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Home Care of the Frail Elderly And the Terminally Ill

SUMMARY

This article discusses general principles of managing both elderly and terminally ill patients. The decision to care for the chronically sick in their homes is necessarily a joint one, made by the patient and supported by his or her family and physician. The physician must understand the patient's medical problems, and determine that the home environment is conducive to care and that one family member is available as a fulltime caregiver. The physician can call upon other professionals, including physiotherapists, pharmacists, dietitians, social workers, and clergymen, to help him care for the patient at home. (Can Fam Physician 1984; 30:665-667).

SOMMAIRE

Cet article discute le principe général de la prise en charge des patients âgés et de ceux en phase terminale. La décision de prendre soin des malades chroniques à la maison est nécessairement prise conjointement par le ou la patiente avec le support de la famille et du médecin. Le médecin doit comprendre les problèmes médicaux du patient, et déterminer si le cadre résidentiel est compatible avec une qualité de soins acceptables et si un membre de la famille est disponible pour donner les soins à plein temps. Le médecin peut faire intervenir d'autres professionnels, incluant les physiothérapeutes, pharmaciens, diététiciennes, travailleurs sociaux et ministres du culte pour l'aider à dispenser des soins au patient à domicile.

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IN RECENT YEARS, the medical profession has been belabored for its seeming abandonment of home visits as part of its professional role. In fact, I am sure most physicians make home visits to chronically disabled patients, but may sensibly make fewer visits to those with severe or sudden illness where there is access to laboratory and radiological studies.

Most people wish to remain at home even when they are seriously ill, but need the support of a physician in order to achieve better control of chronic symptoms and for rapid help during acute illness or adverse change. Therefore, the decision for the patient to remain at home or to be discharged from hospital is best made after a full assessment and discussion with all concerned, and involves a tacit agreement between the patient and physician.

Physical Health

Physical health may be assessed in the office or during a hospital stay, and will allow the physician to identify the multiple pathologies experienced in the elderly or terminally ill patient. Adequate time should be booked for this assessment; careful observation will save problems later. If the patient finds it difficult to leave home, a physical examination can be conducted there and can be nearly as complete. For example, a visiting technician or the physician can take blood for laboratory tests.

Family Support

As part of the initial assessment, it is important to identity the family in their home, to determine their level of commitment to the patient, and to get telephone numbers and details of neighbors and friends.

The very frail elderly, or terminally ill patient will need one person's full-time commitment. This person does not need to be available 24 hours a day, but must coordinate the care and provide coverage at night. Frequent discussions and explanations to family members are important and should be scheduled. They will relieve much of the anxiety experienced by caring relatives and may prevent panic telephone calls in the middle of the night, or frantic visits to the emergency department.

The general health of the supporting family should be reviewed at this point.

Assessing the Home

The well trained public health nurse is probably the best person to assess the home. He or she can assess everything from potential fire hazards to dangerous stairways, help decide the best room for the patient so that he or she is not too isolated from general ac-

tivities and, depending on local resources, may be able to call upon an occupational therapist to help improve safety and put in some aids, such as a raised toilet seat, a stool for the shower or a grab bar for the bath.

Rehabilitation

In many urban areas, it is possible to call on the assistance of both occupational therapists and physiotherapists. The services of a speech pathologist may also be available. These members of the patient's team can assist in the initial assessment and can also provide ongoing care. For example, the physiotherapist can assist the patient recovering from a stroke, teach patients how to use a cane, and teach the family the range of motion needed to prevent contractures in the bedridden patient. The therapist with an interest in geriatrics is invaluable to the frail elderly. Those without this interest need encouragement to persist; otherwise, they may simply leave the patient with a list of exercises and expect compliance.

The Pharmacist

The neighborhood pharmacist is another key person. It is worth talking to the pharmacist directly if the patient is terminally ill or if medications are unusual or complicated. The pharmacy telephone number should be recorded and it is important to note whether or not it delivers to the home.

The pharmacist will have a list of the patient's medications, and is a friendly guide in the modern maze of polypharmacy.

Medications

While as few medications as possible should be used, medication schedules may become complicated. It is worth writing out the medication schedule and making copies for the patient, the nurse, the pharmacist, and your office record. If the patient is alone at medication times, it may be necessary for another team member to put out the pills 'eggcrate' fashion or in a dosette. In certain instances, the nurse may pour the medications for a week in a dosette. It would then be part of his or her job to ensure compliance.

Dietitian

A dietitian rarely needs to visit a patient at home, but invaluable advice and support can be given over the telephone. A well balanced diet is desirable but not always possible for patients who have dentures that can never be made to fit, a poor appetite or the depression that accompanies chronic disease. Possible supplements such as Ensure can be suggested. These alternatives remove the anxiety and guilt family members feel when they believe they are not feeding their patient properly.

Social Worker

A knowledge of the local agencies and resources is of great assistance to physicians, but few will be conversant with the various benefits available to elderly patients through pension schemes or government grants. If there is access to a good social worker, many mountains will become molehills.

Many social workers are good at listening and may provide supportive counselling.

Pastoral Care

Chronically ill patients have time to contemplate their spirituality, and even if they are not terminally ill they will have time to think about death. The physician may not feel comfortable discussing death with patients, but as the team coordinator he or she is probably responsible for ensuring that patients have easy access to their spiritual counsellor. Although this team member is mentioned last, he is not last in importance to the patient and family.

The Team

The caregiving team has now been identified, and it is worthwhile considering the patient as the teamleader. Patients must be allowed as much control as possible, because they are losing control of many other aspects of their lives. The physician is obviously essential to the team and should be accessible to all the other team members. They should be encouraged to refer back to him or her as much as possible. For example, if a visiting nurse wishes to change the frequency of visits (perhaps due to a change in the patient's condition or to economic constraints), it is important he or she consult with the physician.

The team may be large and sophisticated in the city or consist of the pa-

tient, his family, a nurse and physician in a rural area.

Home visits by the physician are one of the most important factors in keeping patients comfortable in their own homes. Visiting should be regular and the approximate time of the next visit should be scheduled. This relieves much of the anxiety in the home and leads to fewer emergency calls at awkward times.

If the patient is scheduled for an office visit and does not arrive, the office staff should call the home, gently ascertain the reason and make a new appointment.

The Revolving Door Policy

This is an adjuvant to a carefully monitored home program. The patient may be admitted to hospital for reassessment, adjustment of medications, etc., or to allow the family a break from providing care. Then he or she is discharged home. This may occur several times for one patient and gives the patient and family confidence and support. It is often instrumental in allowing the patient to remain at home.

Palliative Care in the Home

Most people would like to die in their own bed at home, but do not wish to die alone. However, many deaths now occur in hospital, and a planned death at home is uncommon. It is necessary for the physician to explore with the patient and family whether they do wish a home death, or whether someone in the household has a horror of death and could not use the bed or room afterwards.

The terminally ill patient will need all the measures already outlined in this article, but will also need more time for discussion and explanation. The dying patient will be encouraged to voice his fears if the physician sits by the bed and allows him to progress at his own rate. If the patient does not talk about death and dying, it doesn't mean that he is denying the seriousness of his illness. Only by listening is it possible to learn that person's fears. Assumptions are nearly always incorrect.

The family must be monitored carefully for fatigue, and neighborhood or home care resources tapped to allow time off for shopping, recreation or sleep. If the patient deteriorates and requires hospitalization, the family must be assured that it is not a failure on their part.

After the patient's death, a visit by the physician to pronounce death is not mandatory but is most helpful to the family and enables the forms for vital statistics to be filled out without delay. If possible, a member of the professional team should stay with the family until after the funeral directors remove the body. This final exit is often more painful than the death itself.

The nurse can give comfort and praise the family when he or she visits to remove equipment as soon as possible, so that the family can return to a more normal lifestyle.

This is also a good time for the professional team to consider whether or not family members are at risk in their bereavement, and what help they will need in the months that follow.

Conclusion

Caring for the frail elderly or the terminally ill patient at home can be demanding, but with careful planning and good use of both professional and family resources it can be very satisfying and is always instructive.

The individual families who benefit from home care are nearly always aware of the sacrifices involved and are very grateful for the health care team's time and effort.

They are probably not aware, however, that the home visit is poorly reimbursed by most provincial health care plans.

In Alberta, a physician is paid $32.75 for the first visit, and $16.30 for subsequent visits in office hours. Emergency calls at night and on weekends are better paid.[1] As the total time taken for a home visit, including travel time, is about an hour, these fees do not acknowledge the continuing office overhead and the travel expenses, and force the physician to use what should be leisure or family time for patients at home.

That so many are cared for in the home is a tribute to the family physician and his team.

Reference

1. Schedule of Medical Benefits. Edmonton, Ministry of Hospitals and Medical Care, 1983.