# Teaching end-of-life care in the home

**Sandy Buchman** MD CCFP FCFP **Marnie Howe** MD CCFP

Family medicine teachers have a responsibility to prepare students to provide skilled, humane, and compassionate care. Caring for people at home, from the disabled to the frail elderly along the continuum to the end of life, together with their families, is a core professional task of family physicians. Thus, home-based care becomes an essential component of that task, especially with our aging population and more Canadians choosing to die at home.[1] The role of the family doctor is to provide lifelong continuous care across multiple settings. It is thus imperative that we conduct house calls. The benefits of keeping patients in their homes have been widely documented, from saving on the high cost of hospital admission to patients' improved general well-being.[2]

Unfortunately, teaching care in the home environment is uncommon in undergraduate medical education.[3,4] The home is an outstanding setting for education of medical students, providing wonderful opportunities to enrich students' appreciation of the patient-physician relationship; of interdisciplinary care; and of the challenging biomedical, psychosocial, and spiritual aspects of care. Physician educators get the chance to show students what it really means to be a family physician.

## Why teach home-based care?

In general, patients with terminal illnesses choose to remain at home. Many choose to die at home. Although the absolute number of physicians performing house calls has dropped dramatically since the 1950s, the National Physician Survey has revealed a trend of increasing home visits across Canada, likely reflecting increasing home care needs—not surprisingly, 100% of such visits were performed by general practitioners or family physicians.[5] In Ontario, where the provincial government has instituted the Aging at Home Strategy, home care is the fastest-growing sector of health care provision. There are approximately 1.5 million seniors in Ontario, and this number is estimated to double by 2028. As the population ages, home care demands will grow exponentially.

Learners are more willing to perform home visits and feel more prepared to do so when they have had adequate training.[6,7] There are no developed standards for undergraduate medical education or residency programs to teach home-based care. The National Physician Survey also found that fewer younger physicians offered home visits compared with older practising physicians.[5]

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Providing a home visit to a housebound patient, who can only be transported by ambulance, prevents the unnecessary stress for the patient of going to the emergency department or office. It has been suggested that nearly half of emergency department visits could be prevented by home visits.[2] Home visits have also been shown to keep people out of institutions when performed following hospital admission. Additionally, they provide guidance and support to caregivers, which can help prevent burnout.

## Unique differences in the home setting

***Power differentials.*** The relationships a family doctor has with his or her patients are the essence of family medicine, and these relationships are highlighted in home visits, where you are essentially a guest in your patients' homes. There is a shift in the power differential. Home visits provide opportunities to see your patients in their own environments and experience their usual demeanour. It is crucial for learners to appreciate how different environments can transform relationships and for them to understand the power differential.

There might be situations in which the physician feels vulnerable, entering unfamiliar territory. No 2 days are the same with home visits, and although personal safety is not often a concern, it is important to keep it in mind and take appropriate precautions. Trust your instincts and leave if you feel uncomfortable in any way. As part of their training, learners should be made aware of basic safety issues, such as police contact information and "no go" areas at night.

### *What can be taught most effectively through home-based teaching?*

*Greater emphasis on quality of life (QOL):* Patients' evaluations of QOL are now being used more frequently in practice and clinical trials, in addition to traditional biomedical parameters such as mortality and survival. Patient evaluations of QOL are useful in identifying treatment modifications, aiding decision making, and reflecting on patient perspectives. Medical students and physicians recognize QOL to be important, but few feel comfortable assessing QOL in practice.[8] Medical school curriculums should emphasize the importance of QOL and introduce validated tools for measuring it. Quality of life is a central reason for remaining at home, making the home an ideal teaching environment.

*Focus on patient-centred care:* Each patient has a unique story and set of circumstances for why he or she is being treated at home, and the patient's specific goals of care need to be explored. The home provides a unique

environment for decision making, where options are discussed among patient, physician, and often family members. Physicians will treat within the limits of the home, based on patient decisions.

*Deeper appreciation of patient and family illness experiences:* Seeing patient's neighbourhood, home, bedroom, and kitchen, students see the patient more fully. Personal possessions and religious and cultural icons help physicians understand patient values and assist in the psychosocial and spiritual components of care. The home reveals an important life story that might be invisible in the clinical setting.[4]

*Management of seriously ill patients using a low level of technology:* In the home, physicians must go back to basics; their history and physical examination skills are crucial to developing differential diagnoses and treatment plans. Blood tests and imaging are not simple in the home, and transfer might not be in accordance with the patient's wishes. Clinical judgment is enhanced in the absence of automatic tests.

*Psychological and spiritual support at the end of life:* Medical students understand the importance of discussing end-of-life issues with their patients, but believe they receive inadequate training in this area and welcome enhanced education.[9] During home visits, learners have the unique opportunity to experience the value of providing compassionate care to dying patients and their families.[10]

*Role in an interdisciplinary and collaborative care setting:* As in hospital, communication is central to good patient care. However, the home is unique in that the patient is commonly seen without another team member present. It takes extra effort to contact the nurse, social worker, or specialists involved in care, and the home physician often plays the role of quarterback, advocating for the patient and coordinating appointments, investigations, and hospital admissions. It is critical to maintain contact, share information, and discuss future care plans.

Palliative home visits also allow for learning about community resources. Contact with home care agencies and other community supports provides learners with a context for future hospital work. They will have a better understanding of what resources should be in place before patients are discharged and appreciate the complexities of the home setting.

*Competency in independent pain and symptom management:* As the primary provider, family physicians are responsible for adequate treatment of pain and other symptoms that arise. Treatments usually offered in hospital, such as continuous infusion pumps for opioid administration, can also be used in the home. The home is not a controlled environment, and therefore safety issues must be considered when prescribing certain medications, especially opioids. This experience enhances student appreciation and understanding of the responsibility of appropriate prescribing.

## Performing a home visit

***Home assessment.*** Physicians begin assessments even before they enter the front door. What is the neighbourhood like? Is it well kept or run down? How safe does it feel? How accessible is the home?

It is always a good sign when the patient answers the door. We are able to immediately assess functional status. Once in the home, perform a safety assessment by walking through the bedroom, bathroom, and kitchen. A quick scan of the refrigerator and cupboards allows for a nutritional estimation. The home is also a great environment to assess medication use and compliance.

During a home visit, the patient is rarely the only one seen. Usually multiple family members, caregivers, and occasionally neighbours are involved. This is an important opportunity to observe others' interactions with and care of the patient, as well as to assess for caregiver burnout. This is also an opportunity to assess family dynamics and possibly identify various forms of elder abuse. In the home, family members are not always on their best behaviour, as they might be in the clinic.

Physical examination is performed on the couch or patient's bed and might have to be done on the nontraditional side or while kneeling on the ground.

***Equipment: the "doctor's bag."*** Basic equipment includes a stethoscope, a blood pressure cuff, a penlight, a pulse oximeter, and hand sanitizer.[11] A laptop or tablet computer with remote access to the electronic medical record is quickly also becoming essential. Certain medications can come in handy for urgent and after-hours visits, such as haloperidol (for agitation, delirium, and nausea), phenobarbital and midazolam (for seizures), parenteral morphine (for pain management), and furosemide (for congestive heart failure [CHF]). Subcutaneous butterfly needles allow for easy parenteral administration. A key piece of nonmedical equipment is either a city map or a global positioning device.

***Be prepared for the unexpected!*** On an initial visit, you never know what environment you will be entering, and a planned day can turn out very differently with urgent telephone calls and visits. It is important to note that if the visit is urgent, getting a good history and assessment on the telephone is key, allowing you to bring additional equipment and medication.[12]

## Case

Mary, an 86-year-old woman, has been Dr Smith's patient for more than 5 years. Since they met, Mary has suffered multiple CHF exacerbations requiring hospital admission. She was recently discharged after another exacerbation secondary to poor medication and dietary compliance. Aside from CHF, she has multiple comorbidities, including coronary artery

disease, hypertension, and type 2 diabetes mellitus causing peripheral neuropathy and retinopathy. Mary was widowed many years ago, has no family nearby, and lives alone in a 2-storey home in the city.

Mary misses her scheduled appointment after hospital discharge. When called, Mary explains that she no longer has the energy to make it into the clinic. Dr Smith takes this opportunity to visit Mary at home, and brings a medical student along.

Mary comes to the door in her housecoat. She appears much frailer than only a few months ago. When the student notes bedding on the couch, Mary explains that her shortness of breath and leg edema make the steep stairs much more difficult these days. They also note her ill-fitting slippers and the cluttered floors, which make ambulation quite treacherous. After asking permission, Dr Smith and his student survey the kitchen. A portrait of the Pope hangs over the table, where there are multiple empty pill bottles. The cupboards and refrigerator are nearly empty.

It is obvious that Mary is not coping well at home, and her lack of social support is contributing to her inability to manage her CHF. Mary breaks down during the visit, expressing fear she will be placed in a nursing home. Dr Smith addresses these fears and they work on a treatment plan together. Mary's goals of care are to stay at home and live independently; ultimately she wants to die at home and wonders if this is realistic. She understands the safety concerns of remaining at home. She agrees to home care nursing for regular weight checks in conjunction with furosemide titration, as well as to personal support workers for help with activities of daily living. Dr Smith suggests that an occupational therapist assess and address home safety issues. Meals on Wheels deliveries are arranged to ensure at least 1 nutritious meal a day. Dr Smith asks the local pharmacist to dispense Mary's medication in blister-packs for improved compliance. Finally, Dr Smith schedules a follow-up visit in 2 weeks' time.

After leaving Mary's home, Dr Smith and the medical student reflect on how valuable the visit was. Without going into the home, they would not have seen how Mary's disease had affected her function. The home visit illuminated the barriers to controlling her CHF, including poor nutrition and disorganized medication management. After seeing the religious cues, they make a note to ask about community supports she might be open to in the future. In the end, the student is surprised by how differently Mary acted in her home; she was much more relaxed and actively participated in her management plan. They agree that the home visit provided a teaching opportunity that they both thoroughly enjoyed—and the summer sunshine was an added bonus.

**Dr Buchman** is Education Lead and a family physician practising home-based palliative care with the Temmy Latner Centre for Palliative Care at Mount Sinai Hospital in Toronto, Ont, and President of the College of Family Physicians of Canada. **Dr Howe** is a family physician practising home-based palliative care with the Temmy Latner Centre for Palliative Care.

**Competing interests**
None declared

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## TEACHING TIPS

- Home visits provide a variety of wonderful teaching opportunities. Learners are more willing to perform home visits and feel more prepared to do so when they have had adequate training. There are many benefits to keeping patients at home, and it has been estimated that half of all emergency department visits could be prevented by home visits.
- Home visits emphasize patient quality of life and focus on patient-centred care. They give students a greater appreciation of patient illness experiences and allow for development of competence in managing patients with a low level of technology, in providing psychological and spiritual support at the end of life, and in independent pain and symptom management.
- Home visits provide an opportunity to assess how the home environment is affecting health, which could lead to treatment modifications that address existing barriers. You are often also able to interact with family, caregivers, and neighbours, who have their own insights to provide and who might also require guidance and support.

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