



National Hospice and Palliative Care Organization  
**Palliative Care Resource Series**

# **CONSIDERATIONS FOR COMPLEX PEDIATRIC PALLIATIVE CARE DISCHARGES**

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Arranging care at home for medically complex children after an extended hospital stay takes skill. Children with chronic complex conditions requiring care provided at home through a home health agency, private duty or hospice provider are at risk for unplanned hospital readmission. This article will focus on the best practice experiences of John Hopkins Pediatrics at Home (PAH) and describe five areas that are considered the Pediatric Pearls to effective patient discharge and coordination to home, improving chances to prevent frequent unplanned hospital admissions.

## BACKGROUND INFORMATION: JOHN HOPKINS PEDIATRICS AT HOME

In Maryland and the District of Columbia, at Johns Hopkins Pediatrics at Home (PAH), approximately 2000 new patients each year are served in our certified home health division, only one component of several lines of business within the company. The home health patients require multiple nursing, social work, and therapy visits. PAH works in tandem with 9 Hospice Agencies throughout Maryland and DC.

In fiscal year 2017:

- The team completed 13,500 home visits; with an average visit time of 75 minutes per visit
- The active daily census in the home health division this past fiscal year was 550 patients per day. Of these active patients:
  - ◆ a recent audit of ICD 10 codes demonstrated that 65% have at least 1 diagnosis meeting the needs for palliative care
  - ◆ 40% have at least 2 diagnoses typically referred to palliative care.
  - ◆ Caring for complex patients is PAH's specialty with an average readmission rate of 8%.

## SERVING PEDIATRIC PATIENTS: WHAT WE KNOW

Children diagnosed with medically complex conditions share the following characteristics:

- Receive health care services across settings.
- Day to day care often relies on technology (such as infusion pumps, feeding pumps, a ventilator, suction).
- Use multiple medications and often have frequent hospitalizations.
- Represent the patients eligible for palliative care and possibly hospice services.
- Move in and out of acute care facilities and require intensive work and planning to care for at home.
- Approximately 5,000 children are within 6 months of life on any given day.
- Approximately 15,000 children annually die from conditions that could benefit from supportive services such as palliative care.

### 1. Assessment

Despite the mantra "discharge planning begins the day of admission", anyone working in a children's hospital facility knows the reality, discharge is often difficult and chaotic. There is much uncertainty when working with medically fragile children and even though you plan, the discharge date may come and go. Suddenly, the family says, "The doctors making their rounds this morning

said he/she can go home today!”. This information is either met with excitement, as in, “get us out of here” or anxiety, as in “I can’t do all of this at home”.

Coordinators need to assess families early in the admission process and work with the home care or hospice organization to plan a safe discharge. Assessment of the family unit, the culture, decision making processes, communication styles, home environment and basic demographics needs to be completed in advance. Patients (age appropriate) and families should be intimately involved in discharge planning and setting goals of care. These plans should include a discussion on short and long-term goals to keep the patient home.

Children requiring the most pre-planning are those discharged to home with high tech equipment. This can range from ventilators and respiratory equipment, to infusion and enteral therapy. Children going home with a ventilator for the first time usually require at least two to three weeks of caregiver training, including a home assessment prior to discharge.

- Every company providing respiratory services is a bit different. Infusion therapy can range from a single antibiotic infusion to multiple antibiotic infusions, sometimes coupled with fluid replacement, continuous pain management or chemotherapy.
- Total Parenteral Nutrition (TPN) with or without lipids is another infusion therapy that caregivers must learn to hang a certain way, mix additives and inject them into the bag, and take down properly every day. TPN may also be combined with other infusion therapies.
- When you add enteral therapy into this mix and perhaps a dressing change for a wound that’s become infected or a central line change, you can imagine the time required to plan for a discharge and to educate and relieve parents’/caregivers’ increased anxiety.

The key is to plan ahead and complete a thorough assessment of the family unit, identify the primary caregiver, a back-up caregiver, and get a sense of the family daily routine. Usually the schedule when medications are given in the hospital is adjusted for home, so it is more suitable for the patient and family. This is important information for families because the case managers on the units and the families sometimes go home with the impression that all the care must be done exactly at the times and in the manner, it was in the hospital. This is not true and is a primary focus of confusion for families.

The primary caregivers should meet with the home care organization prior to discharge. Single parent households; and/or caregivers with additional young children at home are at increased risk and a back-up caregiver should always be identified prior to discharge. Single parents with no back up adult caregiver often become overwhelmed providing care; especially when there are additional young children at home also requiring attention. In addition to the administration of therapies, dressing changes, or medication adherence caring for a child with complex needs takes time, a great deal of organizational skills, practice and confidence. Home care clinicians should spend time on visits up front, to allow time for the caregiver to become independent and comfortable providing care.

## **2. Teaching Parents/Caregivers**

Teaching equipment used at home is an important aspect of discharge planning. Simulation teaching using the actual equipment including teach back is best practice. Use of an interpreter during

hospital teaching is a must if a family is non-English speaking. Videos of how to use equipment for non-English speaking patients and families has proved to be a real enhancement to their education. We make these videos available to our families in the hospital via an IPAD and are working on different language videos for our web site and a phone app.

Traditionally, teaching of equipment for home use has been done at the bedside; however, parents have reported improved satisfaction and comprehension when taken out of this setting. Pediatrics at Home completed a process improvement project comparing teaching at the bedside versus taking parents off the unit to a simulation room.

- 75% of caregivers preferred the simulation experience out of the patient's room (fewer interruptions) and rated themselves higher in self - confidence prior to discharge.
- The 25% of caregivers who preferred to remain at the bedside were mostly families of patients in the NICU and infant unit. Parents were hesitant to leave the NICU bedside.

### **3. Medication Management**

Medication management is a vital component to safe discharge. At Johns Hopkins Children's Center, we have a concierge program. The Johns Hopkins out-patient pharmacy delivers oral medications right to the bedside prior to discharge and a pharmacist reviews medication with each parent or caregiver. Medication reconciliation is an important focus prior to discharge as well as when the nurse makes a home visit.

In our practice, 20% of the time, the discharge instructions do not match the medications prescribed to patients. Most of our referrals come from large medical centers in our region. During fiscal year 2017, 31% of our safety events were related to medication discrepancies discovered by the home care nurse during medication reconciliation in the home. A common example:

- The parent has watched the floor nurse give 5ml of a medication by mouth the entire hospital stay. When discharged, the retail pharmacy mixes a totally different concentration of the medication (what is available in the out-patient environment). The new directions are to administer 1ml orally. This is much different than what was given in the hospital. But it's very easy for the parent to dismiss the directions and remember that 5ml was given in the hospital. This can result in a serious over-medicating error for the patient.

Nurses need training in medication reconciliation. Best practice is to stick to one method, teach and monitor compliance through supervisory home observation. Simply asking the caregiver, "have any of the medications changed?" does not suffice. Every organization should have a standard operating procedure for medication reconciliation. Asking caregivers to read the prescription bottle and verbally describe their process is important. Medication reconciliation should be completed on every home visit.

### **4. Establishing Home Visit Frequency**

Today, everyone in healthcare is trying to find efficiencies as we are all charged with doing more with fewer resources. When a child with complex illness and multiple therapies is discharged to home, the first few weeks at home should be front loaded. Schedule visits with increased frequency

immediately after discharge home, while you are teaching families, building their confidence, partnering with private duty or home health care providers and providing increased support. The visits don't need to be long. After the initial visits and training, even a quick visit lends itself to build the family's trust and confidence and will allow the caregivers to demonstrate care and the staff to observe and reinforce. This process will improve overall compliance and may lower unplanned readmissions. It is especially true for single parent households or foster families that have additional children in their care.

As one example, a patient with new Total Parental Nutrition Therapy (TPN) requires more than one nursing visit post discharge. This is a complex therapy that often requires a set up visit, a take-down visit and additional visits the same week to observe correct procedures. Multiple teaching visits in the hospital prior to discharge may decrease the number of visits the first week. Take advantage of these multiple visits and send therapists out with the nurse to introduce additional disciplines such as social work. If you are partnering with an agency such as private duty or home care this is a perfect time to make visits together and introduce the team approach.

### **5.Communication Post Discharge**

Any home-based health service requires clear and frequent communication with the case manager or home care coordinator prior to discharge. Discharge planning meetings for complex cases, especially patients needing private duty, should be frequent and all parties caring for the child at home should attend. Planning the exact day and time of discharge and synchronizing that with the timing of the patient/family receiving orders upon discharge from the hospital is extremely relevant to any home care provider, especially when infusion or home medical equipment needs to be delivered to the home for immediate use.

Demographic information taken from the hospital chart should always be reviewed with the parent or caregiver well in advance of discharge. Confirm everything – patient's living situation and insurance information can change between the time of admission and time of discharge. Community palliative care provider follow up with the ordering physician, specialist or hospital case manager is always considered best practice. This builds trust with acute care providers and builds your business.

Once home, the concept of "welcome calls" by the home care agency is common practice. In Pediatrics at Home, a customer service representative makes calls to every patient 24 to 48 hours post discharge. This person calls to welcome them to the organization and to rate their discharge experience, check on the first home care admission and to ask if anything was left undone or unsatisfactory. These calls are unscripted, but the customer service rep has a standard operative procedure to follow. It's also a great reminder to check on follow up pediatrician or specialist visits.

## **A NOTE ON UNPLANNED RE-ADMISSION**

A pediatric readmission rate is documented every quarter for the admissions to the Pediatrics at Home program. This is not the hospital readmission rate, which includes all patients discharged from a facility. Admissions from all referral sources are tracked as are trends by diagnosis, reason and facility. Over the last five years, our average rate of pediatric readmission has been 8%.

There will always be unplanned hospital admissions with this vulnerable patient population; this is unavoidable. The most frequent reason we find is due to premature infants having respiratory or feeding issues, followed by admissions for fever (mostly Oncology and GI patients). We trend these reasons and develop action plans to address prevention and report back to our referring facilities. We also track any readmission within 24 hours after discharge. In these cases, we look for issues related to discharge planning or unstable clinical conditions.

## DESIRED OUTCOMES

Care at home is not for every child. However, for most children and their families, the desired outcome is to help them find their way back to their family home, school and community as this will improve their quality of life during this journey. Consequently, our goal must include a safe and effective discharge plan to secure a safe stay at home and avoid frequent readmissions to a facility. Supporting families to bring their children home and empowering them to provide care builds trust and develops a relationship that is essential when end-of-life care is needed.

## REFERENCES

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