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An outline of evidence-based practices for, and benefits of, care co-ordination for people with dementia. A Scottish case is included for local context.

This outline presents practices associated with better care co-ordination and the key benefits of dementia care co-ordination for which there is evidence identified by WHO¹, NICE² or Healthcare Improvement Scotland³ or drawn from recent systematic review evidence. Also included are the findings of a recent appreciative inquiry into a dementia care service in Scotland which is considered an exemplar for co-ordinated care.

As the concept of care co-ordination is broad and relatively ill-defined, and the evidence base is partial, other sources of information will be needed to make decisions about how services are configured to best deliver co-ordinated care along the whole dementia care pathway in Scotland.

Defining Care Co-ordination

“a proactive approach to bringing together care professionals and providers to meet the needs of service users to ensure that they receive integrated, person-focused care across various settings”.¹

Co-ordination includes planned handover of responsibility and transfer of care, collaboration among professionals with agreed sharing of responsibility, and enabling co-ordination through protocols, technology, incentives or education for example. Care co-ordination therefore cannot be seen in isolation from the complexity of an integrated service delivering person-centred care along the whole patient journey through the healthcare system.

Practices associated with better continuity and co-ordination of care

In particular, WHO¹ identifies evidence (in relation to those who are older with complex needs) that continuity *“enables care co-ordination by creating the conditions and relationships to support seamless interactions among multiple providers within interdisciplinary teams or across care settings or sectors”*. Through a review of literature on practice interventions, it identifies 8 practices associated with better continuity and co-ordination of care:

1. Continuity with a primary care professional
2. Collaborative planning of care and shared decision-making
3. Case management for people with complex needs
4. Collocated services or a single point of access
5. Transitional or intermediate care
6. Comprehensive care along the entire pathway
7. Technology to support continuity and care co-ordination
8. Building workforce capability in delivering continuity and care co-ordination

Care co-ordination in practice

A conceptual framework for health and care system integration can help understand how the practices are best implemented at different levels in the system. WHO identifies three levels of integration, that are important for care co-ordination. At **macro** (wider organisation and system) level, elements of the health and care system should work in co-ordination to enable a holistic response to a person's health and social care needs at any one time. At **meso** level there needs to be co-ordination within and between professions (for example, through interdisciplinary team working and transitional care services) as well as organizationally, such as through co-location of services, single integrated point of access. At the **micro** (or clinical) level, effective co-ordination is at the level of the relationship between the person receiving care, their family and individual care practitioners (such as a dementia care co-ordinator). Co-ordination across and between each of these three levels is supported by functional integration (financial, management and information systems, technology enabled care) and normative, values-based integration. Guiding values, such as person-centred care, inclusivity and openness throughout help bring these levels together.

Benefits of better continuity and co-ordination

Headline findings from WHO (2018)¹

- High continuity means 13% fewer hospital admissions (GP England)^a
- High continuity means 27% fewer visits to an emergency department (Canada)^b
- 63% Patients who value seeing someone they know and trust (GP/Walk-in England)^c
- 75% Patients who value seeing their usual primary care provider (GP/Walk-in England)^c
- Co-ordinated home-based primary care results in 17% lower medical costs (ill-elders, US)^d

Dementia specific benefits (NICE² and HIS³)

This section summarises the findings from dementia-specific evidence, based primarily on NICE NG97 and also drawing on a Healthcare Improvement Scotland evidence summary for palliative care.

- Case management can reduce the likelihood of admission to an institution after six months, and where delaying institutionalisation is a specific goal of the case management intervention, it can reduce this likelihood up to 12 months.
- Advance care planning for dementia patients at end of life is associated with positive outcomes including reduced hospitalization, death in usual place of care, and increased satisfaction with care and decreased emotional distress for patients and caregivers.
- Case management can help people with dementia re-engage socially or with old hobbies
- Case management for people can reduce caregiver burden and improve their quality of life particularly where the person with dementia has moderate to severe dementia
- Case management can make access to a range of health, social and welfare services easier, and can provide strong reassurance of knowing support can easily be called if needed which is valued by people with dementia and their caregivers.
- Care co-ordination/management can reduce hospitalization amongst caregivers of people with dementia (note only US study)
- Outcome focused care can improve caregivers' feelings of well-being and their view of the well-being of their care recipient

Economic benefits

Research is limited on this, but there is some evidence^e showing that large savings in overall costs of services resulting from case management offset any costs of increased use of community services.

Update: recent systematic review evidence (Sept 2020)

A literature search was carried out to identify systematic review evidence on dementia care co-ordination and published since the NICE guideline. Four studies were selected as relevant to this short summary^f.

Two reviews found some quantitative evidence of effectiveness of co-ordinated care in community settings. One reviewed studies of different models of post-diagnostic dementia care in a primary care setting, and found that models where the primary care professional worked in partnership with a case manager (CM), usually a nurse in this setting, showed most promise **“with impact on neuropsychiatric symptoms, caregiver burden, distress and mastery, and healthcare costs”**⁴. Another reviewed studies of non-pharmaceutical interventions seeking to prevent hospital or nursing home admissions for older people living with dementia in the community⁵. This found that **community co-ordination reduced the rate of nursing home admissions** (compared to usual care). Common elements of the “community care” interventions described in the four studies were “an initial assessment, an individualised care plan, referrals and linkages to services, provision of counselling, information, education and support to caregivers and people with dementia, and regular reassessments”. Three of the four interventions involved a care “co-ordinator” or “manager” role.

Another systematic review of factors influencing palliative care for dementia included synthesis of 28 studies providing qualitative data from the perspective of stakeholders across different care settings, including people with dementia, their carers, and care professionals⁶. This reported that among the most commonly reported **barriers to the provision of palliative care for people with dementia were discontinuity and lack of co-ordination of care**.

Finally, building on the emerging evidence that co-ordination can be effective, a systematic review aiming to understand how co-ordination works, synthesized qualitative data from five studies of moderate to high quality, and involving a total of 100 participants closely involved in dementia care⁷. The studies were set in three high income countries where the state plays a significant role in the running of the healthcare system (UK, Netherlands, and Canada). Case management was central to all the studies. Findings included consistency/agreement in:

- Case managers (CMs) should be warm and empathetic with the ability to develop a strong therapeutic relationship with a sound knowledge of dementia and available local services.
- Professional stakeholders felt training (particularly initially) and mentoring CMs was important, as well as being part of a supportive professional network.
- Tasks of a CM should include assessments, care planning, signposting and referrals, which should be proactive, and with regular contact that includes face-to-face meetings with service users and their carers.
- Successful co-ordination (with a CM) needs active engagement and support from individuals at the core, that is, the individual with dementia, informal caregiver and the CM, as well as from the wider professional network.
- Lack of clarity around the CM role has been found to be a hindrance, as has a lack of time, which is often associated with high case load but also with the CM being based in a primary care setting (in comparison to a community setting).

The Midlothian Health and Social Care Partnership (HSCP) experience

The following is derived from an appreciative inquiry into the successes of the dementia care service in the Midlothian area in Scotland, identified in an earlier evaluation as an exemplar in care co-ordination because of their integrated team approach and considered now established practice. More details can be found in the report⁸.

What they did – key aspects

At a macro level the HSCP enabled greater collaboration (and reduced competition) with and between a range of local organisations, and helped build shared goals. This led to new ideas about ways of working together. At a meso level the dementia team is the cornerstone of co-ordination: it forms a single point of access (including for self-referral); it holds the caseload of everyone with a diagnosis of dementia, and ensures timely communication with families; and it acts as a co-ordinating hub with community-based services facilitating two-way communication throughout the community. This, along with close, forward-looking multi-agency working, has all helped ensure issues are identified early enabling appropriate support and preventing crises. At a micro level the guiding principle is supporting independence and quality of life, working in a person-centred collaborative way. The idea of “discharge” is avoided. At times when no additional support is needed clear information and encouragement is given to self-refer back to the team as soon as needed.

What they achieved – key benefits

Given that this was not a controlled trial and therefore any benefits cannot absolutely be attributed to the care co-ordination approach in the partnership, some of the quantitative data using similar local areas (other Lothian HSCPs) as a comparison is persuasive of the benefits of Midlothian’s success in delivering co-ordinated dementia care. **Midlothian have been able to demonstrate significantly lower costs of care than other partnerships in the area.** Whilst there was a significantly higher use of geriatric long stay beds for people with dementia in Midlothian, unplanned admissions to acute care for people with dementia resulted in significantly shorter average stays in hospital: for acute specialties, the Midlothian bed day rate for people with dementia following unplanned admission, was 8.7 per person, significantly lower than the rate, 12.2 per person, across the other Lothian partnerships. This represents not only a significant cost saving, but also **a reduction in the risks to people from unnecessary time spent in hospital.**

For the last three months of life for people with dementia, the inquiry found no significant differences in rates of unplanned admissions or average length of stay between Midlothian and the other partnerships. However, a **significantly smaller proportion of people with dementia in Midlothian died in hospital when compared to other Lothian partnerships**, with a total of 36.1% of individuals with dementia from Midlothian dying in hospital compared to 49.8% of those in the dementia cohorts from the other Lothian partnerships. (The equivalent proportions for people without dementia dying in the same time period were 49.7% in Midlothian and 53.8% across the other Lothian areas.). Notably too within Midlothian, the rate of attendance at emergency department (A&E) was significantly (24%) lower for the dementia group compared to non-dementia decedents.

Another benefit of Midlothian’s co-ordinated approach found by this inquiry is that carers of people with dementia are increasingly accessing and receiving support, such as funding for regular support and respite. (Note that there is no comparison group for this finding.)

Key references

- (1) WHO (2018) Continuity and coordination of care: a practice brief to support implementation of the World Health Organization (WHO) Framework on integrated people-centred health services. 2018. Geneva, World Health Organization. Available [here](#).
- (2) NICE (2018) Dementia: assessment, management and support for people living with dementia and their carers, NICE guideline NG97, 20 June 2018 Available [here](#).
- (3) Healthcare Improvement Scotland (2019) Continuity and Co-ordination in Palliative and End of Life Care: evidence for what works. Available [here](#).
- (4) Frost, R. Walters, K. Aw, S. Brunskill, G. Wilcock, J. Robinson, L. Knapp, M. Harrison Dening, K. Allan, L. Manthorpe, J. Rait, G on behalf of the PriDem Study project team (2020). Effectiveness of different post-diagnostic dementia care models delivered by primary care: a systematic review. *British Journal of General Practice* 2020; 70 (695): e434-e441. DOI: 10.3399/bjgp20X710165. Available [here](#).
- (5) Lee, D-CA, Tirlea, L, Haines, TP (2020). Non-pharmacological interventions to prevent hospital or nursing home admissions among community-dwelling older people with dementia: A systematic review and meta-analysis. *Health Soc Care Community*. 2020; 28: 1408– 1429. <https://doi-org.knowledge.idm.oclc.org/10.1111/hsc.12984>
- (6) Mataqi M, Aslanpour Z. (2020) Factors influencing palliative care in advanced dementia: a systematic review. *BMJ Supportive & Palliative Care* 2020;10:145-156. Available [here](#).
- (7) Backhouse, A., Richards, D.A., McCabe, R. et al (2017). Stakeholders' perspectives on the key components of community-based interventions coordinating care in dementia: a qualitative systematic review. *BMC Health Serv Res* 17, 767 (2017). <https://doi.org/10.1186/s12913-017-2725-y>
- (8) Healthcare Improvement Scotland, Alzheimer Scotland (2020) Care co-ordination in the community for people with dementia in Midlothian. Available [here](#).

^a Association between continuity of care in general practice and hospital admissions for ambulatory care sensitive conditions: cross sectional study of routinely collected, person level data Isaac Barker, Adam Steventon, Sarah R Deeny <https://www.bmj.com/content/bmj/356/bmj.i84.full.pdf>

^b Continuity of primary care and emergency department utilization among elderly people.(Research)(Report) Ionescu - Ilttu, Raluca ; Mccusker, Jane ; Ciampi, Antonio ; Vadeboncoeur, Alain - Michel ; Roberge, Daniele ; Larouche, Danielle ; Verdon, Josee ; Pineault, Raynald *CMAJ: Canadian Medical Association Journal*, Nov 20, 2007, Vol.177(11), p.1362(7)

^c Interpersonal continuity of care: a cross-sectional survey of primary care patients' preferences and their experiences Baker, Richard ; Boulton, Mary ; Windridge, Kate ; Tarrant, Carolyn ; Bankart, John ; Freeman, George K *The British Jnl. of general practice : Jnl. of the Royal College of General Practitioners*, April 2007, Vol.57(537), pp.283-9

^d Effects of Home-Based Primary Care on Medicare Costs in High-Risk Elders Eric De Jonge, K. ; Jamshed, Namirah ; Gilden, Daniel ; Kubisiak, Joanna ; Bruce, Stephanie R. ; Taler, George *Journal of the American Geriatrics Society*, October 2014, Vol.62(10), pp.1825-1831

^e Reilly S, Miranda-Castillo C, Malouf R, Hoe J, Toot S, Challis D, Orrell M. (2015) Case management approaches to home support for people with dementia. *Cochrane Database of Systematic Reviews* 2015, Issue 1. Art. No.: CD008345. DOI: 10.1002/14651858.CD008345.pub2, Vroomen Janet, M., Bosmans, J. E., Eekhout, I., Joling, K. J., van Mierlo, L., D., Meiland, F. J. M., . . . de Rooij, S., E. (2016). The cost-effectiveness of two forms of case management compared to a control group for persons with dementia and their informal caregivers from a societal perspective. *PLoS One*, 11(9) doi: <http://dx.doi.org/10.1371/journal.pone.0160908>

^f Note that individual studies included in these reviews may have formed part of the evidence base for the NICE guideline.