

UIC SPECIALIZED CARE FOR CHILDREN

Guidelines for Nurses Working in Home Care

I. Introduction to Working in Home Care

Providing nursing care in a home is very different from hospital based nursing for a number of reasons. The following information describes some of the differences and difficulties experienced by families and nurses working together to provide home and community-based services to medically fragile children. What follows is based on surveys of home health nurses and interviews with parents, siblings and children who have been or are participants in home-based care.

A. The Environment

The main difference between hospital and home care has to do with the setting itself. The hospital is a primary setting for nurses and a secondary setting for families. On the other hand, the home is the primary setting for the family and a secondary setting for nurses. Under normal circumstances, nurses are the authorities on nursing care in the hospital and parents are the authority on their family life in the home. In the hospital, nurses do not do much consulting with parents about what is done, and in the home parents rarely consult with anyone on how they function or about the decisions they make. Under normal circumstances, the hospital and the home are two distinct and discrete environments. However, in the context of home care, there is a blending of these two settings which can and often does create a difficult situation for nurses and parents.

Prior to taking the child with a disability home, parents should be taught the child's total care. When this is done, parents usually know more about the individual care of their child than any professional coming to the home. The parents become the experts in the total, day-to-day care of their child at home. Parents are not used to being in charge of nursing care but they are used to being the authority at home. Nurses are not used to providing nursing care in homes but are used to being the authority on nursing care. Conflicts may arise once home care begins because the parents have "home court" advantage and know more about the specific child but do not have the overall knowledge base and experience of the nurse.

The home setting carries with it other differences from the hospital, in addition to the issues related to authority. In a hospital unit there are prescribed and enforced standards of care, there is a fairly contained space in which to carry out care and there are limitations about who can visit and for how long. There are also defined lines of authority for determining care and for enforcing rules and regulations. In the home, there should exist more of a family professional partnership, with the family taking the lead in determining the household "rules and routines" and nurses taking a less directional role. There may be specified standards of care but who, where, and when care will be provided is not as easily defined as in the hospital. Frequency and duration of visits and numbers of visitors or playmates are more relaxed and, therefore, less controlled than in the hospital. Nurses have less control over to whom and to what the child is exposed. They are more at the mercy of the environment in the home setting than they are accustomed to in the hospital. There are a greater number of decisions which need to be made by family and nurses about how to balance normal developmental experiences with care needs and there is a real sense of isolation from other professionals with whom to discuss treatment plans, progress and problem solving.

Similarly, the home is more relaxed than the hospital environment, with fewer backups or supports available to help. While it may be desirable to be able to focus more intensely on one patient, there are also fewer challenges than offered by a hospital environment. Boredom and complacency may be a problem as home care can become almost too casual at times and the professionalism required in the hospital may become diluted by the home environment.

B. The Relationships

The second most significant difference between hospital and home rests within the relationships. In home care, nurses are in the position of being observed and supervised by parents. While this may not be supervision in the classic sense of the word, it is nonetheless a reality. In some cases it

may feel more like being continually “scrutinized” and it can be a difficult adjustment for nurses. There is the basic feeling that a nonprofessional, such as a parent, does not have the education to evaluate the nurses’ performance. This feeling of being evaluated by a nonprofessional can be a major source of frustration for nurses working in home care.

Also, in the home, nurses will be exposed to the inner workings of family life, some of which may be distressing. Nurses may not agree with the way family members are treated and may feel uncomfortable with a variety of aspects of a family’s culture and life-style. In a hospital setting, nurses may have some exposure to the behavior of siblings and parents but generally it is lacking in the intensity and extent to which it will be experienced when working in the home. In the home, nurses may become involved in family relationship issues on a day-to-day basis which, while technically unrelated to the care of the child, are related to the environment in which the care is being provided. This may cause difficulty in maintaining the professional relationship required by the job.

The primary focus of home care nurses is the medical care of the child in the waiver program but nurses can expect to take part in any activities which relate to the child including physical care, daily care of the child’s equipment and environment, and support of educational and developmental programs. Questions regarding other aspects of the child’s life, within the context of the family, will arise for nurses, just as questions about nurses will arise for the family. Although the nursing personnel are employed to care for one child, the fact that nurses will essentially be working in the home requires that relationships be established with other family members as well as other health care professionals. The initial months are especially difficult as everyone adjusts to their roles and relationships with the multiple providers of care.

The following information is provided to help nurses establish and maintain a professional working relationship within a home environment. The general guidelines are designed to help nurses prepare mentally for the experience of home care with the specific guidelines as a way of avoiding identified sources of stress. It is recommended that parents, case manager and/or the hospital personnel meet with nursing personnel who will be in the home after discharge to go over the guidelines. The nursing agency supervisor needs to be involved in the discussions to assure that the guidelines are in line with agency policies and procedures and will be supported by the agency and supervisor.

II. General Information for Nurses Working in Home Care

A. Adjustment to Home Care

For nurses who have not worked in home care before, there will be a period of adjustment no matter how well thought through the experience is by all involved. It is a different environment and nurses need to be aware that it will take time to make the adjustment. There are never going to be the clearly defined roles and responsibilities which exist in other environments. Learning to cope with the home setting will necessitate a willingness and ability to be flexible.

Family members will be experiencing a number of emotionally charged issues over the course of the home care experience. They may react angrily toward nurses in ways which are inappropriate. Nurses do not have to submit to mental or verbal abuse. However, it is important to remember to objectify and not take personally outbursts which are not rational. Experienced professionals do not feel threatened when a parent questions some action and nurses need to be prepared to both listen to the content as well as the meaning of questions or even outbursts. It is important to evaluate what else is going on in the home because even subtle changes may be the source of stress.

B. The Early Months of Home Care

The first six months of home care are a time of high anxiety for everyone, with the first month the most difficult. Parents are nervous about their own ability to care for their child without the backup of the hospital staff and are not yet fully trusting of the home care nurses. Parents will be anxious about everything but especially about the “details” of the care of the child. Nurses may be impacted by these family stressors, simply by virtue of being there.

It is also a time of anxiety for nurses who are new to home care and who are not sure of their own ability or the parents’ ability to handle emergencies. It is during this time that trust must be established between parents and nurses. Because of the parents’ anxiety and nurses’ anxiety, there is a strong risk that inappropriate patterns of communication will be established.

The first six months are also a time of high turnover of nurses who decide they do not wish to work in such an environment. However, it is important to understand that the home care situation will not always be so anxiety or tension ridden. Parents and nurses will develop a routine with the child and anxiety will decrease markedly.

C. Home Care Over the Long Term

Once staffing patterns are established and the home has relaxed into a workable routine, the next “critical incident” time for families commonly occurs at about 20 to 24 months. By that point, the family has generally dealt with the “getting home” and “getting along” aspects of home care but seem to go through an intense experience dealing with “getting on” with a family life which is markedly different than they had anticipated. The fact that this will be a long term or “forever” experience seems to hit parents rather hard after the first two years and can be a major turning point for some families.

The experience can last for several months and is usually characterized by anger, ambivalence and depression. Again, this is a time when nurses, simply by virtue of being present, are going to be the most obvious target for the anger and ambivalence. Parents may begin to find fault with everything which the nurses do, even though the nurses have been doing the exact same things for many months. This is a particularly difficult time for families because it seems so out of sync with what they felt they had already dealt with by coming home. It is a prime time for what can appear to be arbitrary discharge of nurses and home health agencies. Family discord may reach an all time high and the tension in the home can permeate all aspects of family life.

Nurses need to be particularly sensitive to parents getting tired at this time and help in whatever way possible to make things run smoothly. Legitimate concerns about the care of the child can be addressed through proper channels as they arise but it is important to remain as calm and objective as possible through the rough points and not to personalize the situation.

III. Guiding Principles for Nurses in Home Care

There are three guiding principles which are important to assure that the home care experience will be the supportive service it is intended to be. The principles overlap and are interrelated but are presented in the following as discrete entities for emphasis.

A. The Parent as Authority in the Home

With the large number of agencies, organizations and health care professionals involved with the child and family, it is easy to forget that the parents are the ultimate authority over their child and the care that their child receives. Everyone else is there as service providers and/or as consultants but it is the parents who are and should be in

control of the overall situation. In this regard, while nurses may be hired by a home health agency and while funding for home care may come from a payor other than the family, the parents are, in fact, the consumers and therefore equivalent to being the nurse’s employers. They have the authority to both select and remove agencies and individual service providers and to establish the specific guidelines for how service is provided to their child in their home. While the discharge of individual providers and/or agencies is not the recommended first response when dealing with problems in home care, the parents are the authority in their own homes and therefore this can occur.

Nurses need to keep in mind that they are working for the family, not present in the home as a favor to the child or family or out of altruistic concern. Working in home care is a contractual, business relationship. Therefore, inherent in this business relationship is the requirement of respect for parental authority. Efforts to enable parents to develop and maintain the central position of authority are essential. This does not mean that parents have to do everything themselves but rather that they have the authority to oversee the entire home care situation and can assign responsibility to the appropriate people.

Nurses need to consistently carry out their responsibilities in a manner which will gain the trust of the parents. Parents must also feel that the nurses in the home will be supportive of parental decisions and will respect the parents’ ability and right to care for their own child. If nurses are able to develop a supportive, trusting and mutually respectful relationship with parents, then difficulties can be discussed and problems can be resolved in a way which is not threatening to either parents or nurses.

Developing a relationship that is respectful of the parents’ authority and the nurses’ skills and responsibilities is a dynamic process. It takes time and a conscientious, consistent commitment from the nurse, the nursing agency and the parent.

B. Professional and Personal Support

It is of utmost importance for nurses to establish a personal and professional supportive network outside of the home in which they are working to deal with the intensity and stress of home care. Working with one patient in one home, while it has its desirable qualities, also has drawbacks. It can become boring, stressful or all consuming, especially for nurses who work full time in the home. Professional support should be available through the nursing supervisor, home care colleagues, or

their professional organizations. Regular supervision meetings, staff conferences or even nursing support groups may help the individual nurse to put into perspective one's own behavior or the unexpected behavior of family members.

Personal or social support from one's own family and friends is also important. Nurses who try to have personal or social needs fulfilled in the client's environment are at risk of becoming too personally involved with the family. This can lead to an inability to maintain an appropriate professional relationship.

C. Maintaining a Professional Relationship

It is perfectly normal for families consciously or unconsciously, to seek to incorporate the home care nurse into the family unit in order to decrease the stress of having an outsider in the home. This pull is difficult to resist because it feels like an acceptance and statement of affirmation to be considered as a "family member." While this may be appealing for the nurse, this does not necessarily reflect the family's personal statement regarding the nurse as a person. It is, instead, an attempt to decrease the family's own anxiety.

As professionals, nurses are responsible to maintain an appropriate professional distance while at the same time supporting and respecting the family's naturally established boundaries, even when the family attempts to include nurses as family members.

There are families who have no boundaries or boundaries which are so diffuse as to be virtually nonexistent. These families will automatically view nurses as members of the family unit and expect nurses to function as a full member of the family. In these circumstances, it is all the more important for the nurses to help the family establish boundaries by identifying those areas where it is inappropriate for the nurses to be involved even when invited, such as, in family arguments, decisions about family activities or even life style choices.

Becoming overly identified with the child or family can be a problem for nurses as well as the family. It is important for nurses to remain objective in order to execute their role with maximum efficiency and effectiveness. This is not intended to mean that the home care assignment is "just another job," but it is intended to emphasize that it is a job and should not become the nurse's life.

IV. Specific Guidelines in the Home

The next sections will deal with more specific guidelines for nurses working in home care. The specific guidelines are written for all levels of professionals in home care and while some may seem obvious, they are provided as reminders that certain behaviors and actions may have impact beyond the original intent.

A. Common Courtesy in Home Care

There will be many caregivers entering the home and the child's bedroom in particular. It is important to be sensitive to the fact that it is someone's home and treat the furnishings with respect, e.g., wipe up spills on furniture and carpeting; notify the parent if something is broken; wipe feet before entering, etc. With so many additional people coming in and out of the home there will be extra wear and tear on the furnishings and efforts need to be made to minimize that as much as possible.

It is not the responsibility of the nurses to do general housework but it is expected that nurses will help maintain a clean and neat environment for the child, e.g., replacing supplies and equipment in their proper places, making sure the child puts toys away after use, etc.

B. Value Judgments

Nurses may be working in homes in which they experience differences in basic social values and behavior than those of their own. These differences should not be identified to the parents. As long as the life style and behaviors of the family do not risk harm to the child or prevent the nurses from doing the job they are there to do, how a family lives is their own choice. Most concerns in this area center on judgments regarding discipline of the child and/or siblings, housekeeping, and relationships. Similarly, the financial affairs of the family including how a family chooses to spend their funds is not the business of the nurses. It is recognized however, that it can be difficult to work in an environment where values differ dramatically. If nurses find the differences too distressing, it may be necessary to consider the decision not to work with a particular family.

C. Spiritual or Religious Beliefs

The spiritual or religious beliefs of nurses should not be expressed in the work place. In addition, it is important to avoid any attempt to influence the child, siblings, or parents regarding spiritual or religious values which may differ from the family's

own. If the child asks questions of a spiritual or a religious nature, nurses are expected to defer to the parent(s).

D. Day-to-Day Routine

Home care is a 24 hour a day, 7 days a week job for the family and generally a 40 hours or less work week for nurses. Routines which the family has established for the child should be followed as closely as possible. Asking the family how and when they would like to discuss non-emergency updates on the child's care will avoid repetition of information.

E. Authority in the Home

Where there are acceptable options for care, it is important for nurses to support the parents' authority. Unless the child is placed at risk of harm, the parents have a right to determine the care of their child. When it is felt that parents are making inappropriate decisions about the care, it needs to be discussed with the parent and the nursing supervisor. **If this does not resolve the concern**, the nursing supervisor, physician, and the case manager may be helpful in negotiating resolution.

When a written plan of treatment includes a specific activity or routine, nurses are expected to follow written physician orders at all times. If parents wish to alter a plan of treatment which is part of the physician orders, it is up to the parents to negotiate with the physician. However, there will be many daily routines in the care of the child which are not covered by written, physician orders. The parents are the authority in determining general, non-prescriptive routines and procedures and nurses are expected to respect this authority as long as it does not compromise the care of the child.

F. Dependency

Parents are dependent on the services provided by nurses to keep the child at home. This can create a power differential to which nurses need to be sensitive. Parents do not want to antagonize nurses any more than nurses want to antagonize parents. Systematic negotiation of differences of opinion, while everyone's responsibility, should be a skill which the experienced professional brings to the home environment. The primary goal is to foster independent family functioning while providing appropriate support as needed.

G. Documentation

There must be a standard procedure in the home for recording information about the care the child

is receiving. Other than the required charting and recording, it is not appropriate to document in the chart or other places, any aspects of family life or family functioning which is not directly related to the medical care, status, or safety of the child.

H. Reporting Abuse or Neglect

Child Abuse or Neglect: There are occasions when it may be necessary to raise concerns about a parent's or other care giver's ability or willingness to care for a child. Nurses are mandated reporters under the Abuse and Neglect Reporting Act (ANCRA) and are responsible to report any acts of physical abuse, neglect, or sexual abuse to the Department of Children and Family Services (DCFS) at 1-800-252-2873. Physical and sexual abuse are fairly clearly defined in the Act itself. Neglect, on the other hand, is less easy to determine, especially when a medically complex child is involved.

It is necessary to document incidents of neglect including description of alleged neglectful behavior, dates and times. It is important to remember that if the nurse is in the home to care for the child, it is difficult to make a case for the parent or other care giver as neglectful since the nurse is responsible for the child during that time.

However, it can be considered neglect if, for example, the family care giver taking over the care of the child is intoxicated, fails to appear without notice, fails to provide the necessary care, or where the environment is unsafe or potentially life threatening.

In reporting abuse or neglect, nurses are responsible for providing specific information which is pertinent to the allegation. It should be understood that a report is only an allegation of abuse, or neglect. The designated agency for protective services (DCFS), not the nurse, is responsible for investigating the report. While as much information as possible is important, nurses do not have to prove abuse or neglect, only to report it when they suspect that it is occurring.

It is also a professional responsibility for the reporting nurse to remain with the child who is believed to be at risk of harm, until the protective services worker or the police arrive after a report is made. The nurse cannot legally remove the child from the home without the parents' permission unless the child is in need of emergency medical treatment. Only the police or designated protective service worker can legally take custody of a child at risk and, in a nonmedical but protective emergency, the police should be called.

Abused, Neglected Adult with Disabilities: If you suspect abuse, neglect or exploitation of an individual who is 18 years or older with a disability and whose physical or mental disability impairs the ability to seek or obtain protection from same, call the Office of the Inspector General (OIG) 1-800-368-1463 whenever a call is made to OIG, the DSCC case manager and nursing supervisor should also be notified.

V. Specific Guidelines for Dealing With the Child

A. Supporting the Parent-Child Relationship

Nurses need to be diligent about supporting and reinforcing the parent-child relationship and not do anything to undermine that relationship. It is extremely easy to become attached to and feel protective of the child but to usurp the parental relationship with the child is unethical behavior. This is not to say that it is inappropriate to view the child as more than just a "patient." What is inappropriate is to lose objectivity and to try and replace the parent in the child's life.

It is important to be conscious of how home care providers refer to the child. Statements such as "my patient" are common in the hospital but it can be offensive to parents in the home situation. Similarly, when speaking of the family, a nurse should avoid using the word "we" as though the nurse is part of the family. Use of "you" or "they" is more appropriate and less offensive.

B. Communication With the Child

It is not appropriate to discuss any negative reflections about family members with the child. Children will look for support from nurses by speaking negatively about one or both parents when they feel parents are being unfair. Nurses who support children's negative comments about their parents will be interfering in normal family functioning. While children may be initially looking for support, they ultimately resent a non-family member making negative comments about the family. Children should be encouraged by nurses to discuss their feelings with their parents. Even the most innocent of questions, e.g., "Why is my Dad doing that?" can be redirected with a simple "I don't know. I think you should ask him." to avoid falling into the trap of trying to interpret parental behavior to the child.

C. Influencing the Child

Children under the care of an adult for any extended period of time will begin to adopt the traits of that person. This occurs naturally when children

begin school and are influenced by teachers but in home care this may happen at a much earlier age. Nurses need to be sensitive to the fact that their personalities and personal habits may be reflected by the child. Therefore, it is important to remember to be circumspect in attitudes, conversations, and behaviors because the child will adopt a variety of mannerisms and verbalizations which may or may not appear desirable to the family.

VI. Specific Guidelines Regarding the Relationship with Siblings

A. Day-to-Day Involvement

Siblings are an important part of family life. When there are other children in the family, nurses need to be sensitive to those children also. Some siblings may seem like more of a nuisance than a help but it is not the right or responsibility of the nurses to "organize" the rest of the children. If siblings are interfering with the care of the child, then this needs to be addressed directly with the parents and/or nursing supervisor. It is also important to remember that siblings may resent all the attention that the child receives including the child having his or her very own adult with whom to play. Nurses can help foster positive family relationships by including the siblings in activities whenever appropriate, being patient in answering their questions, and by demonstrating a genuine interest in the siblings' activities and feelings whenever possible.

B. Sibling Interactions

It is important for siblings to spend time together. This may include play activities but also may include the normal disagreements and fighting which occur among brothers and sisters. Nurses should encourage and provide the opportunity for as much normal activity among siblings as possible and not be overly protective of the child. Sibling interaction is an important socializing experience and even a good squabble promotes growth and development for all involved as long as it does not endanger the physical well being of the child.

C. Baby-Sitting

Nurses are not expected to baby-sit siblings nor should they take responsibility to do so. This does not mean that nurses may not supervise the play of siblings with the child, only that they should not be responsible for siblings when the parent is out of the home.

D. Discipline

It is recommended that nurses not be responsible for disciplining the other children, however, this is an area which needs to be discussed with the parents. It is important for nurses to be able to exercise some authority over young siblings to avoid problems but how this authority is defined needs to be negotiated.

VII. Specific Guidelines for Involvement with Parents

A. Communication

Good communication between parents and home care staff is critical to the success of home care. Therefore, it is important to clarify with parents what information needs to be reported to parents immediately and which information can wait. Methods and systems of communication need to be established and may entail written as well as verbal communication. If there is repeated breakdown in communication or an inability to resolve communication difficulties, the nursing supervisor or the case manager may be of assistance in helping the nurse problem solve. It is inappropriate to call a consultant of any sort to come in to “fix” the family, but nurses working in the home may profit from talking to others in order to determine an appropriate course of action.

It is also expected that nurses will not call the doctor, D.M.E. provider or other state agencies regarding the child without discussing it with the parents first. Except in the case of an emergency when the parent is unavailable, all home care providers should comply with this expectation.

B. Privacy and Confidentiality

Privacy is a major issue for parents who have other caregivers in their home. Parents need to identify times when they do not wish to be disturbed, e.g., for the first hour in the morning or after coming home from work; places where they do not wish to be disturbed, e.g., in the bedroom or bathroom; and under what circumstances they do not wish to be disturbed, e.g., when on the phone, when visiting with friends.

Nurses are expected to respect the confidentiality of the family and not discuss the family members with anyone outside of the home except with specified health care professionals as it relates to the child. Nurses should not provide information pertaining to the whereabouts of the parent when the parent is not at home. Nurses should respect and protect the family’s privacy appropriately at all times whether in the home or talking with others outside of the home. Any breach of confidentiality by a nurse mandates immediate supervisory action.

C. Interactions Between Parents or Parent and Significant Others

All couples periodically get into arguments. Nurses are expected to avoid involvement in relationship disputes unless the child or the nurse is placed at risk. If it seems as though parents are trying to involve the nurse in a dispute, it is the nurse’s responsibility to identify to the parents that this is inappropriate. At times this may be difficult because sympathy may well be with one parent over the other but it is important for the parents to negotiate their own problems without the involvement of nurses. It is inappropriate for nurses to become romantically involved with a parent in the home where they are working, even if the relationship is with a single parent and is developed after work hours.

Conclusion

Home care is not for everyone. There are stresses for family members and for nurses working in a home environment but with conscientious effort most of the difficulties can be overcome. When attention is provided to assuring good communication and understanding early in the home care experience, the service provided can be supportive to the family and professionally gratifying for nurses.