

References

- Alzheimer's Society (2020) *Worst Hit. Dementia during Coronavirus*. Available at <https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf> downloaded 24/4/21
- Birt, L., Griffiths, R., Charlesworth, G., Higgs, P., Orrell, M., Leung, P., and Poland, F. (2020). Maintaining Social Connections in Dementia: A Qualitative Synthesis. *Qualitative Health Research*, 30(1), 23–42. <https://doi.org/10.1177/1049732319874782>
- Borgstrom, E. (2017) Social Death *QJM: An International Journal of Medicine*, Vol 110:1 Pp 5–7, <https://doi.org/10.1093/qjmed/hcw183>
- Broady, T. R., Saich, F., and Hinton, T. (2018). Caring for a family member or friend with dementia at the end of life: A scoping review and implications for palliative care practice. *Palliative medicine*, 32(3), 643–656. <https://doi.org/10.1177/0269216317748844>
- Caddell, L.S. and Clare, L. (2010) The impact of dementia on self and identity: A systematic review. *Clinical Psychology Review* Vol 30. Pp 113-126 <https://doi.org/10.1016/j.cpr.2009.10.003>.
- Caddell, L. S., and Clare, L. (2011). I'm still the same person: The impact of early-stage dementia on identity. *Dementia*, 10(3), 379–398. <https://doi.org/10.1177/1471301211408255>
- Chapman, M., Philip, J. and Komesaroff, P. (2019) Towards an Ecology of Dementia: A Manifesto. *Bioethical Inquiry* 16, 209–216. <https://doi-org.hull.idm.oclc.org/10.1007/s11673-019-09910-8>
- Dröes, R.-M., Boelens-Van Der Knoop, E. C. C., Bos, J., Meihuizen, L., Ettema, T. P., Gerritsen, D. L., Hoogeveen, F., De Lange, J., & Schölzel-Dorenbos, C. J. M. (2006). Quality of life in dementia in perspective: An explorative study of variations in opinions among people with dementia and their professional caregivers, and in literature. *Dementia*, 5(4), 533–558. <https://doi.org/10.1177/1471301206069929>
- Gerrard, N. (2020) *What Dementia Teaches us About Love*. Milton Keynes: Penguin Random House
- Grobosch, S., Wolf, F., Juchems, S. and Kuske, S. (2020) Emotional safety of people living with dementia: a systematic review, *Journal of Mental Health*, DOI: [10.1080/09638237.2020.1739241](https://doi.org/10.1080/09638237.2020.1739241)
- Handley, M., Bunn, F. and Goodman, C. (2019) Supporting general hospital staff to provide dementia sensitive care: A realist evaluation in *International Journal of Nursing Studies*. Volume 96. 61-71
- Higgs, P. and Gillear, C. (2016) Interrogating personhood and dementia, *Aging & Mental Health*, 20:8, 773-780
- Hill, S. R., Mason, H., Poole, M., Vale, L. and Robinson, L.(2017) What is important at the end of life for people with dementia? The views of people with dementia and their carers. *International Journal Geriatric Psychiatry*, 32: 1037– 1045. doi: [10.1002/gps.4564](https://doi.org/10.1002/gps.4564).
- Huber, M., Knottnerus, J. A., Green, L., Horst, H., Jadad, A. R., Kromhout, D., Leonard, B., Lorig, K., Loureiro, M.I., van der Meer, J.W.M., Schnabel, P., Smith, R., van Weel, C. and Smid, H. (2011) How should we define health? *BMJ* 343 :d4163 doi:10.1136/bmj.d4163

- Kevern, P. (2017) *Why are we so afraid of dementia?* Web article available at <https://theconversation.com/why-are-we-so-afraid-of-dementia-83175> accessed 28/4/21
- Killick, J. and Craig, C. (2012) *Creativity and Communication in Persons with Dementia*, London: Jessica Kingsley
- Kitwood, T. (1997) *Dementia reconsidered: The person comes first*. Open University Press: Buckingham
- Lloyd, J., Patterson, T., and Muers, J. (2016). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia, 15*(6), 1534-1561.
<https://doi.org/10.1177/1471301214564792>
- Lopez, R. P., Rose, K. M., Kenney, L., Sanborn, V., & Davis, J. D. (2020). Managing Shame: A Grounded Theory of How Stigma Manifests in Families Living With Dementia. *Journal of the American Psychiatric Nurses Association, 26*(2), 181-188.
<https://doi.org/10.1177/1078390319832965>
- Malone, M.L. (2014) Acute care of people with dementia in the general hospital in
- Downs, M. and Bowers, B. (Eds) (2014) *Excellence in Dementia Care. Research into Practice. Second Edition.* Maidenhead:Open University Press pp315-330
- Moore, K.J., Davis, S., Gola, A., Harrington, J., Kupeli, N., Vickerstaff, V., King, M., Leavey, G., Nazareth, I., Jones, L. and Sampson. E.L.(2017) Experiences of end of life amongst family carers of people with advanced dementia: longitudinal cohort study with mixed methods. *BMC Geriatrics* 17, 135
<https://doi.org/10.1186/s12877-017-0523-3>
- Oliver, K. and Guss, R. (2019) 'The experience of dementia. Commentary' in Kitwood, T. and Brooker D. (Ed) (2019) *Dementia Reconsidered, Revisited. The Person Still Comes First. Second Edition.* London; Open University Press 97-102
- Sabat, S.R. (2014) A bio-psycho-social approach to dementia in Downs, M. and Bowers, B. (Eds) (2014) *Excellence in Dementia Care. Research into Practice. Second Edition.* Maidenhead:Open University Press pp 107-121
- O'Shaughnessy, M., Lee, K., and Lintern, T. (2010). Changes in the couple relationship in dementia care: Spouse carers' experiences. *Dementia, 9*(2), 237-258. <https://doi.org/10.1177/1471301209354021>
- O'Shea, E., Hopper, L., Marques, M., Gonçalves-Pereira, M., Woods, B., Jolley, H., Verhey, F., Kerpershoek, L., Wolfs, C., de Vugt, M., Stephan, A., Bieber, A., Meyer, G., Wimo, A., Michelet, M., Selbaek, G., Portolani, E., Zanetti, O., Irving K. & the Actifcare Consortium (2020) A comparison of self and proxy quality of life ratings for people with dementia and their carers: a European prospective cohort study, *Aging & Mental Health, 24*:1, 162-170, DOI: 10.1080/13607863.2018.1517727
- Surr, C. (2019) 'The Task of Cultural Transformation. Commentary' in In Kitwood, T. and Brooker D. (Ed) (2019) *Dementia Reconsidered, Revisited. The Person Still Comes First. Second Edition.* London; Open University Press. Pp170-177

van Wijngaarden, E., Alma, M., and The, A.M. (2019) '*The eyes of others' are what really matters*: The experience of living with dementia from an insider perspective. PLOS ONE 14(4): e0214724.

<https://doi.org/10.1371/journal.pone.0214724>

Wolverson, E.L., Clarke, C. and Moniz-Cook, E.D (2016) Living positively with dementia: a systematic review and synthesis of the qualitative literature, Aging & Mental Health, 20:7, 676-699, DOI: 10.1080/13607863.2015.1052777