

# Guidelines for Home Care of Infants, Children, and Adolescents With Chronic Disease

Committee on Children With Disabilities

Many infants, children, and adolescents with long-term, serious health problems require frequent and/or prolonged hospitalizations that separate them from their home environment. Hospitalization interferes with the ability to form the normal, interpersonal family and community relationships that are important for normal growth and development. Caring for a child at home may be a desirable alternative to hospital-based care.

Caring for a child at home, with all the necessary assistance, is more supportive of the family's traditional caretaking and nurturing role, but home care should be initiated only when consonant with the best interests of the child and family and if adequate resources and support are available. Combining the benefits of home care with appropriate medical treatment and support requires the development of innovative programs among hospitals, physicians, parents, home care professionals, and communities.

Although many home health care programs for patients with chronic disease exist, objective data about their efficiency, risks, benefits, and costs are limited. Where documentation exists,<sup>1,2</sup> home care can be shown to be a successful, cost-effective method of health care delivery. Careful planning and coordination of family, hospital, home care providers, and community resources, however, are essential for successful home health care programs, and guidelines for program development and assessment are needed.

The goal of a home health care program for infants, children, or adolescents with chronic conditions is the provision of comprehensive, cost-effective health care within a nurturing home environment that maximizes the capabilities of the individual and minimizes the effects of the disabilities. This may be established to prevent hospitalization or reduce the length of hospitalization.

## PROGRAM DEVELOPMENT

Comprehensive planning should minimize physical and emotional risk to the patient, adverse effects on the family members, or unforeseen finan-

cial burdens. Because of the many factors to be considered, planning should be done by a multidisciplinary Home Health Care Team. This team should include (when available): parents; a primary care pediatrician; other physicians (eg, hospital physicians, subspecialists, other community physicians); nurses; occupational, physical, respiratory, and speech therapists; child development specialists; educational specialists; nutritionists; social workers; teachers; home care providers (eg, home health aide and equipment provider); case managers; and insurers. The team must initially develop the Home Health Care Program, which provides comprehensive care recommendations (the treatment plan) and arrangements based on each individual patient's demonstrated needs (the resources to be utilized, including equipment and service providers). Many of the resources used in the Home Health Care Program may be an extension of existing hospital services.

After the Home Health Care Program is established, each child and family identified for the program needs an Individualized Home Care Plan (IHCP). The family (or other primary caregivers) and the primary care pediatrician must play a major role in developing, implementing, and monitoring the plan, with appropriate subspecialists, when necessary, identified early in this process. A home care service coordinator to support and coordinate the IHCP should be selected (jointly by the team and the family) for each patient. The coordinator, working in conjunction with the primary care pediatrician, works closely with the family, identifying and assisting with their needs in caring for the child at home, including family training about illness, treatment, and advocacy, and assisting families in developing service coordination skills. This family oriented advocate could be an appropriately trained parent of a child with chronic illness who has experience in home care-related issues and concerns. Every effort should be made to identify a single care coordinator for the child and family, even if this requires serving the needs of several programs/systems. If this is not possible, it is essential that a communication system be developed with unique and shared responsibilities delineated for each care coordinator.

## IMPLEMENTATION

### Patient Selection

Eligibility for home health care should be based on a comprehensive analysis of the Home Health Care Program capabilities, whether the child's therapeutic

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The recommendations in this statement do not indicate an exclusive course of treatment or procedure to be followed. Variations, taking into account individual circumstances, may be appropriate.

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needs can be met by home care, the potential benefits and risks, and the available resources. Families should not face excessive pressure to enroll their children in a home care program if this move would be detrimental to the child or family. The patient should participate in the development of the IHCP to the extent possible, with the following factors considered for patient selection.

1. **Patient Factors.** Underlying any potential for home care in chronic disease is the patient's medical stability vis-à-vis the capacity of the Home Health Care Program to provide backup and emergency care. Previous experience with home care in similar situations should be reviewed. As part of the initial discharge planning process, plans should be made to explore home care as an option to begin when the patient's condition is as stable as possible.
2. **Family and Home Factors.** If possible, each family should have at least two members trained and fully able to care for the child in the home. In some situations, two or more trained adults are essential to assure medical safety. The family should provide evidence of sufficient parental/family involvement, proven capability in performing medical and nursing tasks, and an appropriate home situation (eg, physical environment, safety, and geographic location) for the child's medical safety to be reasonably assured. Respite services should be part of the plan as well as emergency staffing in case the care provider is ill. Specialized day care should be explored as well.
3. **Community Factors.** A primary care pediatrician or other provider should be involved in the development of the IHCP before hospital discharge, be knowledgeable about the plan, and agree to participate by providing primary medical care. This physician oversees the medical aspects of the plan after hospital discharge, communicates with the attending physician at the hospital and other involved physicians, and reviews the safety of the plan. The service coordinator must assure the availability of appropriate home health care providers, equipment, and other special needs (eg, oxygen suppliers). Essential equipment must either be portable or available at each site that the child attends. Reasonable contingency plans for emergencies (eg, power and equipment backup for those with life-support devices and appropriate transportation), including clear delineation of the unique and shared medical care responsibilities among physicians on the team, must be available. The "team leader," generally the primary care pediatrician, should be identified.
4. **Home Care Trial.** In order to identify any omissions or lack of clarity in the IHCP, a successful trial of care by the future home health care providers within the hospital setting (using emergency backup by the regular hospital staff) is recommended before discharge. Family members should use equipment and supplies that will be used at home first in the hospital so that they can become familiar and proficient with their use. Any

differences between hospital use and home use should be addressed before hospital discharge. The trial should enable the family and other regular caregivers to develop self-confidence and avoid overdependency upon hospital staff.

#### IHCP DEVELOPMENT

Careful review of the patient's status and needs in the hospital should be made by each professional participating in the patient's care. Each discipline should formulate goals and objectives for the patient and develop daily program components to meet these goals in the home. Thereafter, a meeting should occur to formulate an integrated daily IHCP with specific responsibilities delineated, including the establishment of financial responsibility. This plan includes the following: 1) designation of a home care service coordinator, 2) involvement of a primary care physician who will provide "the medical home," 3) family access to a telephone, 4) specific physician orders for medications, treatments, medical follow-up, and medical tests as appropriate, 5) a plan for monitoring the home care plan that includes designation of the "team leader" and specific responsibilities of the service coordinator and primary care physician, 6) a mechanism for making adjustments to the plan when needed, 7) a defined backup system for medical emergencies, 8) regular or special educational services for school-aged children and early intervention services for eligible infants and toddlers, and 9) criteria procedures for transition from home care, when appropriate.

#### Educational Services

Planning for early intervention and/or educational services should stress the importance of educating children in an environment with peers that promotes and maintains socialization. With school systems providing education in the least restrictive environment, the child's Individual Educational Plan should incorporate therapeutic and nursing care that is coordinated with the daily IHCP. A child should not be denied necessary home care services because he or she is entitled to school-based services.

#### Equipment and Supplies

Equipment and supplies that are appropriate for use in the home must be selected and secured according to each patient's needs. Community suppliers must guarantee continuous availability, maintenance, emergency repair, and replacement of this equipment. Financial reimbursement to the family for necessary equipment, supplies, and maintenance should not be denied because the care of the patient is transferred from the hospital to the home. Any need for equipment changes, including manufacturer recalls, should be arranged in conjunction with the service coordinator and the family. Equipment performance should be documented and tracked by the manufacturer.

#### Child and Caregiver Training

Critical components of the IHCP are education and training for the family and other caregivers, includ-

ing the child to the greatest extent possible, professional and paraprofessional health care providers, school personnel (if the child will be attending school), and all emergency personnel. Before discharge from the hospital, the family rather than the hospital staff should provide as much of the child's care as possible. The family must learn to recognize and record changes in the child's condition that would require consultation and/or modification of care. The patient, especially if an adolescent, should be encouraged to take responsibility for self-care to the extent appropriate. Although it may require time, restraint, and patience, the hospital staff should assume a supportive, rather than primary, role in this stage of the child's care. The plan should also incorporate outreach education for staff at local hospitals and community-based home care providers.

#### **Cost**

The Home Health Care Team should evaluate the projected cost of the child's IHCP and the available methods of financial support and resolve funding problems before hospital discharge of the patient. There should be continuing review and dialogue among the Home Health Care Team, insurers, and public programs to help assure the financial coverage of home care. Creative financing approaches include negotiated arrangements among a diversity of health care and social service funding sources.

#### **Effects of Home Care on the Child and the Family**

During the development of the child's IHCP, a number of issues related to the potential effects of having a severely ill child at home need to be explored with the family, including issues of privacy, physical burdens of care, impact upon other family members such as siblings, time demands of home care, role of the parents in coordinating care, and the social and financial aspects including issues of confidentiality. Assessment should include impact of home care on family dynamics, activities, and schedules including work-related responsibilities. Discussions with the family should explore possible approaches to these issues before discharge, and the family should feel comfortable with their choices.

#### **PROGRAM MAINTENANCE**

Before discharge and at intervals during the child's home care program, there should be a coordinated review of the patient's and family's needs, how the family is managing, the progress toward the home care goals, and other available relevant information. The service coordinator and the family should conduct the program review, soliciting input from all involved providers. This is particularly important since the child's and family's needs will likely change over time, both medically and socially. The type and frequency of the child's specialized therapy should be reviewed, and any new issues that arise should be evaluated. Home care case management conferences are recommended at periodic intervals. They should include all community-based providers and case managers.

#### **PROGRAM EVALUATION AND OUTCOME**

A review of all patients in the Home Health Care Program and an assessment of data from similar programs should be done by the Home Health Care Team on an ongoing basis. Feedback data for review should be obtained from several sources (eg, the child, the parents, the community, local care providers, and school personnel). Sharing experiences will lead to the continued refinement of the Home Health Care Program. Principles of program review should include the analysis and improvement of key clinical and social outcomes, with evaluation of the ultimate value of the care provided. Follow-up and outcome assessments need to be based on the following: 1) survival, 2) the need for subsequent hospitalizations and other morbidity, 3) developmental progress, 4) course of the underlying disease, 5) actual utilization of resources as compared with expected utilization, 6) financial experience (cash flow and continued availability of benefits), and 7) effects on family members, including siblings. As with all elements of family-centered care, input from family members into this process is essential.

#### **ALTERNATIVES**

The use of intermediate or chronic care facilities may be considered as an alternative to home care. The choice of home care or alternative care must be based upon a thorough evaluation of the needs and wishes of the family and the expected course of the illness. Most effective care planning requires the development of a continuum of care options and the evaluation of alternate types of care. The home is one community-based alternative. Components comprise a spectrum of care that may be required over time depending on changing circumstances.

#### **CONCLUSION**

Home health care programs for infants, children, or adolescents with chronic disease may offer the advantages of supporting the child's growth and development in a more nurturing family environment without compromising comprehensive health care delivered in a cost-effective manner. Since the number of children with chronic diseases that may be appropriate for home care is increasing (eg, technology-dependent children, children with human immunodeficiency virus infection), this issue affects all pediatricians. Careful analysis, shared experience, and future controlled studies will help support the appropriateness and cost-effectiveness of home health care programs in the care of patients with chronic disease. The central role of the family in this process must be recognized and continuously supported, with appropriate ongoing assistance as the needs of the child and family change over time.

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