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Extending care to women lay carers

Women represent 71% of the 474 600 primary lay carers in Australia. It is well documented that providing care for family members with a life threatening illness places a strain on the health and emotional wellbeing of the carer. Lay carers are rarely attentive to their own health needs due to lack of time and energy, and owing to feelings of guilt, they are unlikely to seek medical attention for preventive health concerns. This article presents four case studies that illustrate the tragic consequences of delayed review for self detected breast lumps which were proven to be breast cancer.

Case study 1

A woman, 53 years of age, found a self detected breast lump during the period she was caring for her husband (who had a terminal malignant condition). She had previously had biennial screening mammograms conducted, but at the time of noticing the lump her mammogram was 5 months overdue. Following the death of her husband she sought advice from her general practitioner regarding the breast lump. She was referred directly to the specialist centre, where the diagnosis of breast cancer was made. At the time of diagnosis and treatment, the cancer was stage 2A (>2 cm in maximal diameter without ipsilateral axillary lymph node involvement).

Case study 2

A woman, 59 years of age, found a self detected breast lump during the period she was caring for her husband (who had a terminal malignant condition). Following the death of her husband she sought medical advice; at that stage the lump had been present for 8 months. Her GP noted a further breast lump in the contralateral breast. She was referred directly to a specialist centre where she was diagnosed as having bilateral breast cancers; both were stage 3B (>5 cm in maximal diameter with ipsilateral axillary lymph node involvement).

Case study 3

A woman, 66 years of age, found a self detected breast lump during the period she was caring for her husband (who had a terminal nonmalignant condition). Previously she had also cared for her adult child and had subsequently become the guardian for her young grandchild. Following the death of her husband, she sought advice from her GP; at that stage the lump had been present for 4 months. She was referred to the specialist centre where a diagnosis of breast cancer was made. Further investigations were conducted which unfortunately revealed evidence of widely disseminated metastases; stage 4 breast cancer.

Case study 4

A woman, 43 years of age (and mother of teenage children), developed increasing back pain while caring for her husband (who had a terminal malignant condition). Following the death of her husband she sought medical advice. Her pain did not respond to rest, massage, heat, simple analgesics, weak opioid analgesia, or antispasmodic agents. She was referred to a regional specialist centre, where on presentation she was noted to have a large palpable breast mass, which was proven to be cancer on biopsy. Further investigations were conducted which unfortunately revealed evidence of widely disseminated metastases including multiple vertebral metastases; stage 4 breast cancer (*Figure 1a, b*).

Discussion

Breast cancer is the most commonly diagnosed malignancy in Australian women, affecting one in 11 women. Early detection (as well as multimodality treatment) of breast cancer has contributed to a reduction in mortality, although breast cancer remains the most common cause of malignancy related death in Australian women.¹ Women with breast cancers detected on mammography may have a more favourable prognosis when compared to those with breast cancers detected outside of screening programs (including breast cancers of equivalent stage). This may be in part due to the screening detected cancers having more favourable biological and histological features.² Despite recent criticism within the lay press, population based screening using mammography remains the best method available for the early detection of breast cancer.³



Figure 1a. CT scan in cross section revealing widespread destructive lytic metastases within the vertebrae

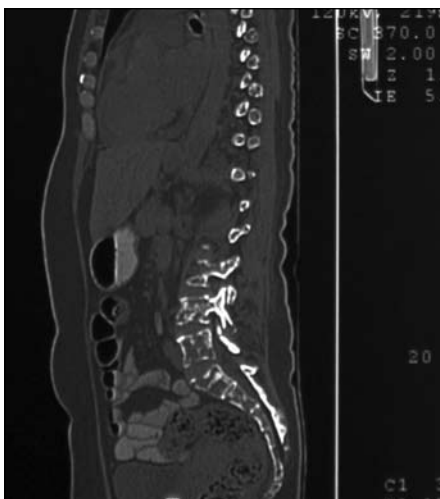


Figure 1b. CT scan in sagittal section revealing widespread destructive lytic metastases within the vertebrae

Women (partners, mothers and daughters) represent 71% of the 474 600 primary lay carers in Australia.⁴ The majority includes women within the target age group who are at risk of developing breast cancer. It has been well documented that providing care for a family member with a life threatening illness places strain on the health and wellbeing of the carer. Much of the literature has focused on the emotional and financial stress, the relatively high incidence of anxiety and depression, and the physical strain caused by tasks such as lifting.^{4,5} It is acknowledged that lay carers are rarely attentive to their own health needs due to lack of time or energy, or owing to feelings of guilt over redirecting attention and resources away from the family member with the life threatening illness.⁶ Additionally, lay carers are noted to be willing to absorb low grade ill health, and rarely engage in preventive medical care. One small study documented that care giving is an independent risk factor for mortality (even after adjusting for sociodemographic factors and physical health status).⁷

As the family member's disease progresses and the need for care increases, the carer is likely to withdraw from employment and leisure pursuits thereby reducing their opportunity for social contact other than with the health professionals assisting them with the care.⁸ General practitioners are well placed as a first point of contact as well as offering longitudinal care for many of the health care needs for both the 'patient' and the carer.

Over time, the GP can foster a relationship with the carer which enables an assessment of the carer's preparedness, involvement of extended family and social supports, as well as serial review of the carer's physical and mental health and self care actions.^{9,10} Qualitative research has documented one of the main barriers to this relationship to be time constraints, noted by both GPs and lay carers alike.¹¹ Furthermore, GPs have noted that private consultations with carers tends to focus either on the carers' needs in relation to the care giving process or solely on the needs of the loved one for whom they are caring.¹⁰

Conclusion

In the case studies presented, none of the women had pre-existing health problems or

a family history of cancer (including breast cancer). They did not attend their GP on a regular basis for personal health checks; three of the 4 women had not had regular biennial screening mammograms, and the fourth had delayed her regular screening mammogram. All deferred seeking medical advice for diagnosis and treatment until a later time, with tragic consequences for families already grieving the loss of one family member.

These four women had regular contact with health professionals (including community nurses, GPs, and specialists) who were caring for and advising on their husband's case. Perhaps this article can serve as a reminder that as health professionals, it often falls to the GP to actively reserve time for the lay carer in order to encourage them to openly discuss their needs (including preventive health needs) and that the lay carer should be encouraged to extend the care to themselves as well.

Conflict of interest: none declared.

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