advertising in local newspapers & carer groups	One principally responsible for providing or coordinating resources required by the person, who was in personal contact with the care recipient at least weekly	Mild to moderate cognitive impairment with >6 month history of memory loss & intellectual decline & MMSE <24 Independent mobility & intact basic self-hygiene	Community dwelling subjects	50 subjects & their carers—4 withdrew consent for participation after randomisation & one withdrew after initial interview

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Table A6.1 (continued): Summary of published Australian studies: methodology

Study	Year data collected	Recruitment	Carer identification & eligibility criteria	Care recipient eligibility criteria	Living arrangements	Number of carers & care recipients
Bruce & Paterson (2000): <i>Barriers to community support for the dementia carer: a qualitative study</i>	January 1996 – June 1997	Carers of people who had been seen by members of the WA Fremantle ACAT	Carer identification & eligibility criteria Principal carer at least 3 months Aged over 18 years Related to person with dementia Able to communicate in English	Dementia	Co-resident carers—12 had relinquished care at the time of interview	24 carers
Leong et al. (2001): <i>Needs of family carers of elderly people with dementia living in the community</i>		Recruited through the community health nursing service of a regional Area Health Service in eastern Australia & dementia support group meetings in several locations in the region	Principal carer at least 3 months Aged over 18 years Related to person with dementia Able to communicate in English	Dementia	Sharing residence or living nearby to person with dementia	94 valid responses—a purposive subsample of ten carers were interviewed
Schofield (2001): <i>Rituals of visiting people with dementia in residential care</i>			Family members who had been primarily responsible for the care of a relative with dementia	Dementia	Person with dementia had recently entered long-term residential care	25 carers
Bruce et al. (2002): <i>Communication problems between dementia carers & general practitioners: effect on access to community support services</i>	1 September 1999 – 30 April 2000	Carers of patients referred for the first time to the WA Fremantle ACAT by their GP	Carers had been in the caring role for at least 6 months	Dementia	Live-in carers of people living in the community	21 carers & 19 referring GPs
Low et al. (2002): <i>A study of pre-morbid personality & behavioural & psychological symptoms of dementia in nursing home residents</i>		11 nursing homes in eastern Sydney	Caregiver visited resident at least weekly	Dementia & depression &/or psychosis	Subjects resided in nursing homes	58 informal caregivers (57 returned questionnaires)

(continued)

Table A6.1 (continued): Summary of published Australian studies: methodology

Study	Year data collected	Recruitment	Carer identification & eligibility criteria	Care recipient eligibility criteria	Living arrangements	Number of carers & care recipients
Ward et al. (2003): <i>Family carers' responses to behavioural & psychological symptoms of dementia</i>		Identified in a survey of mental disorder in general practice or referred by local aged mental health services		Dementia	Included both co-resident & non-resident carers	50 family carers
Bruce et al. (2005): <i>Physical disability contributes to caregiver stress in dementia caregivers</i>	April–December 2001	Subjects who had been referred by their family physicians for the first time for formal support services or memory evaluation	Primary caregivers caring for relatives with verified dementia for at least 6 months	Dementia	Included both co-resident & non-resident carers	91 caregivers
Helmes et al. (2005): <i>Individual differences in the experience of burden in caring for relatives with dementia: role of personality & mastery</i>		Participants were recruited from the Royal Perth Hospital Memory Clinic, advertisement in the local press & other clinical services in the hospital	Carer had to score 23 or above on the MMSE	Dementia	Included both co-resident & non-resident carers Most carers resided in their own home	51 people with dementia & their carers
AIHW: Hales et al. (2006): <i>National evaluation of the Aged Care Innovative Pool Dementia Pilot: final report</i>	2004	Care recipients & their family carers participating in the Innovative Pool Dementia Pilot projects		ACAT approval for residential aged care (usually high level residential care) Cognitive impairment that made a significant contribution to the need for care	Included both co-resident & non-resident carers & carers of people in residential care	249 care recipient & 219 family carers

Table A6.2: Summary of published Australian studies: age and sex distribution of carers

Study	Age			Sex	
	Range	Mean (std dev)	Other details	% female	% male
Victorian Carers' Program					
Schofield et al. (1998b)			>70% 35–64	75	25
Dementia					
Undiagnosed memory loss					
Physical impairment					
Brodady et al. (2005)			4.6% 0–34, 35% 35–49, 30% 50–64 & 30% ≥65	73	27
Dementia caregivers' training programme		67.7 (8.2)		54	46
Brodady & Hadzi-Pavlovic (1990)	29–85	60.2 (13.3)		79	21
Bindoff et al. (1997)	28–82	55 (13.17)		76	24
Dementia		61.1 (12.8)		73	27
Intellectual disability		50.6 (9.7)		84	16
Physical disability		49.4 (12.9)		75	25
Luscombe et al. (1998)		51.7 (12.5)		75	25
Alzheimer's disease					
Huntington's disease					
Other dementias					
LoGiudice et al. (1999)			Most were elderly	78	22
Control		60.7 (12.6)		80	20
Memory clinic		61.4 (14.0)		76	24
Bruce & Paterson (2000)	36–85	69	63% >70	67	33
Leong et al. (2001)	45–97	65.5 (11.5)	Eligible carers >18 69% ≥60	>67	<33
Schofield (2001)	Mid 30s to late 80s			68	32
Bruce et al. (2002)	43–83	68		52	48
Low et al. (2002)	34–84	61 (± 11.6)		54	46
Ward et al. (2003)	42–92	69	Most were elderly	64	36
Bruce et al. (2005)	38–85	Median 62	Bimodal distribution of ages	71	29
Helmes et al. (2005)	31–85	61.1 (14.0)		71	29

Table A7.1: Usual and recommended accommodation setting of ACAP clients, by dementia status, July 2004 to March 2005

Usual accommodation setting	Recommended long-term care setting										Total	Not stated/ inadequately described	
	Private residence	Independent living in a retirement village	Supported community accommodation	Other community ^(a)	RAC—low level care	RAC—high level care	Hospital	Other institutional care	Other				
With dementia													
Private residence	8,442	77	84	91	4,293	5,392	18	8	18,405	261			
Independent living in a retirement village	200	322	12	2	585	357	0	0	1,478	23			
Supported community accommodation	10	2	55	4	102	322	0	0	495	9			
Other community ^(a)	244	8	14	30	241	372	1	2	912	12			
RAC—low level care	13	3	2	19	353	2,882	6	3	3,281	71			
RAC—high level care	18	0	0	0	29	414	6	0	467	14			
Hospital	6	0	0	2	14	64	1	0	87	2			
Other institutional care	5	1	1	2	13	73	0	10	105	1			
Total	8,938	413	168	150	5,630	9,876	32	23	25,230	393			
<i>Not stated/inadequately described</i>	246	13	7	8	82	148	1	1	506	29			
Without dementia													
Private residence	33,595	525	400	458	10,361	9,141	300	26	54,806	3,424			
Independent living in a retirement village	842	1,581	32	28	1,667	708	14	1	4,873	253			
Supported community accommodation	34	9	202	19	282	281	1	6	834	54			
Other community ^(a)	835	26	74	167	702	703	6	20	2,533	217			
RAC—low level care	29	9	7	28	720	2,602	34	5	3,434	273			
RAC—high level care	41	1	1	13	70	442	26	3	597	59			
Hospital	25	1	2	1	29	84	6	2	150	9			
Other institutional care	22	4	2	2	29	97	0	26	182	21			
Total	35,423	2,156	720	716	13,860	14,058	387	89	67,409	4,310			
<i>Not stated/inadequately described</i>	2,225	114	31	314	457	526	59	13	3,739	7,022			

RAC Residential Aged Care.

(a) Includes all other types of settings (as well as boarding house/rooming house/private hotel, short-term crisis, emergency or transitional accommodation and public place/temporary shelter for usual accommodation setting).

Note: Recommended long-term care setting is recorded at the end of a comprehensive assessment for all comprehensive assessments that have ended with development of a care plan for the client (i.e. complete assessments).

Source: AIHW analysis of the ACAP MDS v2.

Table A7.2: Government community program support at time of assessment and recommended government program support, by dementia status of ACAP client, July 2004 to March 2005

Government community program support at assessment	Recommended government community program support										Total ^(b)	None	inadequately described	Not stated/ inadequately described		
	Not applicable ^(a)	CACP	EACH	HACC	Veterans' Home Care	Day Therapy Centre	NRCP	Other	None	Total ^(b)						
With dementia																
Not applicable ^(c)	4,705	75	6	36	3	12	46	24	363	5,012						75
CACP	1,189	1,074	89	171	16	71	296	64	111	2,386						33
EACH	44	38	48	19	2	7	21	5	3	138						2
HACC	2,787	1,429	202	3,122	184	325	1,360	275	306	6,739						48
Veterans' Home Care	529	224	40	179	546	63	237	68	61	1,264						14
Day Therapy Centre	267	169	31	227	53	414	299	37	39	787						10
NRCP	614	314	86	558	77	225	937	102	41	1,651						14
Other	613	357	67	343	84	67	312	418	116	1,518						15
None	4,278	1,558	103	1,201	170	325	1,232	250	2,010	8,672						119
Total^(b)	13,727	4,574	515	4,755	846	1,048	3,660	898	2,715	25,206						298
<i>Not stated/inadequately described or unable to determine</i>	267	51	2	74	9	10	50	22	77	432						222
Without dementia																
Not applicable ^(c)	6,426	199	17	140	22	13	74	61	532	7,120						346
CACP	1,970	3,386	233	484	57	133	563	161	284	5,621						105
EACH	126	162	168	74	12	19	44	11	16	476						6
HACC	6,880	5,875	502	12,303	603	684	3,153	1,102	1,056	22,925						447
Veterans' Home Care	1,369	1,173	86	924	2,374	140	626	300	222	4,806						61
Day Therapy Centre	271	330	36	445	139	666	342	90	42	1,192						15
NRCP	620	582	132	927	146	200	1,471	150	60	2,329						18
Other	1,399	1,264	139	1,264	331	170	725	1,551	398	4,625						87
None	8,207	5,091	297	4,018	558	466	2,424	831	8,498	24,924						1304
Total^(b)	25,329	16,138	1,329	17,685	3,331	1,705	7,509	3,109	10,238	67,723						2,067
<i>Not stated/inadequately described or unable to determine</i>	822	239	12	323	43	21	114	92	516	1,596						11,094

(a) Recorded for people whose recommended long-term care setting is residential aged care, a hospital or other institutional care.

(b) Sum of components may not add to total—clients may have used or be recommended more than one program.

(c) Recorded for people who were permanent residents of residential aged care services, multi-purposes services or centres, Indigenous flexible pilots, hospitals or other institutional settings at the time of assessment.

Source: AIHW analysis of the ACAP MDS v2.

Table A8.1: Condition weights for each ABS CURF code applied to SDAC data for allocation of residential aged care funding allocation to conditions

ABS CURF code	Condition	Condition group^(a)	ABS CURF code	Condition	Condition group^(a)
100	Certain infectious & parasitic diseases	8	910	Heart disease	5
204	Breast cancer	8	913	Angina	5
205	Prostate cancer	8	914	Myocardial infarction (heart attack)	5
299	Other neoplasms (tumours/cancers)	8	919	Other heart diseases	5
300	Diseases of the blood & blood-forming organs & certain disorders involving the immune system	8	922	Hypertension (high blood pressure)	Not included
401	Disorders of the thyroid gland	8	923	Stroke	2
402	Diabetes	8	929	Other diseases of the circulatory system	5
404	High cholesterol	Not included	1002	Bronchitis/bronchiolitis	8
499	Other endocrine/nutritional & metabolic disorders	8	1003	Respiratory allergies (excluding allergic asthma)	8
500	Mental & behavioural disorders nfd	4	1004	Emphysema	8
511	Dementia	1	1005	Asthma	8
512	Schizophrenia	4	1099	Other diseases of the respiratory system	8
513	Depression/mood affective disorders (excluding postnatal depression)	4	1101	Stomach/duodenal ulcer	8
521	Phobic & anxiety disorders	4	1102	Abdominal hernia (except congenital)	8
522	Nervous tension/stress	4	1103	Enteritis & colitis	8
530	Intellectual & developmental disorders nec	8	1104	Other diseases of the intestine	8
531	Mental retardation/intellectual disability	8	1199	Diseases of the digestive system	8
532	Autism & related disorders (including Rett's syndrome & Asperger's syndrome)	8	1202	Skin allergies (Dermatitis & Eczema)	8
595	Attention deficit disorder/hyperactivity	8	1299	Other diseases of the skin & subcutaneous tissue	8
596	Speech impediment	8	1301	Arthritis & related disorders	3
599	Other mental & behavioural disorders	4	1303	Back problems (dorsopathies)	3
604	Parkinson's disease	7	1304	Repetitive strain injury/occupational overuse syndrome	8
605	Alzheimer's disease	1	1306	Other soft tissue/muscle disorders (including Rheumatism)	3
607	Multiple sclerosis	3	1307	Osteoporosis	3

(continued)

Table A8.1 (continued): Condition weights for each ABS CURF code applied to SDAC data for allocation of residential aged care funding allocation to conditions

ABS CURF code	Condition	Condition group ^(a)	ABS CURF code	Condition	Condition group ^(a)
608	Epilepsy	8	1399	Other diseases of the musculoskeletal system & connective tissue	3
609	Migraine	8	1401	Kidney & urinary system (bladder) disorders (except incontinence)	8
611	Cerebral palsy	8	1405	Menopause disorders	8
612	Paralysis	3	1499	Other diseases of the genitourinary system	8
699	Other diseases of the nervous system	8	1600	Congenital malformations, deformations & chromosomal abnormalities	8
703	Retinal disorders/defects	8	1701	Breathing difficulties/shortness of breath	8
704	Glaucoma	8	1704	Pain nfd	8
707	Sight loss	3	1705	Unspecified speech difficulties	8
799	Other diseases of the eye & adnexa	8	1799	Other symptoms/signs & abnormal clinical & laboratory findings nec	8
802	Diseases of the middle ear & mastoid	8	1801	Head injury/acquired brain damage	8
803	Diseases of the inner ear (except noise induced deafness)	6	1802	Arm/hand/shoulder damage from injury/accident	3
804	Tinnitus	6	1804	Leg/knee/foot/hip damage from injury/accident	3
810	Deafness/hearing loss	6	1808	Complications/consequences of surgery & medical care nec	8
811	Deafness/hearing loss—noise induced	6	1899	Other injury/poisoning & certain other consequences of external causes	8
812	Deafness/hearing loss—congenital	8	1904	Restriction in physical activity or physical work	3
899	Other diseases of the ear & mastoid process	6	1907	Other 2003 codes which have no ICD-10 equivalent	8

(a) Condition group refers to the list: 1. Dementia and Alzheimer's disease; 2. Stroke; 3. Mobility; 4. Mental; 5. Other cardiovascular disease; 6. Communication; 7. Parkinson's disease; and 8. Other conditions.

Table A11.1: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role (*carer health and wellbeing*)

ALSWH		
<p>Question: During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?</p> <p>Response:</p> <p>Not at all</p> <p>Slightly</p> <p>Moderately</p> <p>Quite a bit</p> <p>Extremely</p>	<p>Question: In the last 12 months, have you had any of the following...</p> <p>Options include:</p> <p>Headaches/migraines</p> <p>Severe tiredness</p> <p>Difficulty sleeping</p> <p>Depression</p> <p>Anxiety</p> <p>Response: Never, Rarely, Sometimes, Often</p>	<p>Question: During the past 4 weeks, how many different types of medication (e.g. tablets or medicine) have you used which were...</p> <p>Options include:</p> <p>Prescription medication for your nerves (e.g. valium, serapax, ducene etc.)</p> <p>Prescription medication to help you sleep (e.g. normison, mogadon etc.)</p> <p>Prescription medication for depression (e.g. prozac, aropax etc.)</p> <p>Response: One, Two, Three, Four or more (or no response)</p> <p>Notes: Asked of the younger cohort in survey 2</p>
<p>Question: During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives etc.)?</p> <p>Response:</p> <p>All of the time</p> <p>Most of the time</p> <p>Some of the time</p> <p>A little of the time</p> <p>None of the time</p>	<p>Notes: Asked of the mid age cohort in survey 2 (similar questions asked of the younger cohort, mid age cohort in surveys 1, 3 & 4 & older cohort)</p> <p>Question: Please indicate how often you have felt this way during the last week...</p> <p>Options:</p> <p>I was bothered by things that don't usually bother me</p> <p>I had trouble keeping my mind on what I was doing</p> <p>I felt depressed</p> <p>I felt that everything I did was an effort</p> <p>I felt hopeful about the future</p> <p>I felt fearful</p> <p>My sleep was restless</p> <p>I was happy</p> <p>I felt lonely</p> <p>I could not 'get going'</p> <p>I felt terrific</p> <p>Response:</p> <p>Rarely or none of the time (less than 1 day)</p> <p>Some or a little of the time (1–2 days)</p> <p>Occasionally or a moderate amount of the time (3–4 days)</p> <p>Most or all of the time (5–7 days)</p> <p>Notes: Asked of the younger & mid age cohorts in surveys 2, 3 & 4 (similar question asked of the older cohort in survey 2)</p>	<p>Question: Over the last 12 months, how stressed have you felt about the following areas of your life...</p> <p>Options:</p> <p>Own health</p> <p>Health of other family members</p> <p>Work/employment</p> <p>Living arrangements</p> <p>Study</p> <p>Money</p> <p>Relationship with parents</p> <p>Relationship with partner/spouse</p> <p>Relationship with children</p> <p>Relationship with other family members</p> <p>Anything else (please specify)</p> <p>Response:</p> <p>Not applicable</p> <p>Not at all stressed</p> <p>Somewhat stressed</p> <p>Moderately stressed</p> <p>Very stressed</p> <p>Extremely stressed</p> <p>Notes: Asked of the younger cohort in survey 2</p>
<p>Question: During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?</p> <p>Options:</p> <p>Cut down on the amount of time you spent on work or other activities</p> <p>Accomplished less than you would like</p> <p>Didn't do work or other activities as carefully as usual</p> <p>Response: Yes, No</p>	<p>Question: During the past 4 weeks have you had any of the following problems with your work (including your work outside the home & housework) or other regular daily activities as a result of your physical health?</p> <p>Options:</p> <p>Cut down on the amount of time you spent on work or other activities</p> <p>Accomplished less than you would like</p> <p>Were limited in the kind of work or other activities</p> <p>Had difficulty performing the work or other activities (e.g. it took extra effort)</p> <p>Response: Yes, No</p>	<p>Question: During the past 4 weeks have you taken any medications...</p> <p>Options include:</p> <p>For nerves/anxiety/worries</p> <p>For stress (difficulty coping)</p> <p>To help you sleep</p> <p>For tiredness/fatigue</p> <p>For depression</p> <p>Response: Yes, No</p> <p>Notes: Asked of the mid age cohort in surveys 3 & 4 (similar questions asked of the younger cohort in surveys 3 & 4, mid age cohort in surveys 1 & 2 & older cohort in surveys 1, 2 & 3)</p>
<p>Question: In the last 3 years have you been told by a doctor that you have...</p> <p>Options include:</p> <p>Depression</p> <p>Anxiety/nervous disorder</p> <p>Response: Yes (or no response)</p> <p>Notes: Asked of the older cohort in surveys 2, 3 & 4 (similar questions asked of the younger & mid age cohorts in surveys 2, 3 & 4)</p>	<p>Question: During the past 4 weeks have you been told by a doctor that you have...</p> <p>Options include:</p> <p>Depression</p> <p>Anxiety/nervous disorder</p> <p>Response: Yes (or no response)</p> <p>Notes: Asked of the older cohort in surveys 2, 3 & 4 (similar questions asked of the younger & mid age cohorts in surveys 2, 3 & 4)</p>	<p>Questions:</p> <p>In the past week, have you been feeling that life isn't worth living?</p> <p>In the past 6 months, have you ever deliberately hurt yourself or done anything that you knew might have harmed or even killed you?</p> <p>Response: Yes, No</p> <p>Notes: Asked of the younger cohort in surveys 2, 3 & 4 & the mid age cohort in surveys 3 & 4</p>

Table A11.2: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role (*income and financial situation*)

DESP	NRCP	SDAC	
<p>Data item: Pension status</p> <p>Definition: Whether or not the person of concern is in receipt of an income support payment from the Commonwealth Government in the form of a government pension or benefit</p> <p>Data domain:</p> <p>No government pension or benefit Aged Pension Veterans' Affairs Pension Disability Support Pension Carer Payment (formerly carer pension) Carer Allowance (formerly DNCB) Unemployment-related benefits Other government pension or benefit Unknown</p>	<p>Data item: Government pension/benefit status</p> <p>Definition: Statement by a person of receipt of an income support payment from the Commonwealth Government in the form of a pension or benefit</p> <p>Data domain:</p> <p>Aged Pension Veterans' Affairs Pension Disability Support Pension Carer Payment (pension) Unemployment-related benefits Other government pension or benefit No government pension or benefit Carer Allowance Not stated/inadequately described</p>	<p>Data item: Main effect of caring role on primary carer's financial situation</p> <p>Data domain:</p> <p>Not applicable Income not affected Income has increased Income has decreased Has extra expenses Not stated</p> <p>Data item: Whether primary carer has difficulty meeting everyday costs as a result of caring role</p> <p>Data domain:</p> <p>Not applicable Has difficulty meeting everyday living costs Does not have difficulty meeting everyday living costs Not stated</p> <p>Data item: Whether primary carer usually pays significant proportion of living costs of main recipient of care</p> <p>Data domain:</p> <p>Not applicable Regularly pays a large part of living costs Does not regularly pay a large part of living costs Not stated</p>	<p>Data item: Primary carer awareness of Carer Payment</p> <p>Data domain:</p> <p>Not applicable Receives Carer Payment Does not receive Carer Payment but has looked at eligibility Does not receive Carer Payment & has not looked at eligibility Has not looked at eligibility</p> <p>Data item: Main reason primary carer has not looked at eligibility for Carer Payment</p> <p>Data domain:</p> <p>Not applicable Not heard of it Pride Would not be eligible Dual eligibility (eligible for conflicting payment type) Not necessary Does not think of self as a carer Other Currently receiving it Looked at eligibility but does not receive it</p> <p>Data item: Main reason looking at eligibility by primary carer did not lead to receipt of Carer Payment</p> <p>Data domain:</p> <p>Not applicable Did not meet requirements for eligibility Dual eligibility (eligible for conflicting payment type) Changed mind or decided not necessary Other Currently receiving Carer Payment</p>
<p>Data item: Key issues & discussion areas</p> <p>Definition: Service provided (by whatever approach) to the client</p> <p>Data sub-items include:</p> <p>Financial matters</p> <p>Data domain:</p> <p>Financial planning Carer benefits/entitlements Aged care facility costs</p>			

(continued)

Table A11.2 (continued): Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role (*income and financial situation*)

ALSWH		
<p>Question: How do you manage on the income you have available?</p> <p>Response:</p> <p>It is impossible</p> <p>It is difficult all the time</p> <p>It is difficult some of the time</p> <p>It is not too bad</p> <p>It is easy</p> <p>Notes: Asked of the younger cohort in surveys 1, 3 & 4 & the mid age & older cohorts</p>	<p>Question: How many people (including yourself) are dependent on this household income?</p> <p>Response: (Continuous)</p> <p>Notes: Asked of the younger cohort in surveys 2, 3 & 4 & the mid age cohort in surveys 2 & 3</p>	<p>Question: Which of the following are sources of income for you & your spouse or partner (if you have one)?</p> <p>Options:</p> <p>Age Pension</p> <p>Superannuation</p>
<p>Question: What is the average gross (before tax) income that you (& your household) receive each week, including wages, salary, pensions & allowances?</p> <p>Options:</p> <p>Self</p> <p>Household (include self)</p> <p>Response:</p> <p>No income</p> <p>\$1–\$119 (\$1–\$6,239 annually)</p> <p>\$120–\$299 (\$6,240–\$15,999 annually)</p> <p>\$300–\$499 (\$16,000–\$25,999 annually)</p> <p>\$500–\$699 (\$26,000–\$36,999 annually)</p> <p>\$700–\$999 (\$37,000–\$51,999 annually)</p> <p>\$1,000–\$1,499 (\$52,000–\$77,999 annually)</p> <p>\$1,500 or more (\$78,000 or more annually)</p> <p>Don't know</p> <p>Don't want to answer</p> <p>Household income is the same as mine</p> <p>Notes: Asked of the mid age cohort in survey 3 (similar questions asked of the younger cohort in surveys 2, 3 & 4 & the mid age cohort in survey 2)</p>	<p>Question: Are there people who do not live with you who are dependent on this household income?</p> <p>Response:</p> <p>No</p> <p>Yes, one</p> <p>Yes, more than one</p> <p>Notes: Asked of the mid age cohort in survey 3 (similar question asked of the mid age cohort in survey 4)</p>	<p>Partner allowance & Wife pension</p> <p>Carer Payment or Carer Allowance</p> <p>Disability Support Pension</p> <p>Widow allowance (including Widow B pension)</p> <p>War widow's pension</p> <p>Overseas pension</p> <p>Veterans' service pension</p> <p>Veterans' disability pension</p> <p>Veterans' TPI</p> <p>Income from interest, dividends or rent</p> <p>Income from own business or partnership</p> <p>Other government pension or allowance</p> <p>Other income</p> <p>Response: Yes (or no response)</p> <p>Notes: Asked of the older cohort in survey 4</p>
	<p>Question: Which of the following are sources of income for you & your spouse?</p> <p>Options:</p> <p>Wage or salary</p> <p>Own business/farm/partnership</p> <p>Superannuation or other private income</p> <p>Government pension or allowance</p> <p>Response: Yes (or no response)</p> <p>Notes: Asked of the mid age cohort in survey 2 (similar questions asked of the older cohort in surveys 2 & 3)</p>	<p>Question: If you are retired, what are the source of your retirement funding? If you are not retired, or have never been in paid work, what do you expect to be the sources for funding your retirement?</p> <p>Options:</p> <p>Age Pension/Service Pension/Widow's Pension/War Widow's Pension</p> <p>Other government pension or allowance</p> <p>Lump sum superannuation payout</p> <p>A pension or annuity purchased with superannuation or some other funds</p> <p>Income from savings & investments (such as shares & property)</p> <p>Income from a business</p> <p>Income or pension from your spouse/partner</p> <p>Financial support from family</p> <p>Other sources (please specify)</p> <p>Don't know</p> <p>Response: Yes (or no response)</p> <p>Notes: Asked of the mid age cohort in survey 4</p>

**Table A11.3: Mapping of dementia-related data items in Australian dementia-relevant collections:
Impact of caring role (*paid work*)**

NRCP	SDAC	
<p>Data item: Paid employment participation</p> <p>Definition: A record of the person's statement concerning their current participation in the paid workforce</p> <p>Data domain:</p> <p>Full-time</p> <p>Part-time</p> <p>Casual</p> <p>Seasonal</p> <p>Not in paid employment</p> <p>Not stated/inadequately described</p>	<p>Data item: Whether worked just before commencing caring for main recipient of care</p> <p>Data domain:</p> <p>Not applicable</p> <p>Worked prior to caring role</p> <p>Did not work prior to caring role</p> <p>Primary carer permanently unable to work</p>	<p>Data item: Main reason left work just before commencing caring role</p> <p>Data domain:</p> <p>Not applicable</p> <p>To commence care</p> <p>To increase care</p> <p>Retired</p> <p>Became eligible for pension/benefit</p> <p>Other</p>
	<p>Data item: Number of weekly hours primary carer was employed before commencing care for main recipient of care</p> <p>Data domain:</p> <p>Not applicable</p> <p>(Continuous)</p> <p>Did not have job prior to caring role</p>	<p>Data item: Main reason had to leave work to care for main recipient of care</p> <p>Data domain:</p> <p>Not applicable</p> <p>No alternative care arrangements available</p> <p>Financial considerations/cost of alternative care arrangements</p> <p>Unable to change working arrangements</p> <p>Emotional obligations</p> <p>Preferred to care full-time</p> <p>Other</p>
	<p>Data item: Effect on weekly hours worked in all jobs by primary carer since commencing caring role</p> <p>Data domain:</p> <p>Not applicable</p> <p>Weekly hours worked are unchanged</p> <p>Weekly hours worked are reduced</p> <p>Weekly hours worked are increased</p>	<p>Data item: Whether would like to be employed while caring for main recipient of care</p> <p>Data domain:</p> <p>Not applicable</p> <p>Would like to work full-time</p> <p>Would like to work part-time</p> <p>Would not like to work</p>
	<p>Data item: Increase in weekly hours worked since commencing caring role</p> <p>Data domain: (Continuous)</p>	<p>Data item: Main perceived barrier to re-entering workforce while caring</p> <p>Data domain:</p> <p>Not applicable</p> <p>No alternative care arrangements available</p> <p>Disruption to main recipient of care</p> <p>Difficulty in arranging working hours</p> <p>Loss of skills from being out of workforce</p> <p>Age</p> <p>Other difficulty</p> <p>No difficulties expected</p>
	<p>Data item: Reduction in weekly hours worked since commencing caring role</p> <p>Data domain: (Continuous)</p>	
	<p>Data item: Whether primary carer needs time off work at least once a week because of caring for main recipient</p> <p>Data domain:</p> <p>Not applicable</p> <p>Needs time off work at least once a week</p> <p>Needs time off work but not once a week</p> <p>Does not need time off work</p> <p>Unemployed or not in the labour force, excluding those permanently unable to work</p> <p>Permanently unable to work</p>	
	<p>Data item: Whether has ever had to leave work for at least 3 months to care for main recipient of care</p> <p>Data domain:</p> <p>Not applicable</p> <p>Has had to leave work for at least 3 months</p> <p>Has not had to leave work for at least 3 months</p>	

(continued)

Table A11.3 (continued): Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role (*paid work*)

ALSWH			
<p>Question: Which of the following best describes your main current employment status?</p> <p>Options:</p> <p>In full-time paid work</p> <p>In part-time or casual paid work</p> <p>Work without pay (e.g. in a family business)</p> <p>Home duties only—no paid work</p> <p>Studying—no paid work</p> <p>Unemployed—looking for work</p> <p>Unpaid voluntary work</p> <p>Retired</p> <p>Unable to work due to sickness or injury</p> <p>Other (please specify)</p> <p>Response: Yes (or no response)</p> <p>Notes: Asked of the mid age cohort in survey 1 (similar questions asked of the younger cohort in survey 1 & the mid age cohort in survey 4)</p>	<p>Question: Do you normally do any of the following kinds of paid work?</p> <p>Options:</p> <p>Paid shift work</p> <p>Paid work at night</p> <p>Paid work from home</p> <p>Self employment</p> <p>Paid work in more than one job</p> <p>Casual paid work (work in a job which doesn't provide holiday pay or sick leave)</p> <p>Paid work involving none of the above</p> <p>I don't do any paid work</p> <p>Response: Yes (or no response)</p> <p>Notes: Asked of the younger cohort in survey 3 & mid age cohort in survey 4 (similar questions asked of the younger cohort in surveys 2 & 4 & mid age cohort in survey 3)</p>	<p>Question: What is the main reason you would like to do fewer hours of paid work?</p> <p>Response:</p> <p>Child care</p> <p>Other family reasons</p> <p>Health reasons</p> <p>Would like more time for leisure/for myself/to do other things</p> <p>Notes: Asked of those in the younger cohort in survey 2 that would like to do less hours of paid work</p>	<p>Question: At what age do you expect to retire (completely) from the paid workforce?</p> <p>Response:</p> <p>(Continuous)</p> <p>Do not expect to ever retire</p> <p>Don't know</p> <p>Notes: Asked of those in the mid age cohort in survey 4 that were not retired or were partially retired</p>
<p>Question: How many hours do you normally spend in all your paid jobs each week?</p> <p>Response:</p> <p>1–15 hours</p> <p>16–24 hours</p> <p>25–34 hours</p> <p>35–40 hours</p> <p>41–48 hours</p> <p>49 hours or more</p> <p>Notes: Asked of those in the younger & mid age cohorts in survey 1 that were in full-time, part-time or casual paid work (similar question asked of the mid age cohort in survey 2)</p>	<p>Question: How secure or insecure do you feel about your paid job or jobs?</p> <p>Response:</p> <p>I worry all the time about losing my job</p> <p>Sometimes I worry about losing my job</p> <p>I rarely or never worry about losing my job</p> <p>Don't know</p> <p>Notes: Asked of those in the younger cohort in surveys 3 & 4 that were in paid work</p>	<p>Question: What is the main reason you do not do more hours of paid work?</p> <p>Response:</p> <p>Can't find a suitable job (e.g. with right hours/suits my skills/nearby)</p> <p>Child care</p> <p>Other family reasons</p> <p>Health reasons</p> <p>My spouse/partner prefers I don't work (more)</p> <p>Language difficulties</p> <p>Notes: Asked of those in the younger cohort in survey 2 that would like to do more hours of paid work</p>	<p>Question: If you had the choice, at what age would you like to retire (completely) from the paid workforce?</p> <p>Response:</p> <p>(Continuous)</p> <p>Do not want to ever retire</p> <p>Don't know</p> <p>Notes: Asked of those in the mid age cohort in survey 4 that were not retired or were partially retired</p>
<p>Questions:</p> <p>Do you normally do paid shift work?</p> <p>Do you normally do paid work at night?</p> <p>Is your home your normal (paid work) work-place?</p> <p>Response: Yes, No</p> <p>Notes: Asked of those in the younger & mid age cohorts in survey 1 that were in full-time, part-time or casual paid work (similar questions asked of the mid age cohort in survey 2)</p>	<p>Question: Are you happy with the number of hours of paid work you do?</p> <p>Response:</p> <p>Yes, happy as is</p> <p>No, would like to do more</p> <p>No, would like to do less</p> <p>Notes: Asked of the younger cohort in surveys 2, 3 & 4</p>	<p>Question: Do you consider yourself to be completely retired from the paid workforce, partly retired or not retired at all?</p> <p>Options:</p> <p>I am not retired at all (currently working or planning to return to work)</p> <p>I am partially retired (have cut down on hours of work or changed type of job as a way of retiring gradually)</p> <p>I am completely retired from paid work (within the last 20 years)</p> <p>I gave unpaid work over 20 years ago (& do not intend to return to work)</p> <p>I have never been in paid work</p> <p>Response: Yes (or no response)</p> <p>Notes: Asked of the mid age cohort in survey 4</p>	<p>Question: Indicate how important each of the following might be in your decision about when to retire (completely) from the workforce...</p> <p>Options:</p> <p>Reaching the eligibility age for an old age (or service) pension</p> <p>The ability to access other government pensions or benefits</p> <p>The ability to access superannuation funds</p> <p>Being retrenched or made redundant</p> <p>The stresses & pressures of your job</p> <p>A declining interest in work</p> <p>Financial security</p> <p>The number of people for whom you need to provide financial support</p> <p>When your partner retires</p> <p>Your personal health or physical abilities</p> <p>The need to care for your spouse or another family member</p> <p>The desire for a different lifestyle</p> <p>Response:</p> <p>Not important</p> <p>Of limited importance</p> <p>Important</p> <p>Very important</p> <p>Don't know</p> <p>Notes: Asked of those in the mid age cohort in survey 4 that were not retired or were partially retired</p>
		<p>Question: When did you retire or give up work?</p> <p>Response: (Continuous)</p> <p>Notes: Asked of those in the mid age cohort in survey 4 that were retired or gave up work within the last 20 years</p>	

Table A11.4: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role (*other*)

SDAC	ALSWH		
<p>Data item: Why primary carer took on the caring role (multiple response)</p> <p>Data domain:</p> <p>Not applicable</p> <p>Could provide better care than someone else</p> <p>Family responsibility</p> <p>No other family or friends available</p> <p>No other family or friends willing</p> <p>Emotional obligation</p> <p>Alternative care too costly</p> <p>No other care arrangements available</p> <p>Had no other choice</p> <p>Other reason</p> <p>Not stated</p>	<p>Question: Are you happy with your share of the following tasks & activities?</p> <p>Options:</p> <p>Domestic work (shopping, cooking, cleaning etc.)</p> <p>Child care</p> <p>Caring for another adult (who is elderly/disabled/sick)</p> <p>Other household work (gardening, home/car maintenance)</p> <p>Response:</p> <p>Happy the way it is</p> <p>Would like other family members to do more</p> <p>Would prefer another arrangement</p> <p>Not applicable (don't do this)</p> <p>Notes: Asked of the younger & mid age cohorts in survey 1 (similar questions asked of the younger cohort in surveys 3 & 4, mid age cohort in survey 4 & older cohort in survey 1)</p> <p>Questions:</p> <p>How often do you feel rushed/pressured/too busy?</p> <p>How often do you feel you have time on your hands that you don't know what to do with?</p> <p>Response:</p> <p>Every day</p> <p>A few times a week</p> <p>About once a week</p> <p>About once a month</p> <p>Never</p> <p>Notes: Asked of the younger cohort in survey 1 & the mid age & older cohorts in surveys 1 & 2 (similar questions asked of younger cohort in surveys 2, 3 & 4 & the mid age cohort in surveys 3 & 4)</p> <p>Question: Compared to 5 years ago, do you now feel...</p> <p>Response:</p> <p>More rushed/pressured/busy</p> <p>About the same</p> <p>Less rushed/pressured/busy</p> <p>Notes: Asked of the mid age & older cohorts in survey 1</p>	<p>Question: Which of the following events have you experienced?</p> <p>Options include:</p> <p>Major decline in health of spouse or partner</p> <p>Major decline in health of other close family member or friend</p> <p>Decreased income</p> <p>Response:</p> <p>In the last 12 months</p> <p>1–2 years ago</p> <p>More than 2 years ago</p> <p>(Or no response)</p> <p>Notes: Asked of the mid age cohort in survey 2 (similar questions asked of the mid age cohort in surveys 1, 3 & 4 & the older cohort in survey 1)</p> <p>Question: This question is about events you may have experienced in the last 3 years</p> <p>Options include:</p> <p>Major decline in health of spouse or partner</p> <p>Major decline in health of other close family member or friend</p> <p>Decreased income</p> <p>Spouse/partner moving into hostel/institution (institutionalised care)</p> <p>Response: Yes (or no response)</p> <p>Notes: Asked of the older cohort in surveys 2, 3 & 4</p> <p>Question: How happy are you with the amount of time you spend in the following aspects of your life?</p> <p>Options:</p> <p>In paid work</p> <p>In active leisure (e.g. sport, art, drama, music)</p> <p>In passive leisure (e.g. reading, TV, writing letters)</p> <p>Studying</p> <p>Doing voluntary work</p> <p>In religious activities</p> <p>Sleeping</p> <p>Alone</p> <p>Response:</p> <p>Happy the way it is</p> <p>Would like to do more</p> <p>Would like to do less</p> <p>Not applicable (don't do this)</p> <p>Notes: Asked of the younger, mid age & older cohorts in survey 1</p>	<p>Question: In the last week, how much time in total did you spend doing the following things?</p> <p>Options:</p> <p>Full-time paid work</p> <p>Permanent part-time paid work</p> <p>Casual paid work</p> <p>Home duties (own/family home)</p> <p>Work without pay (e.g. family business)</p> <p>Looking for work</p> <p>Unpaid voluntary work</p> <p>Active leisure (e.g. walking, exercise, sport)</p> <p>Passive leisure (e.g. TV, listening to music, reading, relaxing)</p> <p>Studying</p> <p>Socialising</p> <p>Using a computer (for work, study or hobbies)</p> <p>Response:</p> <p>I don't do this activity</p> <p>1–15 hours</p> <p>16–24 hours</p> <p>25–34 hours</p> <p>35–40 hours</p> <p>41–48 hours</p> <p>49 hours or more</p> <p>Notes: Asked of the mid age cohort in survey 3 (similar questions asked of younger cohort in surveys 2, 3 & 4 & the mid age cohort in survey 4)</p> <p>Question: In general, are you satisfied with what you have achieved in your life so far in the areas of...</p> <p>Options:</p> <p>Work/career/study</p> <p>Family relationships</p> <p>Partner/closest personal relationship</p> <p>Friendships</p> <p>Social activities</p> <p>Response:</p> <p>Very satisfied</p> <p>Satisfied</p> <p>Dissatisfied</p> <p>Very dissatisfied</p> <p>Notes: Asked of younger, mid age & older cohorts in the first survey (similar questions asked of the younger & mid age cohorts in surveys 2, 3 & 4)</p>

Table A11.5: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role (social support and relationships)

SDAC	ALSWH	
<p>Data item: Main effect of caring role on primary carer's relationship with main recipient of care</p> <p>Data domain:</p> <p>Not applicable</p> <p>Relationship unaffected</p> <p>Brought closer together</p> <p>Relationship strained</p> <p>Not stated</p>	<p>Question: Does it seem that your family & friends (i.e. people who are important to you) understand you?</p> <p>Response:</p> <p>Hardly ever</p> <p>Some of the time</p> <p>Most of the time</p> <p>Notes: Asked of the younger & mid age cohorts in survey 1 & the older cohort in surveys 1 & 2</p>	<p>Question: How often is each of the following kind of support available to you if you need it?</p> <p>Options:</p> <p>Someone to help you if you are confined to bed</p> <p>Someone you can count on to listen to you when you need to talk</p> <p>Someone to give you good advice about a crisis</p> <p>Someone to take you to the doctor if you need it</p> <p>Someone who shows you love & affection</p>
<p>Data item: Main effect of caring role on primary carer's relationship with other co-resident family members</p> <p>Data domain:</p> <p>Not applicable</p> <p>Relationships unaffected</p> <p>Brought closer together</p> <p>Less time to spend with them</p> <p>Relationships strained</p> <p>Relationships affected in another way</p> <p>Has no other co-resident family members</p> <p>Not stated</p>	<p>Question: Can you talk about your deepest problems with at least some of your family & friends?</p> <p>Response:</p> <p>Hardly ever</p> <p>Some of the time</p> <p>Most of the time</p> <p>Notes: Asked of the younger & mid age cohorts in survey 1 & the older cohort in surveys 1, 2 & 3</p>	<p>Someone to have a good time with</p> <p>Someone to give you information to help you understand a situation</p> <p>Someone to confide in or talk to about yourself or your problems</p> <p>Someone who hugs you</p> <p>Someone to get together with for relaxation</p> <p>Someone to prepare your meals if you are unable to do it yourself</p> <p>Someone whose advice you really want</p>
<p>Data item: Main effect of caring role on primary carer's relationship with spouse or partner</p> <p>Data domain:</p> <p>Not applicable</p> <p>Relationship unaffected</p> <p>Brought closer together</p> <p>Lack time alone together</p> <p>Relationship strained</p> <p>Has no spouse or partner</p> <p>Not stated</p>	<p>Question: Other than members of your family, how many persons in your local area do you feel you can depend on or feel very close to?</p> <p>Response:</p> <p>None</p> <p>1–2 people</p> <p>More than 2 people</p> <p>Notes: Asked of the younger, mid age & older cohorts in survey 1 (similar question asked of the older cohort in surveys 2, 3 & 4)</p>	<p>Someone to do things with to help you get your mind off things</p> <p>Someone to help with daily chores if you are sick</p> <p>Someone to share your most private worries & fears with</p> <p>Someone to turn to for suggestions about how to deal with a personal problem</p> <p>Someone to do something enjoyable with</p> <p>Someone who understands your problems</p> <p>Someone to love & make you feel wanted</p>
<p>Data item: Main effect of caring role on the primary carer's friendships</p> <p>Data domain:</p> <p>Not applicable</p> <p>Friendships unaffected</p> <p>Circle of friends has increased</p> <p>Circle of friends has changed</p> <p>Lost or losing touch with existing friends</p> <p>Not stated</p>	<p>Questions:</p> <p>Do people help you to do odd jobs?</p> <p>Do people lend you small things (e.g. sugar, screwdriver etc.)?</p> <p>Do people lend you small amounts of money?</p> <p>Do people give you information or advice?</p> <p>Do people help you if you call upon them to do so unexpectedly?</p> <p>Do people lend you valuable things?</p> <p>Do people help you, for example, when you are sick, when you have transport problems or when you need them to accompany you somewhere?</p>	<p>Response:</p> <p>None of the time</p> <p>A little of the time</p> <p>Some of the time</p> <p>Most of the time</p> <p>All of the time</p> <p>Notes: Asked of the younger cohort in survey 4 & the mid age cohort in surveys 2 & 4 (shorter question asked of the younger cohort in surveys 2 & 3 & the mid age cohort in survey 3)</p>
<p>Data item: Whether primary carer able to use public transport when accompanied by main recipient of care</p> <p>Data domain:</p> <p>Not applicable</p> <p>Not able to use public transport</p> <p>Able to use with difficulty</p> <p>Able to use without difficulty</p> <p>Able to use but difficulty not stated</p> <p>Does not need or want to use public transport</p> <p>Not stated</p>	<p>Response: Yes, No, I don't need help with this</p> <p>Notes: Asked of the older cohort in survey 2 (similar question asked of the older cohort in survey 3)</p>	

Table A11.6: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role (*respite care*)

NRCP	SDAC		
<p>Data items about respite services booked, respite services purchased, respite hours purchased & cost of respite services purchased for:</p> <p>Commonwealth approved aged care homes residential respite services</p> <p>State/territory funded disability care homes residential respite services</p> <p>Community residential respite services</p> <p>Other residential respite services</p> <p>Community respite services</p> <p>In-home respite services</p> <p>Individualised respite services</p> <p>Indirect respite services</p>	<p>Data item: Primary carer use of respite care</p> <p>Data domain: Not applicable Used respite care in the last 3 months Used respite care but not in the last 3 months Never used respite care</p> <hr/> <p>Data item: Type of respite care used in last 3 months (multiple response)</p> <p>Data domain: Used a day-care centre in the last 3 months Used in-home respite in the last 3 months Used residential respite in the last 3 months Used respite service other than day-care centre, in-home or residential in the last 3 months Has used respite care but not in the last 3 months Has never used respite care Not applicable</p> <hr/> <p>Data item: Whether primary carer used a day-care centre in the last 3 months</p> <p>Data domain: Not applicable Used a day-care centre in the last 3 months Has used respite care in the last 3 months but not a day-care centre Has used respite care but not in the last 3 months Has never used respite care</p> <hr/> <p>Data item: Whether primary carer used in-home respite in the last 3 months</p> <p>Data domain: Not applicable Used in-home respite in the last 3 months Has used respite care in the last 3 months but not in-home respite Has used respite care but not in the last 3 months Has never used respite care</p> <hr/> <p>Data item: Whether primary carer used residential respite care in the last 3 months</p> <p>Data domain: Not applicable Used residential respite in the last 3 months Has used respite care in the last 3 months but not residential respite Has used respite care but not in the last 3 months Has never used respite care</p>	<p>Data item: Whether primary carer used other respite service in the last 3 months</p> <p>Data domain: Not applicable Used respite service other than day-care centre, in-home or residential in the last 3 months Has not used respite service other than day-care centre, in-home or residential in the last 3 months Used respite care, but not in the last 3 months Has never used respite care</p> <hr/> <p>Data item: Primary carer need & receipt of respite care for main recipient of care</p> <p>Data domain: Not applicable Received respite care in last 3 months & does not need it further Received respite care in last 3 months but needs it further Did not receive respite care in last 3 months & does not need it Did not receive respite care in last 3 months but needs it Has never received respite care & does not need or want it Has never received respite care but needs it</p> <hr/> <p>Data item: Main reason primary carer did not use respite care in the last 3 months</p> <p>Data domain: Not applicable Does not need it Not available in area Available respite not suited to needs No affordable respite available Main recipient of care does not want it Carer prefers not to use it Other reason Used respite in the last 3 months Has never used respite care</p> <hr/> <p>Data item: Main reason primary carer has never used respite care</p> <p>Data domain: Not applicable Does not need service Respite care services not available in area Available services not suited to needs No affordable services available Recipient does not want service Carer does not want service Other reason Has used respite care</p>	<p>Data item: Whether primary carer has unmet need for respite care on weekdays (at least once a month)</p> <p>Data domain: Not applicable Needs respite care on weekdays at least once a month Needs respite care on weekdays less than once a month Needs respite care but not on weekdays Does not need or want respite care</p> <hr/> <p>Data item: Whether primary carer has unmet need for respite care on weekends (at least once a month)</p> <p>Data domain: Not applicable Needs respite care on weekends at least once a month Needs respite care on weekends less than once a month Needs respite care but not on weekends Does not need or want respite care</p> <hr/> <p>Data item: Whether primary carer has unmet need for respite care on weeknights (at least once a month)</p> <p>Data domain: Not applicable Needs respite care on weeknights at least once a month Needs respite care on weeknights less than once a month Needs respite care but not on weeknights Does not need or want respite care</p> <hr/> <p>Data item: Whether primary carer has unmet need for respite care on short notice or on an irregular basis</p> <p>Data domain: Not applicable Needs respite care at short notice or on irregular basis Needs respite care but not at short notice or on irregular basis Does not need or want respite care</p>

Table A11.7: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role (*assistance provided*)

SDAC	
<p>Data item: Whether primary carer usually accompanies main recipient of care when going out</p> <p>Data domain: Not applicable Usually has to accompany main recipient Does not usually have to accompany main recipient Main recipient does not leave home</p>	<p>Data item: Whether carer provides assistance with...</p> <p>Data sub-items: Cognitive & emotional needs; Communication; Health care; Home maintenance or gardening tasks; Household tasks; Meal preparation; Mobility; Private transport; Reading & writing; Self-care</p> <p>Data domain: Not applicable Usually assists with... Does not assist with... Not stated</p>
<p>Data item: Whether primary carer usually assists main recipient of care...</p> <p>Data sub-item: To make or maintain relationships; Coping with feelings or emotions; Decision making or problem solving; Financial management; Footcare; Gardening; Health care other than footcare; Heavy housework; Home maintenance; Laundry; Letter writing; Light housework; Manipulating limbs or exercising; Meal preparation; Manage behaviour</p> <p>Data domain: Not applicable Usually assists with... Does not usually assist with... Not stated</p>	<p>Data item: Whether possible primary carer usually assists main recipient of care with...</p> <p>Data sub-items: Communication tasks; Mobility tasks; Self-care tasks; Communication with strangers; Getting in & out of bed or chair; Bathing or showering; Cognitive or emotional tasks; Communication tasks; Dressing; Eating or feeding; Health care tasks; Household tasks; Managing incontinence; Mobility tasks; Moving about the house; Moving around away from home; Paperwork tasks; Property maintenance tasks; Self care tasks; Toileting; Transport tasks; Communication with family & friends</p> <p>Data domain: Not applicable Usually assists with... Does not usually assist with...</p>
<p>Data item: Whether primary carer usually assists or supervises main recipient of care in using public transport</p> <p>Data domain: Not applicable Usually supervises or assists with using public transport Does not usually supervise or assist with using public transport Main recipient of care does not use public transport</p>	
<p>Data item: Whether primary carer usually drives main recipient of care in private transport</p> <p>Data domain: Not applicable Usually has to drive main recipient of care Does not usually have to drive main recipient of care Main recipient of care does not leave home</p>	

Table A12.1: Collection matrix for challenging behaviour and frequency of occurrence

Behaviour	Frequency of occurrence							Not applicable
	Never	Less than once a week, but still occurring	Once or twice a week	Several times a week (three or more)	Once or twice a day	Several times a day (three or more)	Several times an hour (two or more)	
Cursing or verbal aggression								
Hitting								
Grabbing								
Tearing things								
Pushing								
Biting								
Spitting								
Physical sexual advances								
Pacing								
Inappropriate robing/disrobing								
Performing repetitive mannerisms								
Trying to get to a different place								
Handling things inappropriately								
Throwing things								
General restlessness								
Constant requests for attention								
Repetitious sentences/questions								
Complaining								
Negativism								
Making strange noises								
Screaming								
Verbal sexual advances								
Hiding things								
Hoarding things								
Other								

Table A12.2: Coexisting health conditions

Certain infectious and parasitic diseases Tuberculosis HIV/acquired immunodeficiency syndrome (AIDS) Other infections and parasitic diseases
Neoplasms Colon cancer Lung cancer Skin cancer Breast cancer Prostate cancer Brain cancer Hodgkin's disease Lymphoma Leukaemia Other malignant tumour Other neoplasms
Diseases of the blood and blood-forming organs and certain disorders involving the immune system Anaemia Haemophilia Immunodeficiency disorder (except AIDS) Other diseases of the blood and blood-forming organs and certain disorders involving the immune system
Endocrine, nutritional and metabolic disorders Disorders of the thyroid gland Diabetes Obesity High cholesterol Other endocrine, nutritional and metabolic disorders
Mental and behavioural disorders Psychoses and depression/mood affective disorders Schizophrenia Depression/mood affective disorders (excluding postnatal depression) Other psychoses Neurotic, stress-related and somatoform disorders Phobic and anxiety disorders Nervous tension/stress Obsessive-compulsive disorder Other neurotic, stress-related and somatoform disorders Intellectual and developmental disorders Down's syndrome Intellectual disability Autism and related disorders (including Rett's syndrome and Asperger's syndrome) Other developmental disorders

(continued)

Table A12.2 (continued): Coexisting health conditions

<p>Mental and behavioural disorders (continued)</p> <p>Other mental and behavioural disorders</p> <p>Mental disorders due to alcohol and other psychoactive substance use</p> <p>Eating disorders</p> <p>Adult personality and behavioural disorders</p> <p>Attention deficit disorder/hyperactivity</p> <p>Speech impediment</p>
<p>Diseases of the nervous system</p> <p>Meningitis and encephalitis (excluding 'viral')</p> <p>Huntington's disease</p> <p>Motor neurone disease</p> <p>Parkinson's disease</p> <p>Brain disease/disorders—acquired</p> <p>Multiple sclerosis</p> <p>Epilepsy</p> <p>Migraine</p> <p>Muscular dystrophy</p> <p>Cerebral palsy</p> <p>Paralysis</p> <p>Chronic/postviral fatigue syndrome</p> <p>Other diseases of the nervous system (including transient cerebral ischaemic attacks)</p>
<p>Diseases of the eye and adnexa</p> <p>Corneal disorders/defects</p> <p>Cataracts</p> <p>Retinal disorders/defects</p> <p>Glaucoma</p> <p>Refraction and accommodation disorders</p> <p>Visual disturbances</p> <p>Sight loss</p> <p>Other diseases of the eye and adnexa</p>
<p>Diseases of the ear and mastoid process</p> <p>Diseases of external ear</p> <p>Diseases of middle ear and mastoid</p> <p>Diseases of inner ear (except noise-induced deafness)</p> <p>Tinnitus</p> <p>Deafness/hearing loss</p> <p>Other diseases of the ear and mastoid process</p>

(continued)

Table A12.2 (continued): Coexisting health conditions

<p>Diseases of the circulatory system</p> <p>Heart disease</p> <p>Rheumatic fever/chorea with heart disease</p> <p>Rheumatic heart disease</p> <p>Angina</p> <p>Myocardial infarction (heart attack)</p> <p>Other heart diseases</p> <p>Diseases of the circulatory system</p> <p>Rheumatic fever/chorea without heart disease</p> <p>Hypertension (high blood pressure)</p> <p>Stroke</p> <p>Arterial or aortic aneurysm</p> <p>Hypotension (low blood pressure)</p> <p>Peripheral vascular disease</p> <p>Other diseases of the circulatory system</p>
<p>Diseases of the respiratory system</p> <p>Influenza and pneumonia</p> <p>Bronchitis/bronchiolitis</p> <p>Respiratory allergies (excluding allergic asthma)</p> <p>Emphysema</p> <p>Asthma</p> <p>Asbestosis</p> <p>Other diseases of the respiratory system</p>
<p>Diseases of the digestive system</p> <p>Dental caries/gum disease</p> <p>Stomach/duodenal ulcer</p> <p>Abdominal hernia (except congenital)</p> <p>Enteritis and colitis</p> <p>Other diseases of the intestine</p> <p>Diseases of the peritoneum</p> <p>Diseases of the liver</p> <p>Other diseases of the digestive system</p>
<p>Diseases of the skin and subcutaneous tissue</p> <p>Skin and subcutaneous tissue infections</p> <p>Skin allergies (dermatitis and eczema)</p> <p>Other diseases of the skin and subcutaneous tissue</p>
<p>Diseases of the musculoskeletal system and connective tissue</p> <p>Arthritis and related disorders</p> <p>Deformities of joints/limbs—acquired</p> <p>Osteoporosis</p> <p>Other acquired deformities of the musculoskeletal system and connective tissue</p> <p>Other disorders of the musculoskeletal system and connective tissue</p>

(continued)

Table A12.2 (continued): Coexisting health conditions

<p>Diseases of the genitourinary system</p> <p>Kidney and urinary system (bladder) disorders (except incontinence)</p> <p>Renal failure</p> <p>Stress/urinary incontinence</p> <p>Prostate disorders</p> <p>Breast disorders</p> <p>Menopause disorders</p> <p>Other diseases of the genitourinary system</p>
<p>Certain conditions originating in the perinatal period</p> <p>Congenital malformations, deformations and chromosomal abnormalities</p> <p>Spina bifida</p> <p>Deformities of joints/limbs—congenital</p> <p>Other chromosomal abnormalities</p> <p>Congenital brain damage/malformation</p> <p>Other congenital malformations and deformations</p>
<p>Symptoms, signs and abnormal clinical and laboratory findings not otherwise specified</p> <p>Breathing difficulties/shortness of breath</p> <p>Bowel/faecal incontinence</p> <p>Headaches</p> <p>Pain not further defined</p> <p>Unspecified speech difficulties</p> <p>Malaise and fatigue</p> <p>Blackouts, fainting, convulsions not elsewhere classified</p> <p>Incontinence not further defined</p> <p>Insomnia not further defined</p> <p>Other symptoms and signs not elsewhere classified</p>
<p>Injury, poisoning and certain other consequences of external causes</p> <p>Head injury/acquired brain damage</p> <p>Arm/hand/shoulder damage from injury/accident</p> <p>Amputation of the finger/thumb/hand/arm</p> <p>Leg/knee/foot/hip damage from injury/accident</p> <p>Amputation of toe/foot/leg</p> <p>Poisoning/toxic side effects</p> <p>Allergies—food</p> <p>Complications/consequences of surgery and medical care not elsewhere classified</p> <p>Other injury, poisoning and consequences of external causes</p>

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