

## References

- American Cancer Society. Communication. Retrieved from
  - <a href="https://www.cancer.org/treatment/caregivers/what-a-caregiver-does/communication.html">https://www.cancer.org/treatment/caregivers/what-a-caregiver-does/communication.html</a>
- American Heart Association. (2017, 7 Jun, 2017). Communication Tips For Caregivers. Retrieved from http://www.heart.org/HEARTORG/Support/Communication-Tips-For-Caregivers\_UCM\_301841\_Article.jsp#.Wv0gbEiFPct
- American Society of Clinical Oncology. (2017). Tips for Being a Successful Caregiver. Retrieved from https://www.cancer.net/coping-with-cancer/caring-loved-one/tips-being-successful-caregiver
- American Stoke Association. (2017). Caregiver Guide to Stroke. Retrieved from http://www.strokeassociation.org/idc/groups/stroke-public/@wcm/@hcm/@sta/documents/downloadable/ucm\_489454.pdf
- Australian Commission on Safety and Quality in Health Care. (2019). Australian Charter of Healthcare Rights (second edition). Retrieved from https://www.safetyandquality.gov.au/publications-and-resources/resource-library/australian-charter-healthcare-rights-second-edition-a4-accessible
- Australian Government Department of Social Services. (2010). Carer Recognition Act 2010 Guidelines. Retrieved from https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/carer-recognition-act-2010-guidelines
- Australian Government. (2017). Talking to health professionals. *Carer Gateway.* Retrieved from https://www.carergateway.gov.au/talking-to-health-professionals
- Berry, L. L., Dalwadi, S. M., & Jacobson, J. O. (2016). Supporting the Supporters: What Family Caregivers Need to Care for a Loved One With Cancer. *Journal of Oncology Practice, 13*, 35-41. doi:10.1200/JOP.2016.017913
- Better Health Channel. (2016). Assertiveness. Retrieved from https://www.betterhealth.vic.gov.au/health/healthyliving/assertiveness
- British Heart Foundation. (2018). Caring for someone with a heart condition. Retrieved from https://www.bhf.org.uk/publications/heart-conditions/caring-for-someone-with-a-heart-condition
- Burridge, L., Mitchell, G., Jiwa, M., & Girgis, A. (2017). Helping lay carers of people with advanced cancer and their GPs to talk: an exploration of Australian users' views of a simple carer health checklist. *Health & Social Care in the Community*, 25, 357-365. doi:10.1111/hsc.12312
- Canadian Cancer Society. If you're a caregiver. Retrieved from http://www.cancer.ca/en/cancer-information/cancer-journey/if-you-re-a-caregiver/?region=on#good
- Cancer Council Australia. (2017). Rights of carers. Retrieved from https://www.cancercouncil.com.au/cancer-information/when-you-are-first-diagnosed/cancer-care-and-your-rights/rights-of-carers/
- Capala, M. (2018). Global Search Engine Market Share for 2018 in the Top 15 GDP Nations. *Medium*. Retrieved from https://medium.com/@SearchDecoder/global-search-engine-market-share-for-2018-in-the-top-15-gdp-nations-2cf65c11e5f5
- Caregiver Action Network. How To Talk To Your Doctor. Retrieved from http://caregiveraction.org/resources/how-talk-your-doctor

- Carers NSW. Advice for carers: Speak up for yourself. Retrieved from http://www.carersnsw.org.au/advice/advocacy-rights-change
- Centre for Medical Psychology and Evidence-based Decision-making. (2008). Questions to ask a haematologist: Cancer Institute NSW.
- Centre for Medical Psychology and Evidence-based Decision-making. (2008). Questions to ask a medical or radiation oncologist: Cancer Institute NSW.
- Centre for Medical Psychology and Evidence-based Decision-making. (2008). Questions to ask a surgeon: Cancer Institute NSW.
- Chih, M. Y., DuBenske, L. L., Hawkins, R. P., Brown, R. L., Dinauer, S. K., Cleary, J. F., & Gustafson, D. H. (2013). Communicating advanced cancer patients' symptoms via the Internet: a pooled analysis of two randomized trials examining caregiver preparedness, physical burden, and negative mood. *Palliative Medicine*, *27*, 533-543. doi:https://dx.doi.org/10.1177/0269216312457213
- City of Hope. Caregiving for a Cancer Patient: Improving Communication. Retrieved from https://www.cityofhope.org/patients/living-with-cancer/caregiving-for-a-cancer-patient/improving-communication
- Clayton, J. M., Butow, P. N., Tattersall, M. H., Devine, R. J., Simpson, J. M., Aggarwal, G., . . . Noel, M. A. (2007). Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *Journal of Clinical Oncology*, 25, 715-723.
- Dionne-Odom, J. N., Azuero, A., Lyons, K. D., Hull, J. G., Tosteson, T., Li, Z., . . . Bakitas, M. A. (2015). Benefits of Early Versus Delayed Palliative Care to Informal Family Caregivers of Patients With Advanced Cancer: Outcomes From the ENABLE III Randomized Controlled Trial. *J Clin Oncol, 33*, 1446-1452. doi:10.1200/jco.2014.58.7824
- DuBenske, L. L., Gustafson, D. H., Namkoong, K., Hawkins, R. P., Atwood, A. K., Brown, R. L., . . . Cleary, J. F. (2014). CHESS improves cancer caregivers' burden and mood: Results of an eHealth RCT. *Health Psychology, 33*, 1261-1272. doi:http://dx.doi.org/10.1037/a0034216
- East Liverpool City Hospital. Caring for a Family Member in the Hospital. Retrieved from http://www.elch.org/Patients-Visitors/Patient-Right-to-Comfort/Caring-for-a-Family-Member-in-the-Hospital.aspx
- Family Caregiver Alliance. (2018). Communicating with Your Doctor. Retrieved from https://www.caregiver.org/communicating-your-doctor
- Gustafson, D. H., DuBenske, L. L., Atwood, A. K., Chih, M. Y., Johnson, R. A., McTavish, F., . . . Shah, D. (2017). Reducing Symptom Distress in Patients With Advanced Cancer Using an e-Alert System for Caregivers: Pooled Analysis of Two Randomized Clinical Trials. *Journal of Medical Internet Research*, 19, e354. doi:https://dx.doi.org/10.2196/jmir.7466
- Health Service Executive. (2017). Communicating effectively with Health Care Professionals. Retrieved from https://www.hse.ie/eng/services/list/3/carerssupport/communicating/
- Hebert, R. S., Schulz, R., Copeland, V. C., & Arnold, R. M. (2009). Pilot testing of a question prompt sheet to encourage family caregivers of cancer patients and physicians to discuss end-of-life issues. *American Journal of Hospice & Palliative Medicine*, 26, 24-32. doi:10.1177/1049909108324360
- Irish Cancer Society. (2016). Tips on giving medical care. Retrieved from https://www.cancer.ie/support/coping-with-cancer/caring-for-someone-with-cancer/medical-care#sthash.KPc8rFul.dpbs
- John Hopkins Medicine. Supporting a Spouse Through a Health Challenge. Retrieved from https://www.hopkinsmedicine.org/health/healthy\_aging/caregiver\_resources/supporting-a-spouse-through-a-health-challenge
- Laidsaar-Powell, R. C., Butow, P. N., Bu, S., Charles, C., Gafni, A., Lam, W. W., . . . Juraskova, I. (2013). Physician-patient-companion communication and decision-making: a systematic review of triadic medical consultations. *Patient Educ Couns*, *91*, 3-13. doi:10.1016/j.pec.2012.11.007

- Laidsaar-Powell, R., Butow, P., Boyle, F., & Juraskova, I. (2018). Managing challenging interactions with family caregivers in the cancer setting: Guidelines for clinicians (TRIO Guidelines-2). *Patient Educ Couns*, *101*, 983-994. doi:10.1016/j.pec.2018.01.020
- Laidsaar-Powell, R., Butow, P., Bu, S., Charles, C., Gafni, A., Fisher, A., & Juraskova, I. (2016). Family involvement in cancer treatment decision-making: A qualitative study of patient, family, and clinician attitudes and experiences. *Patient Educ Couns, 99,* 1146-1155. doi:10.1016/j.pec.2016.01.014
- Laidsaar-Powell, R., Butow, P., Bu, S., Dear, R., Fisher, A., Coll, J., & Juraskova, I. (2016). Exploring the communication of oncologists, patients and family members in cancer consultations: development and application of a coding system capturing family-relevant behaviours (KINcode). *Psychooncology*, *25*, 787-794. doi:10.1002/pon.4003
- Laidsaar-Powell, R., Butow, P., Bu, S., Fisher, A., & Juraskova, I. (2016). Attitudes and experiences of family involvement in cancer consultations: a qualitative exploration of patient and family member perspectives. *Support Care Cancer*, *24*, 4131-4140. doi:10.1007/s00520-016-3237-8
- Laidsaar-Powell, R., Butow, P., Bu, S., Fisher, A., & Juraskova, I. (2017). Oncologists' and oncology nurses' attitudes and practices towards family involvement in cancer consultations. *Eur J Cancer Care*, *26*, e12470. doi:10.1111/ecc.12470
- Leisa R. Easom. 10 Tips for Caregivers. Retrieved from http://www.rosalynncarter.org/10\_tips\_for\_caregivers/
- Lymphoma Canada. (2018). Tips for Caregivers. Retrieved from https://www.lymphoma.ca/lymphoma/caregiver-support/tips-caregivers
- Marshall, C. A., Badger, T. A., Curran, M. A., Koerner, S. S., Larkey, L. K., Weihs, K. L., . . . García, F. A. R. (2013). Un Abrazo Para La Familia: providing low-income Hispanics with education and skills in coping with breast cancer and caregiving. *Psycho-Oncology*, *22*, 470-474. doi:10.1002/pon.2108
- Moore, C. D. (2008). Enhancing health care communication skills: preliminary evaluation of a curriculum for family caregivers. *Home Health Care Services Quarterly, 27*, 21-35.
- Moore, C. D., & Cook, K. M. (2011). Promoting and Measuring Family Caregiver Self-Efficacy in Caregiver-Physician Interactions. *Social Work in Health Care, 50*, 801-814. doi:10.1080/00981389.2011.580835
- Move: Muscle bone & joint health. Tips for Carers Retrieved from https://www.move.org.au/page/carers
- National Cancer Institute. (2015). Family Caregivers in Cancer (PDQ®)—Patient Version. Retrieved from https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-pdq#section/all
- National Institute on Health and Aging. (2017). Doctor's Appointments: Tips for Caregivers. Retrieved from https://www.nia.nih.gov/health/doctors-appointments-tips-caregivers
- NSW Health. (2011). Walking with Carers. Retrieved from http://www.health.nsw.gov.au/carers/Publications/walking-with-carers-in-nsw.pdf
- Sin, J., Henderson, C., Spain, D., Cornelius, V., Chen, T., & Gillard, S. (2018). eHealth interventions for family carers of people with long term illness: A promising approach? *Clinical Psychology Review*. doi:https://doi.org/10.1016/j.cpr.2018.01.008
- Smith, P. D., Martin, B., Chewning, B., Hafez, S., Leege, E., Renken, J., & Smedley Ramos, R. (2016). Improving health care communication for caregivers: A pilot study. *Gerontology & Geriatrics Education*, 1-12. doi:10.1080/02701960.2016.1188810
- The Mark H. Zangmeister Cancer Centre. Communicating With Doctors. Retrieved from https://www.zangcenter.com/for-patients-families/caregivers-families/communicating-with-doctors/
- Wittenberg, E., Ferrell, B., Koczywas, M., Del Ferraro, C., & Ruel, N. H. (2017). Pilot Study of a Communication Coaching Telephone Intervention for Lung Cancer Caregivers. *Cancer Nursing.*, *27*. doi:http://dx.doi.org/10.1097/NCC.0000000000000535

- Wittenberg, E., Goldsmith, J., Ferrell, B., & Ragan, S. L. (2017). Promoting improved family caregiver health literacy: evaluation of caregiver communication resources. *Psycho-Oncology*, *26*, 935-942. doi:10.1002/pon.4117
- Wolff, J. L., Roter, D. L., Barron, J., Boyd, C. M., Leff, B., Finucane, T. E., . . . Gitlin, L. N. (2014). A Tool to Strengthen the Older Patient—Companion Partnership in Primary Care: Results from a Pilot Study. *J Am Geriatr Soc*, *62*, 312-319. doi:10.1111/jgs.12639