Effective integration of caregivers and families as part of the care team for people with cancer

CPD

Anna Ugalde, Natalie Winter, Ursula M Sansom-Daly, Joel Rhee, Hannah Jongebloed, Rebecca J Bergin, Patricia M Livingston

Background
Informal caregivers (family or friends of people with cancer) are a group of highly important people who support those diagnosed with cancer to remain at home and out of hospital, but this comes at a significant personal cost. Understanding strategies to support cancer caregivers is critical.

Objective
This article will present an overview of cancer caregiving and how the caregivers involved can be assisted by general practitioners (GPs). Two key approaches to general practice teams supporting caregivers will be explored: acknowledging and integrating caregivers as part of the care team and providing referrals into services and supports.

Discussion
The general practice team is ideally positioned to assist in the support of cancer caregivers. GPs can assist caregivers by acknowledging them as valid and important members of the care team and referring them into existing support programs. These strategies are central to supporting this important, but often forgotten, group of people affected by cancer.

ONE IN TWO men and one in three women will be diagnosed with cancer in their lifetimes, and there are more than one million cancer survivors in Australia.[1] The number of cancer survivors is expected to increase substantially over the next 20 years as a result of population-based screening programs, improved treatments and an ageing population.[1] Almost all (>90%) of people with cancer have an informal caregiver: a friend or family member supporting the patient with care provision across their disease and treatment[2] who is to be differentiated from formal, professional caregivers within the healthcare team. Informal caregivers (referred to as caregivers within this article) play a significant part in enabling community-based models of cancer care and survivorship, whereby patients manage much of their disease and treatment outside of clinical settings.[3] Caregivers are fundamental to healthcare in Australia, with a replacement value of $77.9 billion.[4]

Caregivers are a highly important group as they allow people diagnosed with cancer to remain at home and out of hospitals for longer than would have been possible without the caregivers' involvement. This comes at a significant personal cost, and caregiving roles can be long term as people are living for longer after cancer and managing survivorship-related side effects or have end-of-life care. Given this, understanding strategies to support cancer caregivers is critical.

This article will present an overview of cancer caregiving and how the caregivers involved can be assisted by general practitioners (GPs). Two key approaches to general practice teams supporting caregivers will be explored: providing referrals into existing services and supports, and acknowledging and integrating caregivers as part of the care team.

The lived experience of being a cancer caregiver

Despite their importance, caregivers receive little to no support in cancer care provision.[3,5] Their role is extremely demanding, often exceeding 40 hours of direct care per week.[6] It is common for caregivers to experience unmet needs,[7] and caregivers can experience higher levels of distress than patients.[8] A qualitative study on the caregiving experience showed it was so involved and consuming that caregivers felt unable to think about their own needs, with one person stating, 'I'm not focused on myself, I haven't had a think about everything. I don't allow myself the luxury of doing that'.[5] The extensive burden of the role means that unemployment, or reduced employment, social withdrawal and loneliness can be common.[9,10]

The role is complex and challenging, and consequently there are several potential sources of distress for caregivers. Caregivers can have high levels of worry for the person diagnosed with cancer and their health and medical outcomes. Their role can involve complex medical management including monitoring of symptoms and side effects, administering medications and medical decision making. They can be responsible for care coordination[3] including attendance at and travel to appointments, which can be a significant burden for families in rural or regional areas.[11] Caregivers have a significant role in communication with the broader family. They also often assume responsibility of all household tasks and related stressors, including financial burdens. Finally, impacts on quality of life, a lack of sleep, reduced time for themselves and impacts on their own relationships can contribute to caregivers' levels of burden and distress.[12] Given the experience of care provision, it is not surprising that cancer caregivers report high levels of anxiety, distress and burden.[13] However, it is also important to acknowledge that many caregivers are able to identify positive aspects to the role,[5] including allowing the person with cancer to remain home for longer and spending time together.

Caregivers are highly committed to providing care for their family member or friend with cancer, to the extent that they can be reluctant to leave the patient or engage in self-care activities.[14] However, caregivers can be segregated from the healthcare team rather than active participants.[15] Their own needs are not always considered by themselves or others; consequently, they may not ask questions or reach out for support.

Cancer caregiving is complicated by heterogeneity, both in patients' individual factors (age, premorbid health, functioning) and clinical experience (diagnosis, treatments, symptoms, side effects) and the caregivers' own factors. Caregivers often come into the role with pre-existing knowledge, skills, vulnerabilities and sources of resilience that may inform their experience and the extent to which they experience distress. Caregivers are also diverse in terms of the type of relationship they have with the care recipient; most commonly caregivers are spouses or children, but others are parents, extended family or friends. These relationships can vary as there may be family conflict or low cohesion as a couple.[16] It is also common to identify and categorise people as either the 'caregiver' or the 'person with a health problem or disability'.[17] However, this approach fails to acknowledge that both members of the dyad may have health problems that require each of them to perform care tasks for each other. The caregiving role typically emerges out of an existing relationship, such as a wife or husband, where care provision is a part of that established role, as described:

> *Giving care to someone is an extension of caring about that person. Looked at this way, caring and caregiving are intrinsic to any close relationship, that is, they are present in all relationships where people attempt to protect or enhance each others' wellbeing.*[18]

Further, although many support programs and academic literature focus on a single caregiver, who usually takes on the majority of care and support for the person with cancer, it is important to acknowledge that there could be a substantial network of caregivers who can be largely invisible to the healthcare team.[19] There may be conflict or competing priorities within this network.[20] Overall, cancer caregivers are a diverse and complex group.

Support for caregivers

In the Australian context, there are few opportunities and multiple barriers to engaging with family and caregivers to formally assess their needs. Acknowledgement and support for cancer as a family disease is routinely practised within the paediatric setting; however, there is less recognition of cancer as a family disease in the adult setting.[21] Current healthcare standards focus on the patient as the centre of care,[22] and at a national level there is little guidance for healthcare professionals to meet the needs of caregivers. Caregivers have described having to seek support for their own needs, including finding information, resources and community services to help in the home.[14] They can be reluctant to ask for help from clinicians as this takes time away from the person with cancer. Generally, caregiver distress is not managed: caregivers do not tend to seek help as they feel the focus should be on supporting the patient, and support is not routinely offered to caregivers in the outpatient setting.

The role of the general practice team

The general practice team – including GPs, practice nurses, allied health professionals and administrative staff – is ideally positioned to support cancer caregivers.[23] There are three key barriers to identifying and supporting caregivers in primary care.[24] First, taking on the care of another person is often gradual, and it is hard to recognise the commencement of caregiving.[5,24] Second, as the health of the person with cancer deteriorates, the caring role becomes all-encompassing and caregivers are unable to manage their own needs and supports.[5,24] Finally, there is ambiguity regarding the legitimacy of caregiver needs.[24] Health professionals have noted that caregivers can stand on the sidelines and be outsiders, with health professionals facing their own challenges to incorporate caregivers into the unit of care.[15]

There are two key ways in which GPs and others in the primary healthcare team can deliver support for caregivers. These are: 1) acknowledging and integrating caregivers as part of the care team and 2) providing referral into existing support services.

Acknowledging and integrating caregivers as part of the care team

As caregivers are not explicitly involved in the relationship between the patient and healthcare provider, they can be rarely invited to participate.[15] Given that the oncology team – including oncologists, hospital-based specialists, nurses and allied health professionals – can be focused on the patient's physical and mental health, the GP is someone who is well positioned to be able to check on the caregiver's physical and mental health. GPs can play an important part in acknowledging caregivers and integrating them into a care team where they otherwise may feel excluded and isolated. By definition, and when compared with care provided by specialists such as oncologists, GP care is accessible, comprehensive and provided by clinicians who are generalists, which suits the array of physical and psychological issues with which both cancer caregivers and people diagnosed with cancer may present. Caregivers often believe general practice teams are a good source of information about cancer.[25]

Acknowledgement and identification of the caregiving role is an important factor in enabling carers to access supports. This could be done through asking a person about their involvement in care provision, acknowledging the potential challenges associated with the role and empowering caregivers through legitimising their roles as a key member of the care team.

GPs are also in a position to promote self-management to both patients and caregivers, where self-management is defined as the individual's management and monitoring of their own health conditions, consequences of the health conditions and emotional responses.[26] Encouraging and empowering caregivers to consider and manage their own needs may be important in validating caregivers' concerns and distress and encouraging them to seek support. Caregivers report valuing when clinicians acknowledge their roles and address the competing priorities they may have in managing the care of the person with cancer.[27] Potentially, caregivers may have poor recognition or awareness of their caregiving role;[5] consequently, they may question their suitability for support programs. Similarly, it is important that all health professionals, including general practice teams, recognise that caregivers can have a poor understanding of the diagnosis and prognosis of the person with cancer.[25]

Communication between GPs and tertiary health services may not always be optimal, yet this serves an important purpose in information transfer and continuity of care.[28] This communication represents an opportunity to integrate caregivers into the care team through acknowledging their role, involvement and how they can be supported.

GPs have the potential to monitor and provide timely assessment and treatment for caregivers experiencing significant psychological distress including depression or anxiety. GPs could use an array of supports, such as the GP Mental Health Treatment Plan and referral for psychological treatments under the Better Access to Mental Health Care program. Some tertiary health services may also employ psychologists with experience in supporting both patients and caregivers. Overall, GPs are uniquely positioned to acknowledge and integrate caregivers into the care team.

Referral into support services

Several existing information and support services can be used to assist cancer caregivers. GP endorsement and referral to psychological or support services can result in higher uptake and engagement than if caregivers attempted to access these services themselves.[29] This may be especially important for caregivers who tend to neglect their own needs. An overview of key support services is presented in Box 1. Engagement with support services is likely to lead to improved carer outcomes through reducing worry and increasing carer knowledge and support.[30]

Information about cancer and accessing support are available through Cancer Council's 13 11 20 service. While this service varies across states/territories, this is a free, confidential telephone support service delivered by trained and experienced oncology health professionals. The Cancer Council website also has reputable publications and booklets that can be downloaded. One of these, *Caring for someone with cancer*, covers topics on practical advice for providing care and caring for yourself as a carer. In addition to receiving calls from people affected by cancer, Cancer Council's telephone service often fields questions from health professionals, including GPs, on how to best assist people affected by cancer. This service may be of use for general practice teams to gain information about local services, supports for caregivers or specific treatments.

For caregivers of patients receiving palliative care or people with advanced cancer, an Australian Government–funded program, the Advance Project (www.theadvanceproject.com.au), is available. This program supports general practices in providing more support for caregivers of patients with palliative care needs. This program includes a caregiver information and assessment toolkit, designed to assess the unmet healthcare needs of caregivers as well as provide strategies on how the general practice team can address and support caregivers.

Conclusion

The lived experience of caregiving and the burden associated with this role indicates that caregivers are a group in need of support, yet there are several barriers to integration with the healthcare team, and there is a potential to improve the recognition and support of caregivers. General practice teams are well placed to integrate caregivers into care teams and provide them with additional support. GPs can assist caregivers by acknowledging them as valid and important members of the care team and referring them into existing information and support services. These strategies may be central to addressing an important, but often forgotten, group of people affected by cancer.

Key points

- Almost all people with cancer have a friend or family member supporting them with care provision across their disease and treatment. This is a critically important role, but it comes at a cost to the physical and psychological wellbeing of the caregiver.

- The caregiving role is dynamic and complex, with several potential sources of distress for the caregiver.
- Current healthcare models focus on the patient, and there is a need for guidance as to how healthcare professionals can meet the needs of caregivers.
- General practitioners may be well placed to support caregivers. Two ways in which GPs can deliver support for caregivers include acknowledging and integrating caregivers as part of the care team and providing referrals into existing support services.

Box 1. Key information and support programs for cancer caregivers in Australia

- **Cancer Council Australia** (Cancer Council ACT; NSW; NT; Qld; SA; Tas; Vic and WA): The Cancer Council consists of eight members, representing each of the Australian states and territories. Each of these undertakes research, support and education and assists cancer caregivers with practical and support information. The Cancer Council also has a telephone support service (13 11 20) with trained oncology health professionals, and this service can help access other supports including counselling.
  - Website: www.cancer.org.au
- **Carers Australia** (Carers ACT; NSW; NT; Qld; SA; Tas; Vic and WA): Carers Australia consists of eight members, representing each of the Australian states and territories. Each member provides information on training, advocacy, avenues for accessing support and resources specific to supporting carers in their role.
  - Website: www.carersaustralia.com.au
- **Canteen Australia:** Canteen Australia is an Australian organisation that supports young people living with cancer. Canteen now provides significant peer and psychosocial support to parents and carers of young people aged 12–25 years living with cancer.
  - Website: www.canteen.org.au/resource/guide-canteen-parents-carers
- **MyAgedCare:** MyAgedCare is an Australian Government–funded service that supports older Australians and their carers and families in the form of ongoing support at home, short-term care and aged care homes. Respite is available for carers. Support is available to Australians that are aged ≥65 years (≥50 years for Aboriginal or Torres Strait Islander people) who have been diagnosed with a medical condition such as cancer, as well as their carers.
  - Website: www.myagedcare.gov.au
- **Commonwealth Home Support Programme** (CHSP): The CHSP provides access to entry-level services to support older Australians in living independently. Support is available to Australians aged ≥65 years (≥50 years for Aboriginal or Torres Strait Islander people). The CHSP focuses on working with individuals rather than doing things on their behalf and can provide respite for carers.
  - Website: www.myagedcare.gov.au/help-at-home/commonwealth-home-support-programme
- **Department of Human Services – Centrelink:** Cancer caregivers may be eligible for financial support via payments, allowances and pensions via Centrelink, including bereavement allowance, carer allowance, carer payment, carer supplement or carer adjustment payment.
  - Website: www.servicesaustralia.gov.au/individuals/centrelink
- **Palliative Care Australia** (Palliative Care ACT; NSW; NT; Qld; SA; Tas; Vic and WA): Palliative Care Australia consists of eight members, representing each of the Australian states and territories. Each of these assists cancer caregivers to access support and resources. PCA also provides the National Palliative Care Service Directory to assist in accessing local palliative care providers as well as training and fact sheets for carers.
  - Website: https://palliativecare.org.au
- **Psychologists and counsellors**
  - A 'Find a counsellor' search program is available through Cancer Counselling Professionals Australia (www.cancercounselling.com.au).
  - Cancer Council telephone support (13 11 20) can also assist in identifying local services.

Authors

Anna Ugalde BA (Hons), PhD, Senior Research Fellow, School of Nursing & Midwifery and Institute for Health Transformation, Deakin University, Geelong, Vic

Natalie Winter BNurs (Hons), PhD, Research Fellow, School of Nursing & Midwifery and Institute for Health Transformation, Deakin University, Geelong, Vic

Ursula M Sansom-Daly BPsych (Hons), MPsychol (Clin), PhD, Senior Research Fellow, School of Women's and Children's Health, UNSW Medicine, University of New South Wales, Randwick, NSW; Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital, Sydney, NSW; Sydney Youth Cancer Service, Nelune Comprehensive Cancer Centre, Prince of Wales Hospital, Randwick, NSW

Joel Rhee BSc (Med), MBBS (Hons), GCULT, PhD, FRACGP, Associate Professor of General Practice, General Practice Academic Unit, School of Medicine, Faculty of Science, Medicine and Health, University of Wollongong, Wollongong, NSW; Illawarra Health and Medical Research Institute, Wollongong, NSW; General Practitioner, HammondCare Centre for Positive Ageing and Care, Hammondville, NSW

Hannah Jongebloed BCrim/BPsychSci, GDipPsych, Research Assistant, School of Nursing & Midwifery and Institute for Health Transformation, Deakin University, Geelong, Vic

Rebecca J Bergin BA&Sc (Hons), PhD, Research Fellow, Cancer Epidemiology Division, Cancer Council Victoria, Melbourne, Vic; Department of General Practice/Centre for Cancer Research, University of Melbourne, Melbourne, Vic

Patricia M Livingston BA (Hons), PhD, Associate Dean – Research, School of Nursing & Midwifery and Institute for Health Transformation, Deakin University, Geelong, Vic

Competing interests: JR is a member of the *Australian Journal of General Practice* Editorial Advisory Committee.

Funding: AU is funded with a Victorian Cancer Agency Early Career Health Services Research Fellowship.

Provenance and peer review: Commissioned, externally peer reviewed.

Correspondence to:
a.ugalde@deakin.edu.au

References

1. Australian Institute of Health and Welfare. Cancer in Australia 2017. Cancer series no. 101. Cat. no. CAN 100. Canberra, ACT: AIHW, 2017.
2. Ugalde A, Krishnasamy M, Schofield P. Development of an instrument to measure self-efficacy in caregivers of people with advanced cancer. Psychooncology 2013;22(6):1428–34. doi: 10.1002/pon.3160.
3. Olson RE. Is cancer care dependant on informal carers? Aust Health Rev 2012;36(3):254–57. doi: 10.1071/AH11086.
4. Carers Australia, Deloitte Access Economics. The value of informal care in 2020. Canberra, ACT: Deloitte Access Economics, 2020.
5. Ugalde A, Krishnasamy M, Schofield P. Role recognition and changes to self-identity in family caregivers of people with advanced cancer: A qualitative study. Support Care Cancer 2012;20(6):1175–81. doi: 10.1007/s00520-011-1194-9.
6. Wolff JL, Dy SM, Frick KD, Kasper JD. End-of-life care: Findings from a national survey of informal caregivers. Arch Intern Med 2007;167(1):40–46. doi: 10.1001/archinte.167.1.40.
7. Heckel L, Fennell K, Reynolds J, et al. Unmet needs and depression among carers of

people newly diagnosed with cancer. Eur J Cancer 2015;51(14):2049–57. doi: 10.1016/j.ejca.2015.06.129.

8. Chambers S, Girgis A, Occhipinti S, et al. Psychological distress and unmet supportive care needs in cancer patients and carers who contact cancer helplines. Eur J Cancer Care (Engl) 2012;21(2):213–23. doi: 10.1111/j.1365-2354.2011.01288.x.
9. de Moor JS, Dowling EC, Ekwueme DU, et al. Employment implications of informal cancer caregiving. J Cancer Surviv 2017;11(1):48–57. doi: 10.1007/s11764-016-0560-5.
10. Gray TF, Azizoddin DR, Nersesian PV. Loneliness among cancer caregivers: A narrative review. Palliat Support Care 2020;18(3):359–67. doi: 10.1017/S1478951519000804.
11. Ugalde A, Blaschke S, Boltong A, et al. Understanding rural caregivers' experiences of cancer care when accessing metropolitan cancer services: A qualitative study. BMJ Open 2019;9(7):e028315.
12. Geng HM, Chuang DM, Yang F, et al. Prevalence and determinants of depression in caregivers of cancer patients: A systematic review and meta-analysis. Medicine (Baltimore) 2018;97(39):e11863.
13. Ugalde A, Krishnasamy M, Schofield P. The relationship between self-efficacy and anxiety and general distress in caregivers of people with advanced cancer. J Palliat Med 2014;17(8):939–41. doi: 10.1089/jpm.2013.0338.
14. Heynsbergh N, Botti M, Heckel L, Livingston PM. Caring for the person with cancer and the role of digital technology in supporting carers. Support Care Cancer 2019;27(6):2203–09. doi: 10.1007/s00520-018-4503-8.
15. Ekstedt M, Stenberg U, Olsson M, Ruland CM. Health care professionals' perspectives of the experiences of family caregivers during in-patient cancer care. J Fam Nurs 2014;20(4):462–86. doi: 10.1177/1074840714556179.
16. Siminoff LA, Wilson-Genderson M, Baker Jr S. Depressive symptoms in lung cancer patients and their family caregivers and the influence of family environment. Psychooncology 2010;19(12):1285–93. doi: 10.1002/pon.1696.
17. Torgé CJ. Using conjoint interviews with couples that have been living with disabilities and illnesses for a long time: Implications and insights. Qualitative Studies 2013;4(2):100–13.
18. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: An overview of concepts and their measures. Gerontologist 1990;30(5):583–94. doi: 10.1093/geront/30.5.583.
19. Burns CM, Abernethy AP, Dal Grande E, Currow DC. Uncovering an invisible network of direct caregivers at the end of life: A population study. Palliat Med 2013;27(7):608–15. doi: 10.1177/0269216313483664.
20. Laidsaar-Powell R, Butow P, Boyle F, Juraskova I. Managing challenging interactions with family caregivers in the cancer setting: Guidelines for clinicians (TRIO Guidelines-2). Patient Educ Couns 2018;101(6):983–94. doi: 10.1016/j.pec.2018.01.020.
21. Coyne E, Grafton E, Reid A, Marshall A. Understanding family assessment in the Australian context; what are adult oncology nursing practices? Collegian 2017;24(2):175–82.
22. Australian Commission on Safety and Quality in Health Care. Partnering with consumers Standard. Sydney, NSW: ACSQSH, 2019. Available at www.safetyandquality.gov.au/standards/nsqhs-standards/partnering-consumers-standard [Accessed 25 May 2021].
23. Rubin G, Berendsen A, Crawford SM, et al. The expanding role of primary care in cancer control. Lancet Oncol 2015;16(12):1231–72. doi: 10.1016/S1470-2045(15)00205-3.
24. Carduff E, Finucane A, Kendall M, et al. Understanding the barriers to identifying carers of people with advanced illness in primary care: Triangulating three data sources. BMC Fam Pract 2014;15:48. doi: 10.1186/1471-2296-15-48.
25. Burns CM, Dixon T, Broom D, Smith WT, Craft PS. Family caregiver knowledge of treatment intent in a longitudinal study of patients with advanced cancer. Support Care Cancer 2003;11(10):629–37. doi: 10.1007/s00520-003-0501-5.
26. Howell D, Mayer DK, Fielding R, et al. Management of cancer and health after the clinic visit: A call to action for self-management in cancer care. J Natl Cancer Inst 2021;113(5):523–31. doi: 10.1093/jnci/djaa083.
27. Washington KT, Craig KW, Parker Oliver D, et al. Family caregivers' perspectives on communication with cancer care providers. J Psychosoc Oncol 2019;37(6):777–90. doi: 10.1080/07347332.2019.1624674.
28. Kripalani S, LeFevre F, Phillips CO, Williams MV, Basaviah P, Baker DW. Deficits in communication and information transfer between hospital-based and primary care physicians: Implications for patient safety and continuity of care. JAMA 2007;297(8):831–41. doi: 10.1001/jama.297.8.831.
29. Frey Nascimento A, Tondorf T, Rothschild SI, et al. Oncologist recommendation matters! Predictors of psycho-oncological service uptake in oncology outpatients. Psychooncology 2019;28(2):351–57. doi: 10.1002/pon.4948.
30. Boltong A, Ledwick M, Babb K, Sutton C, Ugalde A. Exploring the rationale, experience and impact of using Cancer Information and Support (CIS) services: An international qualitative study. Support Care Cancer 2017;25(4):1221–28. doi: 10.1007/s00520-016-3513-7.

correspondence **ajgp@racgp.org.au**