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Caring for someone dying at home

Abstract

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Keywords

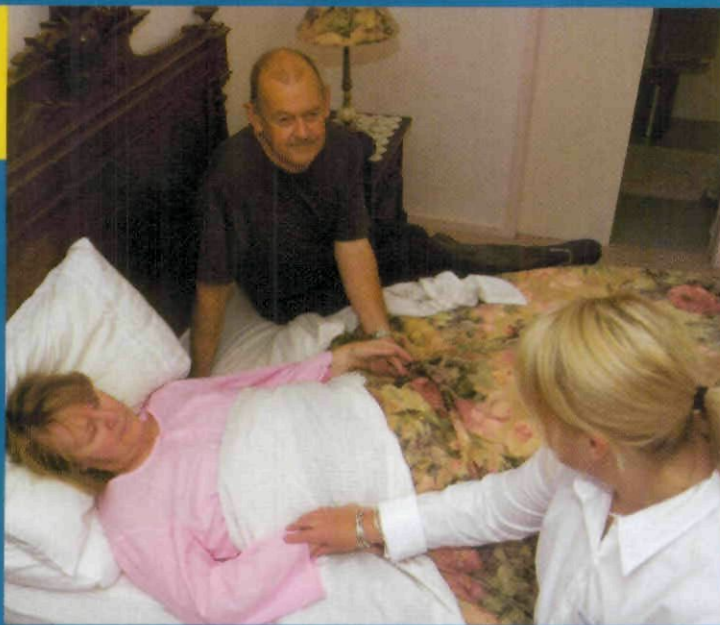
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'To die at home offers a meaningful way of living for the person dying, their family and friends.'

Assisting those caring for a terminally ill family member at home can be a rewarding but challenging nursing experience. Providing adequate nursing support is critical to the success of this type of caring.

By Sharon Bourgeois and Amanda Johnson

Increasingly, people with end-stage and chronic diseases are being cared for by family members in their own homes.^{1,2,3} Family members have assumed or had forced on them the primary caregiver role because of changes in health care funding and an ageing population, coupled with an increased incidence of terminal disease.⁴

In recognising the role caregivers undertake and to make this role achievable, nurses must acknowledge that providing quality care requires extensive input from them as health professionals. For nurses working with family caregivers, this can be both a worthwhile and challenging experience. It means focusing on understanding the family, caregiver roles, and the information and support the family will require in the palliative context.⁴

To die at home offers a meaningful way of living for the person dying, their family and friends.^{5,6} This can be achieved through sharing time, space, relationships and memories. Family-based caregiving has the potential to draw families together, to promote positive feelings that arise from meeting difficult challenges and from a feeling of satisfaction, even within a framework of impending loss.⁷ Sharing experiences during the dying process creates a sense of community, empowering all the participants involved with the person dying.³ Caring for someone dying is an active process.

It offers caregivers the opportunity to create some meaning out of chaotic events.^{5,8} Family and friends often express a desire to be involved in caring for the person dying. Coupled with this is the wish of the one dying to stay in their home environment. Thus, in part, the care provided by family members fulfils a deficit in the health care system.⁹

However, in assuming the primary caregiver role, family members often have minimal understanding of the person's diagnosis, treatment regime or future care needs. Additionally, family and friends often have little knowledge of how the health system works. Consequently they are limited in their ability to access community resources and services to support care activities in the home.¹⁰ The caregiver, as a co-user of services, is often co-opted to assume a nursing role through participating in complex and technical tasks and delivering skilled nursing care.³

Nurses fulfil an essential role in supporting families to care for the person dying at home. The nurse engaging with the family must recognise that each family is unique and has individual care needs.² The well-being of the person dying is profoundly affected by the quality of any informal care they receive,¹¹ and, in order for family to provide quality care, nurses must provide adequate support.^{3,9}

The complex nature of the care required im-

CARING FOR

poses an enormous burden on caregivers. Minimal acknowledgement is given to the scope of care required,^{11,12} which, delivered either alongside or in the nurse's absence, can be anywhere along the caring continuum. Care can range from essential needs such as bathing, to more complex care such as administering treatments.¹³ In addition, the impact of providing and sustaining care in the home is both complex and multidimensional.⁵ Being able to sustain caregiving becomes far more difficult if the person's illness becomes protracted. Family and friends may suffer fatigue, isolation and stress. Pivotal to providing optimum care is the role and responsibility undertaken by the nurse to assess and intervene as necessary. The nurse, then, has a unique opportunity to promote a palliative care environment for the person dying and their family, throughout the illness trajectory.^{14,15}

This article explores some of the challenges nurses and families face when caring for someone dying at home. The two exemplars on page 13 illustrate the life experiences of one of the authors, Sharon Bourgeois, who undertook a care-giving role for her dying mother in a small New Zealand country town. Drawn from unpublished data from 2000, the exemplars outline the family's perceptions of their ability to care, the nature of the care provided and the assistance given by the attending nurse.

The first exemplar, "Having to make do!" raises the challenges the nurse and family faced when accessing physical devices for providing optimal care. While some resources were eventually sourced, the family experienced a lot of frustration due to the slowness of their arrival. The family was forced to become innovative in order to meet the challenges of everyday living care until nurses were able to intervene.

In order to access equipment, nurses must be proactive and political. They must be able to advocate for a fair share of the health budget to ensure resourcing meets community needs. This suggests that nurses need to be more active as political lobbyists, or at least be able to advocate for the redirection of these resources to the community. In this exemplar, earlier intervention to provide physical resources would have assisted both the caregivers and the person dying.

The adjuncts to care that nurses can provide make life easier for caregivers and allow them to feel in control.¹⁶ The nurse's role as a coordinator of resources is essential and assists

R SOMEONE DYING AT HOME

HAVING TO MAKE DO!

In order to care for Mum at home, I only needed to ask the nurses and they gave us as much help as they could. However, the lack of available equipment became a real issue. It appeared there was very little equipment in the "pool", possibly because of the number of patients being cared for at home at that time.

Another issue was the lack of funding available to support these nurses. Early on in our care routine, we had asked for a wheel chair to take Mum to the toilet. This chair only became available the day before she died. We made good use of it, though, and wheeled her outside to see the double yellow daffodils and her first tulip in flower for the year. Until its arrival, we used a borrowed office chair with wheels. We would help Mum to stand, then swivel the chair behind her. One sister would push, another would carry her legs and another would carry the oxygen. For almost two weeks, this is how we moved Mum around the house, to the shower, out-

side onto the veranda for a change of scenery or up to the table, because she really did not have the "puff" to walk anywhere. The arrival of the wheel chair took a lot of pressure off our backs, plus there were leg supports for Mum. We found a way of supporting the oxygen cylinder through the use of a large hook placed on the back of the chair. This we found among Dad's fishing gear in the garage.

To shower Mum, we first tried an outside plastic BBQ chair without sides, but that took up too much room. Then the nursing team brought us a shower chair with sides that made showering Mum so much easier. In addition, we had organised for the local plumber to come to the house to change the shower fitting, but he never turned up, even though he promised continually that he would. In the end we used a jug as an adjunct to the shower attachment to upend over Mum when we were rinsing her. While not perfect, it worked very well. ●

caregivers to provide complex and technical care for the person dying at home. Nurses need to be able to access not just physical resources, however. They also need to know how community agencies, support groups and community mechanisms function. Timely access to resources is essential in order to support families adequately.

The next exemplar, "To beg, borrow and steal", demonstrates the lengths nurses will go to ensure the needs of both the person dying and the family are met. The nurse's commitment demonstrates a capacity to embrace palliative care principles within their everyday practice. The perceived benefits for the person dying and their family ensure that a holistic approach to care is taken.

Several pertinent issues associated with the availability of resources for caregivers are evident in this exemplar. Firstly, nurses need to be aware how communities operate, where resources can be acquired and how to get them. Knowing this information opens up a vast avenue of resources that can be made available to caregivers. Nurses who know their communities well can establish a network of contacts that helps get the needed resources. These contacts can further support caregivers by provid-

ing them with good information and timely resources.¹⁷

Families approach caring in different ways. Caregivers need to be supported in a non-judgemental manner in order to facilitate family decision making. For example, for the family in the second exemplar, it was important the

hospital bed was set up in the lounge rather than the bedroom. Family wishes often dictate the nature of these caring moments. Sensitivity to these actions enhances the collaborative relationships between the nurse, the caregiver and the person dying.

Examining the nurse's role

The exemplars enable the role of the nurse in relation to the family caregiver in a palliative care context to be examined. The retelling of one of the authors' personal experiences highlights the need for an improved understanding of what the family caregiver and the nurses' roles are in relation to the person dying at home. The exemplars also display the difficulties associated with implementing a palliative care philosophy in the home setting, due to the complexity and individuality of the care situation.

Integral to providing care to the person dying and their family is the need for nurses to be able to listen and respond to the needs expressed.¹⁸ Understanding that these needs are unique to each family is paramount, if the nurse is to plan individually tailored care. Nurses must be aware of differing family needs and be able to ensure the safety and well-being of both the person dying and her/his caregivers.⁴

The role of family caregiver is either determined by choice or forced upon them by circumstance. Nurses must recognise that, during the illness trajectory, however altruistic the caregiver may initially have been, they may also experience

TO BEG, BORROW AND STEAL

Mum was not fully conscious on the morning of her final day but she was able to be roused throughout most of the day. When the district nurse came, I asked for a hospital bed to make it easier for us to care for Mum, as she was no longer able to go to the shower and found it extremely difficult to move her limbs.

To access the hospital bed, we needed to contact a man in town who had the key to the ambulance hall. We arranged for a trailer and, with the help of family and friends, transported the hospital bed to the house. We positioned it in the lounge next to Mum's chair and made up the bed.

I had asked the district nurse that morning if she could come back to help lift Mum into

the bed. I was worried my sisters would hurt themselves, as they had no training in lifting someone from a chair to a bed. It was fortunate the district nurse had a student on placement with her. With their help, mine and that of one of my sisters, we could manage this task.

The district nurse also brought with her a special mattress to provide comfort and to avoid pressure. This meant we had to remake the bed; however we valued the new resource as it showed the nurses were really caring about Mum too and thinking of the little things that would help her at this difficult time. Apparently they had to beg, borrow and steal to get that mattress. ●

'NURSES MUST ALSO BE ABLE TO ASSESS WHEN THE CAREGIVER ROLE IS NO LONGER THERAPEUTIC.'



'Nurses may need to assume a greater caregiving role in order to promote the caregiver's well-being.'

times of negativity towards the role.¹⁸ The amount and type of care delivered by family caregivers is determined by the disease process, which is not static.⁴

Family involvement in care is central to the palliative care philosophy. However, nurses must also be able to assess when the caregiver role is no longer therapeutic.¹⁸ At this juncture, nurses may need to assume a greater caregiving role in order to promote the caregiver's well-being. Part of nurses' ongoing assessment of family caregivers is determining the nature and timing of the information and support required.⁴ This must be based on an understanding that each family caregiver is unique.⁴ Several authors have attempted to

qualify what constitutes and determines the kind of support family caregivers need.^{6,7,19} The nature and degree of information and support nurses offer is enhanced when decisions affecting the person dying, the caregiver and the nurse are made collaboratively.

Typically, the support provided to someone dying at home focuses on information needs, patient comfort, practical care and emotional support. Support can be as simple as activities of daily living, financial support, transport, meal preparation and housekeeping assistance.^{6,7,19} While caregivers themselves confirm they want their needs to be individually tailored, they centre on information and advice, practical assistance, emotional support, respite, and access to financial support.³ The continuum of care may consist of as little as companionship through to the provision of complex nursing tasks.⁴

Assessing bereavement needs

Through providing information and support to the family caregiver, nurses are in an ideal position to assess their bereavement needs.²⁰ Achieving a "healthy" grief reaction for the family caregiver is a pivotal component of the work nurses undertake in this setting.⁴ Nurses are privileged to support the family caregiver through the transition to a new beginning.²⁰ Research that determines the needs of family caregivers when caring for the person dying at home within a cultural context is important. Research of this nature will provide the opportunity for family caregivers to shape future health policy and funding arrangements so that

services not only meet the needs of health professionals, but are equally responsive to the needs of the family caregiver. The exemplars provide some insights into the benefits, frustrations and burdens that family caregivers can encounter.

Conclusion

Nurses act as conduits between health care facilities, community resources and families to promote "healthy" dying at home. The challenge for nurses is to ensure that care is adequately co-ordinated and that caregivers are well supported in the home. The nature of the supportive strategies provided are complex and wide ranging, encompassing the practical, physical, emotional and spiritual dimensions of care. Nurses are essential in making available this support to facilitate the provision of complex and quality care for the person dying. Home care nursing is reliant upon nurses who know their communities, can access resources in a timely fashion and who can advocate for the needs of caregivers and those they care for during the final phase of their lives. •

This article was reviewed by Kai Tiaki Nursing New Zealand's editorial review committee in October 2005.

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