



# Managing Home Infusion Therapy

Instructions and tips for caregivers supporting family members.

This article is part of a series, *Supporting Family Caregivers: No Longer Home Alone*, published in collaboration with the AARP Public Policy Institute. Results of focus groups, conducted as part of the AARP Public Policy Institute's No Longer Home Alone video project, supported evidence that family caregivers aren't given the information they need to manage the complex care regimens of family members. This series of articles and accompanying videos aims to help nurses provide caregivers with the tools they need to manage their family member's health care at home. Nurses should read the articles first, so they understand how best to help family caregivers. Then they can refer caregivers to the informational tear sheet—*Information for Family Caregivers*—and instructional videos, encouraging them to ask questions. For additional information, see *Resources for Nurses*.

Care provided at home is becoming increasingly complex, with many family members performing medical and nursing tasks for loved ones who have physical, cognitive, or behavioral health issues.<sup>1</sup> Although many caregivers report that providing care gives them a sense of purpose and adds meaning to their lives, these positive feelings are often accompanied by stress, worry, and isolation.<sup>2</sup> Caregivers performing medical and nursing tasks often report that they feel they have no choice but to provide this complex care, find these tasks difficult to perform, and worry about making a mistake.<sup>1</sup> They say that additional or more effective instruction—and more help from others—would make it easier for them to provide the complex medical and nursing tasks their family members need.<sup>1</sup>

Such tasks include the provision of infusion therapy to family members who reside at home. This article provides nurses with useful instructions and practical tips they can use to educate and support caregivers of people receiving home infusion therapy, as well as an informational tear sheet for caregivers (see *Information for Family Caregivers*).

## THE BENEFITS AND RISKS OF HOME INFUSION THERAPY

Home intravenous therapy is most commonly used to provide antibiotics, chemotherapy, total parenteral nutrition, and medications to manage nausea or pain.<sup>3</sup> More than 1.2 million courses of infusions are given at home annually, most commonly via

central catheters, ports, or peripherally inserted central catheters (PICCs).<sup>4</sup> People receiving home infusion therapy are no more likely to experience adverse events than those receiving this treatment in medical settings, such as skilled nursing facilities or outpatient and infusions clinics—in fact, adverse effect, adverse drug event, and complication rates are not significantly different in these groups; moreover, home infusion therapy is associated with lower costs and higher patient satisfaction.<sup>5-7</sup> Complications related to the central venous catheters used for infusions include central line-associated bloodstream infections, venous thromboembolism, phlebitis, and occlusion.<sup>8-10</sup>

## CARE PLANNING

Ensuring the safety and effectiveness of home infusion therapy is a key priority when developing the plan of care. Three areas for consideration were identified by a technical expert panel convened in 2018 with support from the Centers for Medicare and Medicaid Services: (1) patient health and clinical appropriateness, (2) the home environment, and (3) caregiver ability.<sup>11</sup> The person's overall health, the specific condition for which she or he is being treated, the medication that will be used for treatment, and expectations regarding the quality of care that can be provided at home compared with other venues (such as skilled nursing facilities, infusion clinics, or physicians' offices) must be carefully considered when developing the plan of care. To support the safe administration and management of



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A nurse teaches a family caregiver how to properly use an infusion pump. Photo courtesy of the AARP Public Policy Institute.

home infusion therapy, a comprehensive assessment of the home environment should address cleanliness; safety; access to electricity, refrigeration, telephone services, and emergency transportation; and the health of other household members.<sup>11</sup> The Food and Drug Administration provides a useful resource for planning care, including specific issues related to the use of medical devices, such as infusion pumps, in the home environment (see [www.fda.gov/medical-devices/home-use-devices/unique-considerations-home](http://www.fda.gov/medical-devices/home-use-devices/unique-considerations-home)).

Home infusion therapy requires that the patient have support from a motivated, capable, and willing caregiver. Although the home health care agency or infusion pharmacy nurse generally provides training and support during the period of treatment, the patient and caregiver are responsible for infusions on a day-to-day basis. Discharge planning should begin as early as possible during a hospitalization to allow family caregivers sufficient time to prepare for the additional responsibilities associated with providing complex infusion care at home. Most caregivers report that they received less than one day's notice of their family members' planned discharge, leaving them feeling unprepared and adding to their stress.<sup>1</sup> The use of an extension set may enable the independent administration of infusions and flushes by a dexterous and motivated patient, but other aspects of home infusion care,

including dressings and site care, require assistance from a caregiver.

Managing costs for patients is an important component of care planning. Payments from Medicare have historically covered only some elements of home infusion therapy. This is changing as a result of the 21st Century Cures Act, but it remains important to verify insurance coverage, copayments, and out-of-pocket expenses. Services such as home health care nursing, for instance, may be covered by insurance only if a patient is certified as being "homebound." In this case, patient expectations about which activities can occur while she or he receives home infusion therapy need to be explored and managed. If patients are not homebound—that is, if they plan to leave their home regularly or frequently while receiving infusions—care at home may not be covered by their insurance, although infusions provided at an outpatient clinic may be. To minimize patient expenses, the selection of a home infusion service provider should be based on patient choice, quality metrics, and insurance coverage. Caregivers have reported that they frequently worry about their ability to pay for care and the potential negative impact of caregiving on their employment, with levels of concern rising along with care complexity.<sup>1</sup> Patients and caregivers need to be actively involved in care planning and provided with clear information about potential



## Information for Family Caregivers

### Tips for Managing Infusion Medications and Supplies

- Infusion medications need to be given at the right time and over the right amount of time. Ask the home infusion nurse to help you make a calendar that you can follow. If needed, it may be possible to adjust times to better fit with your schedule. Ask the nurse or health care provider about this.
- In the calendar or a notebook, keep track of the time each infusion starts and finishes, so you can share this information with the nurse or provider.
- Ask the nurse or provider what to do if an infusion is missed or given late.
- Practice using the infusion equipment and supplies when the home infusion nurse is present and until you feel confident you can manage them alone.
- Keep the phone numbers of the home infusion or home health care nurse, infusion pharmacy, and prescribing health care provider available, including after-hours or on-call numbers.
- When the infusion medications are delivered, check that the name of the medication is correct and that each is labeled with your family member's name.
- Check the medications and supplies regularly to be sure you have enough. Call the infusion pharmacy or nurse to reorder, ensuring the delivery arrives before the supply runs out.

### Tips for Caring for a Peripherally Inserted Central Catheter (PICC) Infusion Site

- To avoid infection, cleanliness is very important. Wash your hands carefully before and after giving infusion medications or taking care of the infusion site.
- Check the PICC site regularly, looking at the skin, dressing, line, and connections for any problems, such as irritation, redness, swelling, leaking fluid, or blood.
- Cover the PICC site with a stockinette or light bandage in between care to avoid pulling on the line.
- Keep the PICC site clean and dry. If it gets wet, the dressing might come off, and the infusion line could move or fall out. Call the home infusion nurse if the dressing gets wet.
- Before showering, the arm with the PICC should be wrapped with plastic wrap or covered in a waterproof sleeve to keep it dry. Advise your family member not to swim with a PICC line.
- Never use sharp objects like scissors or safety pins near the PICC site—you could accidentally puncture or cut the infusion line.
- Don't wrap the infusion line around the arm or fold it over—it could become pinched and the infusion might not flow properly.
- Your family member should avoid heavy lifting or strenuous activity that requires use of the muscles of the arm with the PICC line. This can increase the risk of the PICC line moving out of place.




#### Safe Storage and Disposal Tips

- Store the medications and supplies as recommended. Keep refrigerated medications on a clean shelf in the refrigerator and only remove when ready to use.
- Keep nonrefrigerated medications and supplies in a clean, dry place away from children and pets. Do not store them in a garage or car, which can get too hot.
- Use a sharps container to dispose of needles and other sharp items used during infusions. Putting them in the trash might injure other family members or sanitation workers.
- Never overfill a sharps container—two-thirds full is full enough. Ask the home infusion nurse or pharmacy about how to dispose of the filled container and for a replacement.

#### When to Contact the Health Care Provider

- If the infusion is running slower than expected, first check the settings on the pump or device you are using and then check the line for pinches or closed clamps. If your family member has a PICC, ask them to relax their arm and shoulder. If this doesn't help, call the infusion nurse or health care provider.
- Call the infusion nurse or health care provider if
  - your family member has a fever higher than 100.5°F (38°C).
  - there is skin irritation, redness, heat, bruising, or swelling at the infusion site.
  - your family member reports pain at the infusion site.
  - it's difficult to flush the line.
  - yellow drainage, pus, or a bad smell is coming from the infusion site.
  - blood or fluid is leaking from the infusion site.
  - the line is loose or looks like it's falling out.
  - the infusion site dressing is wet or loose.
- Call 911 if your family member has signs of a more serious problem, such as
  - difficulty breathing.
  - a very fast heart rate.
  - chest pain.

**A family caregiver instructional video about home infusion therapy can be found on AARP's website:**

 Operating Specialized Medical Equipment: Home Infusion Troubleshooting  
<http://links.lww.com/AJN/A191>

For additional information, visit AARP's Home Alone Alliance web page: [www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone).

costs before home infusion plans are finalized. To help patients select the best home infusion provider from the available options, nurses can share information from prior experiences, including insight from patients regarding, for example, a provider's responsiveness (including after hours), the integration or collaboration between an infusion pharmacy and home health agency or infusion nurse, and the potential for out-of-pocket costs.

Planning for the transition from hospital to home is essential to avoid any interruption in infusion therapy. Insurance authorization should be secured in advance. Ideally, patients should be discharged to home early in the day on a weekday, and only when there is a clear plan for the timely start of home therapy by the infusion provider. Medications and supplies need to be available in the patient's home prior to the start of home infusion therapy, along with a complete home infusion prescription from the patient's provider, who will oversee the person's care at home.


#### IMPLEMENTATION AND MONITORING

Home infusion therapy requires coordination of care among the patient and caregiver, infusion nurse, pharmacy, laboratory, and prescribing provider.<sup>12</sup> Clear and frequent communication will facilitate effective collaboration, improve patient care, and reduce complications.<sup>13</sup> Patients have reported that good communication and care increases their confidence in the care team, particularly when they're experiencing problems.<sup>5</sup>

## Patients have reported that good communication and care increases their confidence in the care team, particularly when they're experiencing problems.

Laboratory monitoring is an important component of infusion therapy. For patients receiving intravenous antibiotics at home, weekly laboratory testing is typical. Ongoing and deliberate action by the nurse is needed to coordinate testing logistics, including timely reporting of laboratory results to the patient's provider, so these can be reviewed and any changes to the plan of care communicated to the patient and home infusion provider without delay. Insufficient testing and delays in the review of results are associated with increased readmissions,<sup>14</sup> whereas the active coordination of care and

### Resources for Nurses

 Operating Specialized Medical Equipment: Home Infusion Troubleshooting<sup>a</sup>  
<http://links.lww.com/AJN/A192>

<sup>a</sup> Family caregivers can access this video, as well as additional information and resources, on AARP's Home Alone Alliance web page: [www.aarp.org/nolongeralone](http://www.aarp.org/nolongeralone).

team management by a nurse can reduce the risk of readmission.<sup>15</sup>

When a person is receiving home infusion therapy, the role of the home health or home infusion nurse is broadly defined. The nurse's responsibilities may include the following: assessment of the patient's health and progress; a psychosocial and environmental assessment; care coordination; patient and caregiver education and support; and the evaluation and revision of the care plan, as needed. Specific guidance for home health nurses regarding the use of infusion pumps in the home can be found here: [www.fda.gov/medical-devices/infusion-pumps/infusion-pump-risk-reduction-strategies-home-health-nurses](http://www.fda.gov/medical-devices/infusion-pumps/infusion-pump-risk-reduction-strategies-home-health-nurses).

#### GUIDANCE FOR CAREGIVERS AND CARE RECIPIENTS

For caregivers, supporting a family member who is receiving home infusion therapy can be a complex and often stressful experience. Before choosing this option for care, the patient and caregiver should understand all that is required, including the role of

the caregiver in giving infusions and monitoring the patient's condition; assisting with the activities of daily living that may be complicated by the venous access device and the patient's illness; and the management of medications, equipment, and supplies. The duration and anticipated outcome of home infusion therapy should be articulated. The caregiver's manual dexterity and cognitive capacity should be assessed and the plan of care tailored appropriately. An elastomeric infusion pump, for example, is a prefilled, ball-shaped device that uses pressure rather than battery power or electricity to drive the



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flow of the medication. It might provide a less complex alternative to an infusion pump for some caregivers or in certain situations (for more information about elastomeric infusion, see [www.wolfmed.com/blog/elastomeric-pump-uses](http://www.wolfmed.com/blog/elastomeric-pump-uses)). For a list of patient-friendly resources about medical devices used in the home, see [www.fda.gov/medical-devices/home-use-devices/additional-resources-home-use-devices](http://www.fda.gov/medical-devices/home-use-devices/additional-resources-home-use-devices).

Caregivers may feel stressed and anxious about safety when providing infusions at home and about the risk of complications and adverse reactions. They may also feel tired due to anxiety and missed sleep while providing care, worry about the financial burdens of providing care, and lack time for themselves due to caregiving.<sup>16</sup> It's important that the nurse recognizes and acknowledges this anxiety, provides emotional support, and educates caregivers in a way that allows them to develop the skills and confidence they need.

a patient handout addressing PICC care, see [www.dana-farber.org/legacy/uploadedFiles/Library/health-library/articles/picc-catheter.pdf](http://www.dana-farber.org/legacy/uploadedFiles/Library/health-library/articles/picc-catheter.pdf).

**Safe storage and management of infusion medications and supplies.** Infusion medications need to be stored appropriately to ensure their clinical efficacy. Some medications and infusion solutions must be kept in the refrigerator, whereas others can be safely stored at room temperature. Caregivers should be advised to keep the former in a clean, separate space in the refrigerator, removing the medication only when needed for an infusion. Medications that don't require refrigeration and other supplies should be safely stored in a sealed container in a clean area away from children and pets. They should not be exposed to excessive heat or moisture. Caregivers should monitor supplies to ensure there is sufficient stock on hand. Supplies should be reordered in a timely and regular manner to ensure infusions are administered as prescribed.

## Home infusion therapy requires that patients and caregivers are comfortable acting independently.

**Educating caregivers and patients.** Home infusion therapy can enable patients and caregivers to be more independent and requires that they are comfortable acting independently. Effective caregiver and patient education is essential to successful home infusion therapy. Caregivers are usually responsible for providing daily infusions and flushing lines to maintain patency, and the infusion nurse is responsible for weekly dressing changes and blood work. Understanding the caregiver's responsibilities allows the nurse to effectively prepare the caregiver for her or his role.

Education needs to be tailored to the caregiver and patient's level of education and health literacy, as well as language, culture, and preferred learning style. Reduced hospital readmissions have been achieved when education begins prior to discharge and continues at home, with hands-on mastery of managing the infusion site, lines, and equipment repeatedly demonstrated by the caregiver prior to taking independent responsibility.<sup>17</sup> Teach-back methods can be used to evaluate patient understanding.<sup>18</sup> Supplementing hands-on, in-person teaching and learning with written materials (in the appropriate language and reading level) and online resources can enhance learning. For an example of

When medications or infusion solutions are delivered, they should be carefully checked by the caregiver to ensure the name of the family member and medication are correct.

Medical sharps are a hazard for patients, caregivers, and other family members. The home infusion agency or nurse should provide containers for the collection and disposal of sharps, and caregivers should be taught how to safely dispose of sharps and blood-soiled items, when to order a new container, and how to dispose of the filled container. For a patient-friendly brochure that explains sharps risks and the dos and don'ts of proper sharps disposal, see [www.fda.gov/media/87634/download](http://www.fda.gov/media/87634/download).

**Administration of infusion medications and flushes.** For safe and effective treatment of a person's condition, infusion medications need to be given at the right time and over the right amount of time. The caregiver needs to understand the dose, schedule, and infusion duration for all the medications prescribed, including flushes, and what to do if an infusion is delayed or missed. The caregiver should know when and who to call if there's a problem. If an infusion pump is used, the pharmacy or infusion nurse will typically program the flow rate to deliver the prescribed dose for the appropriate time. The caregiver should understand

the alarms that may sound and how to troubleshoot common problems with the infusion flow. If using an ambulatory pump, spare batteries should be available, and the caregiver should be instructed in how to recognize a low-battery warning and change the batteries. Most plug-in stationary infusion pumps have built-in battery backup in case of power failure. Caregivers should be advised to keep the pump plugged in to ensure the backup battery is fully charged. They should also know how long the backup battery power will last and what to do if the infusion stops.

**When to seek medical help.** Patients and caregivers need to understand which signs or symptoms may indicate there is a problem, and when they should call the infusion nurse, pharmacy, or health care provider, even when it's after usual business hours. The most common infusion site and line complications include infection, occlusion, thrombosis, line leaking, line breakage or dislodgment, phlebitis, and skin irritation from the dressing.<sup>6, 10, 19</sup> Signs of an infection, such as fever, redness, swelling, drainage, or pus at the infusion site, should trigger a call to the infusion nurse or prescribing clinician. Potential line occlusion might be indicated by difficulty flushing the line, pain when flushing or infusing medication, or leakage of blood or fluid from the infusion site. This should also prompt a call to the infusion nurse. The line might shift or become dislodged if accidentally pulled, or if the dressing loosens. The patient and caregiver should know to apply pressure at the infusion site and call the nurse if the line falls out or is loosened and bleeding. Skin irritation may require a change in the type of site dressing used and should be discussed with the infusion nurse. Chest pain, trouble breathing, or a very rapid heart rate may be signs of a serious problem, and the caregiver should call 911. ▼

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