## Supplementary Table 1. Papers included in meta-review of dementia caregiving, interventions, coping and stress 1988-2014.

1R	Authors	Systematic Review	Search Methods	ta- sis	Z	led	Z	led	Conclusions
AMSTAR	and date	Focus		Meta- analysis		included		excluded	
7	35 Acton	To evaluate	Searched MEDLINE (1966-1990, CINAHL	Yes	4	24		22	Multicomponent intervention affected CG,
	& Kang	intervention	(1982-1999), PsycINFO (1966-1999), ERIC						support groups, education, psychoeducation
	(2001)	strategies to help	(1966-1999), SSI (1989-1999), SSA (1983-						counselling and respite care did not.
		caregivers cope with	1999) for keywords caregiver, caregiving,						Suggested that "Burden" too global an
		CG burden.	dementia and Alzheimer's disease						outcome to be useful.
9	9 Bates,	Psychosocial	Search of 15 electronic databases + 10 grey			3		3694	Small Numbers of cases in primary sources
	Boote &	interventions for	literature sources + general internet search						reviewed (19-28.)
	Beverley,	people with milder	(Google). Lead researchers contacted. Search						No effects found for counselling or
	(2003)	dementing illness.(ie	terms included dement*, Alzheimer*,						procedural memory stimulation (practise on
		MMSE > 15 and <	psychosocial, cognitive therap*, behavio(u)r*						ADL, such as brushing teeth.)Reality
		23)	therap*, reality orientation, exercise*, etc.						orientation showed some positive effects on
			No date restriction.						cognition as indicated by MMSE and these

							seemed to be maintained.
4	22 Black	To assess	Searched MEDLINE, PsycINFO, CINAHL,		32	656	Pooled correlations indicated moderate
	& Almeida	associations	1990-2001, for dementia AND behavior OR				associations between BPSD and CG
	(2004)	between Behavioral	Mental disorders; Caregivers AND				burden, CG distress and CG depression.
		and Psychological	depression.				Limited data suggested CG variables more
		Symptoms of					important than BPSD in predicting
		Dementia (BPSD)					institutionalization.
		and CG burden, CG					
		depression and					
		institutionalization.					
7	10 Brodaty	To assess	Searched MEDLINE, Embase, PubMed,	Yes	23	1642	Psychosocial interventions effective in
	&	effectiveness of	PsycINFO, Scopus, 1985-2010, for				reducing behavioural and psychological
	Arasaratna	community based	combinations of condition terms: dementia,				symptoms in patients (moderate effect
	m (2012)	non-	Alzheimer*,				sizes) and reducing CG distress (small
		pharmacological	Care provider terms: caregiver*, carer*,				effect size but significant).
		(psychosocial)	Intervention terms: treatment*, therap*,				
		interventions for	counsel*, intervention*, support, support				

		dementia patient	group*,, psychosocial, nonpharmacologic*				
		symptoms and CG	and symptom terms:				
		Distress.	Behavioural and psychological symptoms of				
			dementia, BPSD, abberant motor behaviour,				
			aggression, anxiety, etc.				
7	2 Brodaty,	Meta-analysis of	Search MEDLINE (1985-2000), PsycInfo	Yes	30	24	Caregiver (CG) interventions had modest
	Green &	psychosocial	(1984-2000), Ageline (1985-2000), CINAHL				but significant benefits for CG knowledge,
	Koschera	interventions for	(1985-2000), Cochrane Library (1991-2000),				psychological morbidity and coping skills.
	(2003)	caregivers of people	Embase (1998-2000). For caregiver, carer,				The only intervention feature related to
		with dementia	self-help groups, support groups, education,				outcome was involvement of the patent as
			training, skills training, counselling,				well as the CG.
			psychotherapy, intervention, and therapy				
			combined with random allocation, control				
			group, dementia, Alzheimers disease.				
3	33 Cooke,	Psychosocial	Search PsycLit (1970-2000); MEDLINE		40	2211	67% of studies showed no effects on any
	McNally,	interventions for	(1966-2000); ISI (1981-2000); Embase				outcomes. Social support alone or in
	Mulligan,	carers of people	(1980-2000); Cochrane Library (2000-Issue				combination with problem focused

	Harrison	with dementia	3), for (dement* OR Alzheimer*); carer*,				approaches showed some benefits for
	&		caregiv* OR supporter*; AND (trial*,				psychological well-being. Interventions to
	Newman,		intervention* OR program*). Also hand				increase knowledge generally did so but
	(2001).		searching of reference lists.				without impact on well-being or burden
							Typically small sample sizes limited
							chances of uncovering effects.
7	36 Chien,	Assess effectiveness	Searched OVID, NCBI, Cochrane Library,	Yes	30	146	Support groups showed significant positive
	Chu,	of support groups	MEDLINE, PubMed, PsycArticles,				effect on caregiver's psychological well
	GuoCho	for CGs	PsycINFO, ERIC, Ageline, CINAHL (1998-				being, depression and burden.
	u (2011)		2009), for dementi* or Alzheimer's disease,				
			Support* or psychoeducation* or education*				
			or training*, group* or program*, caregiv*				
			or carer*.				
8	17 Cooper,	To assess prevalence	Searched Allied & Complementary Medicine		33	497	C. 25% of CGs affected by significant
	Balamurali	and correlates of	(1985-), British Nursing Index (1994-),				levels of anxiety. Confrontative and escape
	&	anxiety in CGs of	CINAHL (R) (1982-), Embase (1974-),				avoidance coping, CG burden, poor CG
	Livingston	people with	MEDLINE (1951-), PsycINFO (1887-),				health associated with higher anxiety levels.

	(2007).	dementia.	up to June 2005, for				
			Carer OR caregiver, AND dementia OR				
			Alzheimer's disease AND anxiety.				
6	36 Cooper,	Synthesise	Search MEDLINE, Embase, PsycINFO,		24	506	Few interventions showed efficacy re
	Balamurali	information re	CINAHL(R), British Nursing Index, Allied				anxiety. The only RCT to be effective
	, Selwood	interventions to	and Complementary Medicine.				involved CBT and a relaxation based
	&	reduce CG anxiety.					intervention specifically devised for
	Livingston						anxiety. Some evidence (not from RCTs)
	(2007)						for benefits of yoga and relaxation; nut not
							for behavioural management, exercise or
							respite.
9	37 Cooper,	To assess	Search PubMed, Web of Science, Cochrane	Yes	20	1049	Coping-strategy based family carer therapy,
	Mukadam,	effectiveness of non-	systematic reviews databases to January				with or without patient involvement,
	Katona,	pharmacological	2011, for Dementia OR Alzheimer; Quality of				improved QoL of dementia patients living
	Lyketsos	interventions in	life OR well-being; AND treatment OR				at home
	et al	improving QOL of	intervention.				
	(2012)	people with					

		dementia.				
4	18	To assess prevalence	Searched Medline and Psychinfo up to May	10	Not given	Overall prevalence of depressive disorder
	Cuijpers	of depressive	2004 for caregiv* AND depression			22%. Relative risks ranged from 2.8 to
	(2005).	disorders in CGs of				38.68 (all significant).Being a CG for PWD
		PWD				a risk factor for depressive disorder.
5	32 Del-	Caregivers coping	Search MEDLINE, Pubmed, CINAHL,	10	687	Avoidance coping associated with greater
	Pino-	and subjective	EBSCO, EMBASE, Elsevier, PsycInfo, Ovid,			subjective burden.
	Casado,	burden	Scopus, ISI Proceedings up to 2010 for			No consistent pattern between problem
	Frias-		(caregiv* or supporter* or carer*) and			focused, approach and emotion based
	Osuna,		(burden or strain) and (coping or cope). Also			strategies and burden emerged.
	Palomino-		hand searching of journals, reference lists.			
	Moral &					
	Pancorbo-					
	Hidalgo,(					
	2011).					
6	38 Elvish,	Psychological	Quantitative and qualitative lit search of	20	1093	Psychoeducational skill building to
	Lever,	interventions for	MEDLINE, PsycInfo, ERIC and PubMed			increase knowledge of AD and emotional

	Johnstone,	carers of people	2005-2011, for (caregiver or caregiving or			coping was generally beneficial in
	Cawley &	with dementia.	care or caring) AND (dementia or			maintaining well being. Multicomponent
	Keady,		Alzheimer's or cognitively impaired or			interventions (eg support groups, individual
	(2013)	Updates previous	cognitive impairment or mild cognitive			counselling, telephone support) and
		reviews by Pinquart	impairment or MCI) AND (intervention study			technology based approaches were useful.
		& Sorensen,(2006)	or evaluation study or experimental design or			
		and Gallagher-	quasi-experimental design or memory clinic			
		Thompson & Coon	or counselling or psychoeducation or			
		(2007).	technology or support group or			
			psychotherapy or case management or care			
			management or multicomponent or			
			environmental or cognitive behavioural			
			therapy or CBT or family or systemic).			
3	39 Etters,	To identify factors	Searched CINAHL, MEDLINE, and	58	N/A	Individually developed multicomponent
	Goodall &	influencing	PsychInfo (1966-2006) with keywords CB			interventions decrease CG burden, improve
	Harrison	caregiver burden	and dementia			QoL and delay institutionalisation.
	(2008).	(CB) and describe				

		evidence-based				
		interventions to				
		reduce CB				
4	27	Caregivers stress &	Search Current Contents, PsycInfo,	17	NA	Wishfulness & fantasy coping had negative
	Gottlieb &	coping	Sociological Abstracts, Social Science			impact; problem solving, acceptance and
	Wolfe,(20		Abstracts, (1984-2000), for coping,			social support based coping were
	02).		eldercare, caregiving, carer, dementia,			beneficial.
			Alzheimer's disease, older adults, caregiver			
			stress.			
7	40 Hall &	To identify evidence	Searched CINAHL, MEDLINE, Amed,	17	6	Cognitive behavioural and reminiscence
	Skelton	re current role of	PsychArticles, PsycInfo, ASSIA, Social			therapy can be effective re outcomes for
	(2011).	OTs in supporting	Services Abstracts, Cochrane Library for			CGs on eg., CG burden, stress, strain,
		caregivers of people	caregiver, dementia, occupational therapy,			health and mood.
		with dementia (UK	intervention and treatment, (1999-2010).			
		only).	Hand searching also done.			
7	11 Hogan,	Management of mild	Searched PubMed and Embase, for dementia	305	1310	Insufficient evidence that cognitive
	Bailey,	to moderate AD: (ie	OR Alzheimer's disease AND mild OR			training/rehabilitation is effective.

	Carswell	MMSE >10 and <	moderate AND therapy OR treatment., 1996-				Individualised exercise programmes
	et al.	26).	2006.				helpful.
	(2007)						Behavioural problems aided by support
		28 evidence based					groups, psychoeducational intervention.
		recommendations.					
							Involvement of CG and CR in intervention
		Focus on non-					helps.
		pharmacological					
		recommendations.					
4	28	Caregivers stress &	Search MEDLINE, Psych-Info to 1999 for		16	N/A	Applying Lazarus & Folkman's 1984
	Kneebone	coping	Alzheimer's disease, dementia, caregivers				model, found benefits re health and
	& Martin,		burden, adaptation, psychological, coping,				depression from problem solving and
	(2003).		stress				acceptance styles of coping.
4	1 Knight,	Assess effectiveness	Searched relevant journals and Ageline,	Yes		na	Individual psychosocial interventions and
	Lutzky &	of interventions for	MEDLINE, PsycINFO and SSI, 1980-1990.				respite programs moderately effective;
	Macofsky-	CG distress.	Keywords not given.				Group psychosocial interventions less so.

	Urban						
	(1993)						
5	21 Lee,	To assess	Searched PubMed, PsycInfo and Embase up		56	711	Patient behavioural problems, caregiver
	Bakker,	determinants of	to December 2013 for burden, distress,				coping and personality traits and
	Duivenvoo	subjective CG	stress, strain, overload, well-being AND				competence were most consistent
	rden &	burden in dementia	caregiver, family, spouse, informal, relative,				determinants of CG burden, depression and
	Droes		home AND psychogeriatrics, geriatric				mental health. Behavioural problems were
	(2014)		psychiatry, dementia, behaviour,				more significant than cognitive disorders or
			neuropsychiatric symptoms OR theoretical,				lack of self-care. Of CG personality traits,
			concept, predictors, prognostics, model,				neuroticism had strongest impact on
			scale, limited by (old) age and human.				burden. CG feeling competent or higher
							self-efficacy were beneficial re burden and
							mental health.
8	30 Li,	Do changes in	Searched Embase, MEDLINE, PsycINFO,	Yes	8	425	Surprisingly, dysfunctional coping
	Cooper,	coping style explain	Web of Science, Cochrane Library, CINAHL				increased when depressive symptoms
	Austin &	effectiveness of	and AMED, up to July 2011, for carer OR				declined. Some evidence that emotional
	Livingston	interventions for	caregiver OR caring OR relative OR				support and acceptance based coping

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4	43 Luppa,	To assess factors	Searched MEDLINE, Web of Science,		42	467	CG burden, life satisfaction, health related
	Luck,	influencing	Cochrane Library and PSYNDEX for				QoL and dysfunctional coping strategies
	Brahler,	institutionalisation	keywords, Institutionalisation, Nursing home				linked to earlier institutionalization
	Konig &	of persons with	placement, nursing home admission and				
	Riedel-	dementia.	dementia.				
	Heller						
	(2008)						
8	12	To review	Searched MEDLINE, CINAHL, PsycINFO,		25	93	Effect sizes v controls mostly small;
	O'Connor,	psychosocial	Cochrane databases up to 2006.				moderate to large effects with
	Ames,	treatments of	Keywords not given.				aromatherapy, ability focused career
	Gardner &	behaviour symptoms					education, bed baths, music and muscle
	King	in AD					relaxation training.
	(2009).						
5	13	To evaluate effects	Searched MEDLINE, PsycINFO, CINAHL,	Yes	179	1134	Strong evidence that Multicomponent
	Olazaran,	of	Embase, Lilacs, Cochrane Dementia and				interventions for CGs education and
	Reisberg,	Nonpharmacological	Cognitive Improvement Group Specialized				support delayed institutionalisation.
	Clare,	Therapies on	Register, up to September, 2008.				Some evidence for improvements linked to

	CruzM	Quality of Life of	Keywords not given in paper.			multicomponent interventions for PWD
	uniz	PWD and CGs of				cognition, Activities of Daily Living,
	(2010)	PWD.				behaviour & mood, and for CG mood, well-
						being and Quality of Life.
6	25	To determine	Searched MEDLINE, Pubmed and PsycINFO	35	673	Depression, aggression and sleep
	Ornstein &	whether particular	for dementia OR Alzheimer, caregivers OR			deprivation were most frequently identified
	Gaugler	symptoms or	caregiving, behaviour symptom OR BPSD			patient symptoms to impact negatively on
	(2012)	symptom clusters	OR psychiatric OR neuropsychiatric OR			CGs. However, overall, a wide range of
		exert undue negative	hallucination OR delusion OR aggression			symptoms was associated with CG
		impact on CG	OR agitation OR wandering OR psychosis			depression and burden.
		depression and	OR depression OR behaviour.			
		burden.				
7	44 Parker,	To assess	Extensive search of CINAHL, MEDLINE,	40	645	12/13 psychoeducational interventions had
	Mills &	effectiveness of	PsycINFO and Cochrane databases.			positive results for depression and burden.
	Abbey	interventions to				Studies of support showed a small but
	(2008)	assist CGs to				significant benefit for burden.
		provide support for				10/12 multicomponent studies reported

		dementia patients in					significantly improved outcomes.
		the community.					
7	45	To assess	Searched CINHAHL, Pubmed, PsycINFO		11	81	None of the types of interventions (case
	Peacock &	interventions to	1992-2002, for keywords caregiver, carer,				management, education, psychotherapy,
	Forbes	improve well being	Dementia, Alzheimer, burden, depression,				computer networking) had consistent
	(2003)	of CGs	strain, stress, support, respite, education,				effects overall.
			intervention, effective, assess, evaluate and				
			measure.				
			Also hand searched relevant journals.				
7	34	Which interventions	Searched PsycINFO, MEDLINEe, Ageline,	Yes	127	No info	CG interventions had positive immediate
	Pinquart &	for caregivers of AD	PSYNDEX (dates not specified), for				effects on CG's burden, depression, well
	Sorensen	patients help and	(dementia OR Alzheimer's disease) AND				being, ability/knowledge, and CR
	(2006)	how much?	(caregiver OR care OR caregiving) AND				symptoms. Effect sizes small.
			(intervention OR trial OR support OR				Psychoeducational interventions had
			training).				broadest effects and were most effective
			Note: overlaps strongly with Brodaty et al				when involved active participation.
			(2003) but extends coverage to more recent				

			studies.			
7	19	To assess correlates	Searched PsycINFO, MEDLINE, PSYNDEX	176	Not given	Negative effects on CG health most
	Pinquart &	of physical health of	for keywords health AND (caregiving OR			common in in psychologically distressed
	Sorensen	informal CGs	Caregivers OR carer OR support provider)			CGs facing dementia –related stressors.
	(2007).		AND (elderly OR old age)			
4	46 Powell,	To assess	Searched MEDLINE, Embase, CINAHL,	15	1441	Interventions were multifaceted with
	Chiu &	effectiveness of	PsycINFO, AMED up to 2007, for dementia,			inconsistent outcomes, but interventions
	Eysenbach	networked ICT	Alzheimer's, carer, caring, AND network,			tended to have moderate effects on CG
	(2008).	interventions in	internet.			stress and depression.
		supporting CGs of				
		people wirh				
		dementia.				
7	29 Pusey	Assess effectiveness	Searched MEDLINE, CINAHL, Embase,	30	361	Study quality generally poor. Individualised
	&	of psychosocial	Cochrane Library, HMIC, SCI, SSCI, Age			interventions stressing problem solving and
	Richards	interventions for	Info, National Research Register and Health			behaviour management most effective.
	(2001)	CGs	CD. Plus hand searching of relevant journals.			

			Keywords not given.				
5	47 Quinn,	To explore impact	Searched, PsycINFO, SSCI, MEDLINE and		10	2	CGs' well being affected by nature of
	Clare &	of meaning and	CINAHL, 1960-2008, for keywords				motivations. Finding meaning had a
	Woods	motivation on well	caregiver*, carer*, caregiving, dementia,				positive impact on CGs' well being.
	(2010)	being of CGs	Alzheimer's, motiv*, drive*, oblig*, duty,				
			filial and meaning*				
8	48	Effects of home care	Search of MEDLINE, Embase, Cochrane	Yes	26	880	On a meta-analysis, Psychosocial
	Schoenma	intervention on carer	Database of Systematic Reviews, Database of				intervention had small positive but non
	kers,	well being	Abstracts of reviews of Effects, Cochrane				significant effects on depression and
	Buntinx &		Register of Controlled Trials and ACP				burden.
	deLepeleir		Journal Club, (1980-2007), for dementia,				
	e, (2010).		primary caregiver, interventions , home care				
			and their abbreviated terms.				
4	49 Schulz,	To assess clinical	Searched MEDLINE, PsycINFO, CINAHL,		50	na	Relatively few studies showed clinically
	O'Brien,	significance of	(1996-2001), for caregivers and dementia or				significant effects so far but conclude that
	Czaja,	caregiver	Alzheimer's disease.				interventions are promising and may show
	OrySte	interventions.					up more strongly with improved methods.

	vens					
	(2002)					
6	50	To identify effective	Databases searched and keywords not	62	182	Individual behaviour management therapy
	Selwood,	psychological	reported.			re patients' behaviour effective. Teach
	Johnston,	interventions for	Search went up to 2003.			caregivers coping strategies also effective.
	Katona,	CGs				Education re dementia, group behaviour
	Lyketsos					therapy and supportive therapy not
	&					effective.
	Livingston					
	(2007).					
6	16 Smits,	Assess evidence for	Search MEDLINE and Psychinfo 1992-	25	27	Best results were for CG general mental
	de Lange,	benefits of	2005., for dementia, family members,			health. Effects on cognitive, physical
	DroesPo	combined	caregivers, caregiver burden, support			functioning, behaviour problems and
	t (2007)	intervention	programme, training, counselling, care-			survival of patents were small and
		programmes (ie that	giving skills, intervention, combined			inconsistent, although their mental health
		address both the	intervention, integrated intervention, effect*,			and time to admittance to long term care
		patient and the CG)	effic*			were positively affected.

		for patient and CG.					
7	51	Determine	Searched PsycINFO, MEDLINE,	Yes	78	61	Interventions generally successful.
	Sorensen,	effectiveness of	PSYNDEX, for caregiver or carer or				Effects larger on ability/knowledge than on
	Pinquart &	interventions for	caregiving, intervention or support or				burden/depression.
	Duberstein	CGs	training, and elderly or old age.				Psychoeducational/ therapeutic effects most
	, P. (2002)						consistent overall.
7	14 Spijker,	Assess effectiveness	Searched MEDLINE, Web of Knowledge,	Yes	13	442	Support programmes significantly
	Vernooij-	of support programs	PsycINFO, (January 1990-March 2006), for				decreased odds of institutionalisation and
	Dassen,	in delaying	controlled studies, dementia costs,				lengthened time to institutionalisation.
	Vasse,	institutionalisation	institutionalisation, time spent giving care,				Actively involving CGs in choices about
	AdangV	of AD patients	caregivers				treatments was key to programme
	erhey						effectiveness.
	(2008).						
4	15 Thinnes	To review evidence	See Arbesman & Leiberman (2011) for		43	7402	Interventions that jointly engage patients
	& Padilla	re effectiveness of	method				and CGs in education and training more
	(2011)	educational and					effective. Interventions providing CGs with
		supportive strategies					problem solving, technical skills, home

		for CGs					modification and referral to community
							resources are useful.
8	52	To examine whether	Searched Specialized Register of Cochrane	Yes	44	97	Group based interventions had positive
	Thompson	information and	Dementia and Cognitive Improvement Group				impact on psychological morbidity;
	,	support	2003-05 for computer*, telephon*, training*,				technology and individual based
	Spilsbury,	interventions	education*, information, "care-planning",				interventions not effective.
	Hall,	imppove Quality of	carer*, caregiv*				
	Birks,	Life for CGs					
	Barnes &						
	Adamson,J						
	. (2007).						
8	53	To evaluate	Searched Cochrane Library, MEDLINE,	Partly	11	73	Cognitive reframing reduced psychological
	Vernooij-	cognitive reframing	Embase, PsycINFO, CINAHL and LILACs,				morbidity, specifically anxiety, depression
	Dassen,	interventions for	using extensive keyword lists.				and stress.
	Draskovic,	CG's psychological					
	McCleery	morbidity and stress					
	& Downs						

	(2011).						
4	20	To assess physical	Searched Current Contents, MEDLINE,	Yes	23	Not	Evidence found of links between being a
	Vitaliano,	health risks for CGs	PsycINFO, Sociofile, Social Work Abstracts,			reported	CG of PWD v controls and level of stress
	Zhang &	of PWD.	and CINAHL to April, 2001, using keywords				hormones (23% higher in CGs), antibodies
	Scanlan		dementia, Alzheimer's disease, cognitive				(15 % lower in CGs) and global reported
	(2003).		disorders, health, physical and health,				health.
			physiology*, illness*, hormones, cholesterol,				
			cardiovascular diseases, blood pressure,				
			obesity, diabetes, immune*, mortality, death				
			and caregiv*				
9	3	To identify effective	Searched MEDLINE, CINAHL, PsycINFO		23	743	Cognitive rehabilitation effective at early
	Zabalegui,	interventions to	and ISI Web of Science, 1990-2012 for				stages of AD. Case managers reduce
	Hamers,	improve quality of	principal keywords dementia, Alzheimers				institutionalisation and use of other
	Karlsson	care	disease, patient care and home care				services.
	,Cabrer						
	a (2014).						