

Person-centred planning and dementia: literature search summary

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This is a summary of the results of a literature search for publications about person-centred planning and dementia.

Our approach

A literature search was conducted in three databases as well as key organisation websites in April 2021. The databases searched were the Cochrane Database of Systematic Reviews, Medline, and PyschInfo. The search was limited to English language publications from the last ten years. 39 publications were found: three guidelines & evidence summaries, 25 journal articles, and 11 grey literature publications (reports, webpages etc). The title and abstract of the results were screened for relevance by four members of the Focus on Dementia Team and an agreed score was given to each. The score was based on a number of factors, such as: publication type, currency, relevance to the topic and current point of the programme of work. Four publications were excluded at this stage, leaving 35 publications for inclusion in the summary below.

What we found

Some of the themes identified in the literature are:

- There is not a lot of literature published on the topic.
- The key documents highlighted are all guidance documents about developing person-centred care plans (PCCP). They offer an overview of what the key components are to developing person-centred care plans.
- There are various publications relating to two Focus on Dementia areas of work: post-diagnostic support (PDS) and dementia in hospitals. We found two publications on PDS and three publications on dementia in hospitals. More details about this other work can be found on the [Focus on Dementia](#) pages of the ihub website.

- The literature also illustrates there are clear links between PCCP and Advanced Care Planning (ACP). We found seven publications about ACP in relation to person-centred planning and dementia. All of these are journal articles: Boerner *et al* 2021, two by Goosens *et al* 2020, Pettigrew *et al* 2020, Bryant *et al* 2019, Lee *et al* 2019, and Garand *et al* 2011. The ihub website has a dedicated [ACP section with an ACP toolkit](#).

The 35 publications are split in to three lists: [key publications - table 1](#), [important publications - table 2](#), and a [reading list](#). Tables 1 and 2 have been sorted by publication type, then by publication date (newest first), and then alphabetically by Author.

[Table 1](#) contains five grey literature resources that are deemed to be key publications on the topic. Author, title and date are provided to identify the publications with titles hyperlinked to make it easier to access them. Additional information is included as way of summarising the publications. All five a guidance documents about developing person-centred care plans. They offer an overview of what the key components are to developing person-centred care plans. Only one publication is dementia-specific, the other four have a wider focus that includes dementia. Two publications relate specifically to Scotland, both by the Mental Welfare Commission for Scotland, and the other three contain information that relates to good practice in general.

[Table 2](#) has 11 publications (two grey literature and nine articles) identified as being important to the topic. Author, title and date are provided to identify the publications with titles hyperlinked to make it easier to access them. For each publication some brief comments have been noted as well as the topic and/or setting they relate to and the type of publication. The topic was: ACP, dementia in general, PCCP in general, or PDS. Settings specifically mentioned in the publications were: care homes, community, hospital, nursing homes, and primary care.

The [reading list](#) has 19 publications (two guidelines, five grey literature and 12 articles). These are publications seen as additional reading on the topic. Some provide general context to the topic so could be useful as documents to refer to while others are quite specific so could provide quite particular information that could be important. The citation details for these publications are given with links provided to make it easier to access them.

Key publications - table 1

Author	Title	Date	Main points	Country
Mental Welfare Commission for Scotland	Person centred care plans: good practice guide	2019	<p>“This guidance is about good practice in the development of person centred care plans for people using mental health, dementia and learning disability services.”p5</p> <p>It is produced by the MWCS with details about how it was produced (which is in more detail in their care plans publication).</p> <p>It contains information and context relevant to Scotland.</p> <p>16 page document</p>	Scotland
Mental Welfare Commission for Scotland	Care plans: how people with lived experience and their friends and family want to be involved	2019	<p>This report gives more information about the process for involving people in the development of the MWCS good practice guide.</p> <p>23 page document</p>	Scotland
Health Service Executive	A National Framework for Person-Centred Planning in Services for Persons with a Disability	2018	<p>This framework is produced by the Irish Health Service Executive (a national organisation that provides all of Ireland's public health services).</p> <p>It is wider than just dementia care, it covers disability.</p> <p>It has useful definitions and is comprehensive regards person-centred care planning.</p> <p>124 page document</p>	Ireland
NHS England	Dementia: Good Personalised Care and Support Planning	2017	<p>This guide to personalised care plans, from NHS England, is specifically for dementia care.</p> <p>It is aimed at primary care providers and commissioners in England.</p> <p>It explains the core components of personalised plans and contains some examples.</p> <p>18 page document</p>	England
Social Care Institute for Excellence	Care planning, involvement and person-centred care	2017	<p>This webpage relates to the Mental Capacity Act 2005, so it is not dementia specific.</p> <p>The Mental Capacity Act 2005 applies to England and Wales.</p> <p>The webpage focuses on two key themes: involvement, and keeping the wishes of the person at the centre of their care and support.</p> <p>One section of the webpage is specifically about person-centred care and support plans.</p>	England and Wales

Important publications - table 2

Author	Title	Date	Summary notes	Topic / Setting	Publication type
Boerner <i>et al</i>	Insufficient Advance Care Planning? Correlates of Planning Without Personal Conversations	2021	Socially isolated people need extra support for ACP.	ACP	Article
Isaac <i>et al</i>	The outcomes of a person-centered, non-pharmacological intervention in reducing agitation in residents with dementia in Australian rural nursing homes	2021	Use of person-centred care planning with other things can reduce stress and distress.	Nursing home Dementia	Article
Sefcik <i>et al</i>	Person-Centered Care Plans for Nursing Home Residents With Behavioral and Psychological Symptoms of Dementia	2020	Optimal PCC discussed and example of PCCP given.	PCCP Nursing home	Article
Featherstone <i>et al</i>	Routines of resistance: An ethnography of the care of people living with dementia in acute hospital wards and its consequences	2019	Observations of acute ward routines and cultures as barriers.	Hospital Dementia	Article
Lee <i>et al</i>	Advanced Care Planning for Persons With Dementia in Primary Care: Attitudes and Barriers Among Health-Care Professionals	2019	Staff knowledge doesn't always correlate with ACP completion. More training for staff in memory clinic.	Primary care ACP	Article
Orsulic-Jeras <i>et al</i>	The SHARE program for dementia: Implementation of an early-stage dyadic care-planning intervention	2019	It describes SHARE (Support, Health, Activities, Resources, and Education). SHARE is care-planning intervention for early-stage dementia.	PCCP Dementia	Article
Mariania <i>et al</i>	The impact of a shared decision-making training program on dementia care planning in long-term care	2018	Shared decision-making training helps with care planning.	Nursing home PCCP	Article
Mullay <i>et al</i>	'They're just who they've always been': The intersections of dementia, community and selfhood in Scottish care homes	2018	Cultural identity and differences among residents and workforce in Scotland.	Care home PCCP	Article
Handley <i>et al</i>	Dementia-friendly interventions to improve the care of people living with dementia admitted to hospitals: a realist review	2017	Mentions factors such as risk, staff training, capacity, staff support.	Hospital Dementia	Article
Alzheimer Scotland	Facing Dementia Together Project: East Renfrewshire & Renfrewshire Final Report	No date	It was the precursor to formal PDS. Although old there is some good information.	PDS	Report
Gloucestershire County Council	The Gloucestershire 5 Step Approach: Personalised Care Planning for Behaviours that Challenge in Dementia	No date	Looks comprehensive and practical, however reservations about the term "behaviour that challenges".	PCCP Dementia	Webpage

Reading list

Ahmad N, Ellins J, Krelle H, Lawrie M. Person-centred care: from ideas to action. 2014 [cited 2021 Apr 05]; Available from:

<https://www.health.org.uk/sites/default/files/PersonCentredCareFromIdeasToAction.pdf>

Alzheimer Scotland. Delivering Integrated Dementia Care: The 8 Pillars Model of Community Support. 2012 [cited 2021 Apr 05]; Available from:

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National Collaborating Centre for Mental Health. The Dementia Care Pathway: full implementation guidance. 2018 [cited 2021 Apr 05]; Available from:

https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/dementia/nccmh-dementia-care-pathway-full-implementation-guidance.pdf?sfvrsn=cdef189d_8

National Institute for Health and Care Excellence. Dementia: assessment, management and support for people living with dementia and their carers. 2018 [cited 2021 Apr 05]; Available from: <https://www.nice.org.uk/guidance/ng97/resources/dementia-assessment-management-and-support-for-people-living-with-dementia-and-their-carers-pdf-1837760199109>

National Institute for Health Research. Person-centred care improves quality of life for care home residents with dementia [online]. 2018 [cited 2021 Apr 05]; Available from: <https://evidence.nihr.ac.uk/alert/person-centred-care-improves-quality-of-life-for-care-home-residents-with-dementia/>

Pettigrew C, Brichko R, Black B, O'Connor MK, Austrom MG, Robinson MT, *et al.* [Attitudes toward advance care planning among persons with dementia and their caregivers.](#) International Psychogeriatrics. 2020;32(5):585-99.

Elliot R, Adams J. [Using a practice development project to improve standards of care for people with dementia.](#) Nursing older people. 2012;24(8):28-31.

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