



Complex Child E-Magazine

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Patient Centered Care in Home Health Care Companies

by Abby Brogan and Donna Noble

Like many families new to complex medical needs, we struggled at home for seven months before we finally got the help we needed with our home health care needs. Our daughter Ellie was born in 2006 with Jejunal Atresia that resulted in short bowel syndrome. After eight months inpatient, she was sent home on Total Parenteral Nutrition (TPN) and enteral feeds. This dropped us into the challenging world of home health care companies, weekly deliveries, supply forms and inventories. Not knowing about options, we chose among the biggest of the companies thinking they likely didn't get that way by being bad.



But then small mistakes happened. And then bigger things happened.

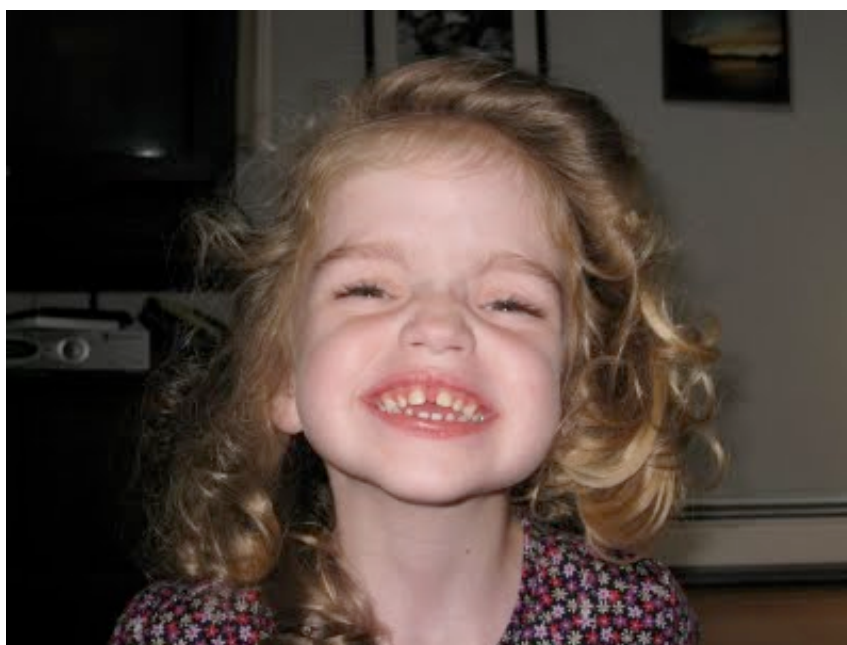
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Missing supplies. Wrong supplies. Late orders. A sense that the people who were supposed to be supporting us were working against us. Struggles and frustration. I simply assumed that this was what everyone dealt with when it came to their home health care companies.

Never ending frustration was our world for the first seven months at home with our daughter.

You Have Options

In the summer of 2007, we went to the Oley Conference on Cape Cod and learned all about our options. During a lunch hour at the conference, I met a mother who had been dealing with TPN and enteral feeds for many, many years. She told me about her experiences with her home health care company, explained that we didn't have to settle for "good enough," and that demanding better care from our current company was within our power. This also introduced the idea that there were companies out there that "get it."



When we got home, we very quickly realized that things were not going to get better with our current company, and it was time for us to start shopping for an alternative. For the next month, we investigated the options beyond the big companies and ultimately settled on ThriveRx (formerly NutriThrive). At the time, this company was a start-up, but spoke about a new concept in supporting patients and their families needing nutritional support: Patient Centered Care. It was this Patient Centered Care that made our lives easier, helped us care for Ellie, and increased our knowledge of nutritional support and all that comes with it.

Eventually I liked what they were doing so much that I joined the team as a Consumer Advocate. That is where I met Donna Noble, the other Consumer Advocate, and learned even more about Patient Centered Care.

Patient Centered Care

What is Patient Centered Care? It is an idea that was started at the Institute for Family and Patient Centered Care, a nonprofit that was established in 1992. Patient Centered Care is based on four core concepts:

1. **Dignity and Respect.** Health care practitioners should listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds must be incorporated into the planning and delivery of care.
2. **Information Sharing.** Health care practitioners should communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families need to receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
3. **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at whatever level they choose.
4. **Collaboration.** Patients and families should also be included on a company-wide basis. Health care leaders should collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

Now what does this patient centered care look like in a home health care company? It involves individualized attention, supplies and services specific to what each individual client needs and wants, and access to continuing education on issues relating to your diagnosis and therapies. This means, for example, that you can choose what enteral or IV pump best fits your needs, what brand supplies you want, and that you have access to copies of your laboratory results and nutrition orders.

Benefits of Patient Centered Care to Everyone

First and foremost, the patient and his or her family benefit by the fact that they are known by their names and diagnoses and are never treated as "just another number." Through the educational tools available to them, patients have a better understanding of their current medical issues, and the options that are available for dealing with their current issues. The patient becomes part of a team that works toward better health. There are people available to help with ideas for coping with a life that can be difficult, and information on how to connect to other consumers and support groups in their area. Collectively, these benefits significantly improve the quality of life for the patient.

The home health care companies benefit by providing Patient Centered Care because they have a better understanding of their clients' current medical issues and health status. The company is more involved in the decisions that are made about their clients' care, and therefore have healthier clients, less errors, and fewer emergencies. They also have a much better understanding of the needs and wants of the client and the demands that a life on nutritional support puts on the client. Most importantly, happy clients spread the word and bring in more clients.

The clinical teams providing care for the patient benefit by getting more complete information about their clients, which is the foundation of good care. The home health care company is also able to provide expertise to improve care, especially for patients who are being treated at smaller hospitals or physician's offices away from care centers with dedicated nutritional support teams. Lastly, the doctor benefits by getting a second set of eyes to monitor the patient, the parenteral or enteral nutrition orders, the patient's labs and new medical advances that may be available to their clients.

Obtaining Patient Centered Care

So how do you get Patient Centered Care from your home health care company? Unfortunately, this common sense approach is not common among all providers. In most cases you must ask for it, demand it, and if you can't get it, you must then go find it.

A good first step is to ask your home health care company about the supplies or services that you want and ask what other services they have to offer you beyond just supplies. There are many different types of tubing and formula and many ways to service each and every consumer. There are many, many companies out there, and if you start knowing what you want from your home health care company, you are bound to find the one that works for you. Ultimately, you are a customer, and you have a choice where you shop and a choice of who services your needs and wants.

And as the mother instructed me back in 2007, never settle for "good enough."

Abby Brogan lives in the Boston area with her husband and daughter Ellie. Ellie was born in 2006, missing 90% of her small bowel and 30% of her colon due to Jejunal Atresia. Ellie is diagnosed as having Short Bowel Syndrome. Ellie has had many surgeries since birth and is on tube feeds, and Home Parenteral Nutrition (HPEN). Abby and her family have faced the many challenges that come along with having a child with tubes, yet lead a remarkably active lifestyle. Abby hosted a round table at the Oley conference in 2009 on How to Get the Most Out of Your Clinic Visit.

Donna Noble is the parent of a child fed by enteral and parenteral nutrition for eight years. She has experience with G-tubes, J-tubes, ostomies and central lines. Donna is a special education teacher and has developed individual health plans, IEPs and 504 plans. Nutritional therapy did not keep the Noble family from traveling both domestically and overseas. Donna has many tips and tricks to make traveling with tube feedings or

parenteral nutrition easier. Donna's professional activities include: presentations at the 2009 Oley Conference on Making the Most of Your Clinic Visits; IHP's, 504 Plans and IEPs--What's the Difference; an article on IHP's, 504 Plans and IEP's published in the Oley LifeLiner Newsletter; the development of Parenting the Child with Special Medical Needs in conjunction with staff at Nationwide Children's Hospital; and a presentation on Family as Faculty at the 4th International Conference on Family Centered Care.