Understanding The Need

For families of a critically ill child, the deluge of needs can seem overwhelming. Tommi McHugh sees and hears it all. As a therapist with Denver Children's Hospital's unique Therapeutic Recreation/Child Life program, she helps patients and families cope with illness or injury, the hospital setting, and the treatments. So working on several recent pilot projects with There With Care (TWC) gave her a lot more resources, and hope.

"How cool is that," says McHugh, delighted that she can now extend assistance beyond the corridors of the hospital. "How cool is she, says her fans at Children's.

In an army of angels, McHugh works with several dozen families at a time, whether for a day, or over a long-term illness. In calming, honest toes, she demystifies the whole process for frightened and confused parents and siblings. Her experience has taught her that the parents go through enormous stress, yet their role is key. "Parents are the number one source of comfort to the kids during scary times."

Whether the child is undergoing a kidney transplant, cystic fibrosis or starting physical rehab, life changes for the whole family.

The New Normal

"We try to promote normalcy, we talk about the family's "new normal,"" says McHugh. "Cancer isn't a 5 minute thing, so we figure out how to get to the 'One normal', so you don't spend the rest of your life living in chaos."

While McHugh and TWC's goals are noble, they are the first to admit that they cannot cure illness, nor eliminate all of life's burdens for the families. What they can offer is assistance with the countless, day-to-day, time-robbing tasks that face all families.

"We give parents the tools to find better balance and handle needs. It's enormous. Just because your child is sick, you don't get to give up everything else. Imagine if suddenly you're a parent of a sick child, you've got kids at home, you've got to be at Children's Hospital 5 days a week. You need normalcy."

Juggling her sick child's needs while settling an older daughter into a new school was stressful but TWC was able to help by stocking the apartment with meals and food. The burden of shopping and cooking for the family was lifted. "The struggle is the day to day tasks, TWC helps with that so the parent can focus on caring for the sick child and siblings," says McHugh.

"It isn't everything but we can say to a few families here's what we can take off your plate and what we can put on it instead. TWC is a tool to get to the 'new normal' faster."

What exactly do families of a sick child require? According to McHugh, the need is varied yet endless. For instance, a bone marrow transplant takes a minimum of 21 days, so the parent needs to be at the hospital daily while managing all other tasks.

"If you have infants or toddlers, you want to be here, or at work, but you can't physically do all these things," says McHugh. "Also, these needs cross boundaries, it's not just oncology, or Denver. She notes, regardless of location or what they are dealing with, they could use a hand." 

A sick child affects all families. "The needs cross the socioeconomic spectrum, even with financial resources, the experience is a drain on their time, energy, emotions."
Volunteer Spotlight

by Jill Sherman

TWC Wish List

New or gently used:
- Cribs
- Crib bedding
- Baby clothes
- Baby blankets
- Car seats
- Strollers

Because of Volunteers

We mentored three teens faced with going through treatment alone.

TWC provided two children cell phones with 'free' minutes to keep connected with their families.

Four families were provided with key psychotherapy for the parents.

TWC News

There With Care (TWC) started receiving family referrals from the Denver Children's Hospital and Presbyterian/St. Luke's Hospital in November 2005. Our first volunteers began providing services to families in early December 2005. As of October, 55 families have been receiving services and the number continues to grow weekly. Here's a story from one of our first volunteers who is experiencing how our services make a difference... one family at a time.

"At this point in my life volunteering has taken on a whole new meaning," explained Nancy Damero, one of the first TWC volunteers working directly with several families caring for their critically ill children. "In the past, I have volunteered at my kids' schools, but I have never really had the time to do much more outside of my own family until now. I had no idea what to expect when I joined TWC. After delivering my first load of groceries to a family, my life has been changed forever."

What It Means to Volunteer

Nancy's story is not unique. Other volunteers have also had the same reaction to helping a TWC family. Initially, volunteers are afraid that getting involved with a family caring for a child with a critical illness will be emotionally draining. However, once they have their first experience and realize how grateful the families are for what they do, it is very uplifting, and they want to help even more.

Some of the families receiving TWC services have been displaced from their homes in order to receive proper medical care. Everyday necessities from food, clothing, transportation, housecleaning, counseling, and more aren't easily accessible. The entire family's lives have changed and keeping everything as normal as possible is difficult to navigate. For example, something as simple as shopping for groceries can be overwhelming and exhausting to organize. TWC volunteers take on these tasks and give the family time with their children.

Lessons Learned

"The first time I went to deliver groceries to a family I was a little apprehensive because people tend to have a hard time accepting help from a stranger and it felt odd giving it," said Nancy. "I didn't want to appear condescending, I just wanted to help out discreetly. At first it was a little awkward, but my relationship with the family evolved slowly. I learned how to communicate with them in a way that felt safe for all of us. I am so grateful they let us into their lives."

Understanding The Need

Another family was recently referred to TWC by a hospital social worker. The sick child was returning from the hospital but needed its own bed because of a compromised immune system, so the one-bedroom home was no longer appropriate. TWC provided basic household supplies, bedding, clothing and more.

To McHugh, the list of resources that TWC offers is unique and comprehensive. "Lots of people come in and say they want to help," she says. "Paula came in with a plan she wasn't just talking. Alan Johnson, our chaplain, and I knew this was going to be Big, and was going to happen. Paula has energy, experience, desire, flexibility, and it's not a short-term vision."

What's next for There With Care? "The need is endless," says McHugh. "For families of critically ill children, TWC is the small comfort that can make a big difference in their lives."  

Continued on Page 3
The volunteers and families go through a process establishing a trusting bond that "it's okay to accept help." It's a delicate balance that gets worked out differently with each family. The kids are most natural and have a beautiful way about helping their parents feel comfortable. It's a little harder for the adults. The unsung energy the kids give off is so moving for the volunteers.

Putting It All Together
Family needs are sporadic and most volunteers are assigned more than one family. Many volunteers also get involved in administrative tasks at TWC's office or out in the field collecting large and small donations. There are times when volunteers are sorting groceries or expanding the volunteer training manual based on something new they learned from helping another family. It's a team effort all around.

"It's two different worlds," continued Nancy. "Coordinating logistics, shopping for groceries, or making connections to professional services, that's the leg-work. But going into a family's home and bringing them the most basic of necessities is when you see how our services matter. There is a gap in the care system. It is so stressful for these families, they need to be able to express their needs and get assistance. I'm surprised that nothing like this has existed until now."

It's a delicate balance that gets worked out...

Keeping It Real
The reality of TWC came all too soon for the staff and volunteers. We recognize that we cannot change a child's medical situation, yet if we did nothing many of these families would be alone. One family lost their child just three weeks after Nancy started working with them. She was able to give the mom a few less things to worry about and a little more time to be with her son before he passed away.

"It's a very humble service you are offering," concluded Nancy. "You're not walking into a situation like a hero, you're not going to make everything better, but you can ease the burden. These families feel alone and isolated. Having a sick child is enough to handle. I am honored to have done what little I did for this family and only wish I could have done more."

Shortly after the funeral the mom told us that she wished TWC had been there for the past two years. Unfortunately we cannot change the past, but hopefully by helping a little we can impact the future for families caring for a critically ill child.

Call for Volunteers
There With Care welcomes new volunteers. If you are interested in learning about becoming a volunteer send an e-mail to info@thereewithcare.org or click here.

Programs
TWC provides Parent's Catch Up Night which is babysitting for the kids of parents staying at The Denver Ronald McDonald House every other Tuesday night giving them a break.

With the Soup Station, we continue to provide soup/sandwiches and sweets every Saturday to the families of the neonatal ICU at Presbyterian/St. Luke's Medical Center. This heartwarming service gives the families support, comfort and community.

We are starting to lay the groundwork to create Medical Educational Programs for medical students to participate in service with patients, allowing them to get credits for school.

Caroline Langley participates in a Monthly Legal Support Group for young people who are sick and over 18-years of age, offering them free legal advice to protect themselves.

We are starting a Cancer Stories Program where a book is created documenting a patient's experience by their volunteer. The books will be bound and given to the patient and each book is paid for through a grant. It's a purposeful way for a volunteer to work with the patient they are mentoring.

Fundraising
We are proud to share we have received the value of over $150,000 in volunteer time and donated professional services getting TWC off the ground so far this year. Funds are also needed to purchase groceries, gas, services at a reduced rate and other administrative expenses (media materials, printing, supplies, etc.)

Recently, the owner and families of Boulder's Harmony Pre-School held the Annual Harmony Pre-School Garage & Bake Sale. Parents brought their items down and many volunteered to sort & set up and man the sale. They raised over $2,000 to help our families! They were quite amazing and it was inspiring to see them pull together as a community.

TWC News
Since the inception of There With Care, we have had the privilege of watching the community grow together to care for the families of critically ill children. The idea of supporting them has now become a reality and the passion and energy from everyone involved is quite amazing.

Every family is different with a broad range of needs. By listening to the parents and social workers, we learn from them how to best meet their needs. We are inspired daily by the children and families and how they endure their ordeal with such grace and strength.

Sadly, the need is greater than we had imagined, yet the work has been positive and is making a difference. Everyone involved is touched by the families and are humbled to be able to help them during a time of crisis. The families, social workers, doctors and other staff share their appreciation daily for the support.

Currently, there are over 50 amazing and talented people volunteering in various capacities to nurture the organization. Without them, none of the work we are doing would be possible. We are building a strong and steady foundation for the model here in Colorado which will serve many more families nationally in the future.

The mission is on track and the need is great. We hope that you will enjoy the update and welcome you to participate in any way that inspires you.

With Gratitude

We express deep gratitude to the volunteers of There With Care. They are caring, kind, loving, generous with their time, thoughtful, hard working, talented, devoted, creative, collaborative and truly people who are There With Care. Thank you to all of you who give of yourselves to help others, you make a difference. With appreciation to Laura, Ali, Jessica & Ingrid for everything you do!

We want to thank the hundreds of people who have donated household items, baby items, clothing, food and so much more which have truly eased the burden for so many families in crisis.

Thank you to our Board and Advisory Board who help guide and support our organization. And thank you to the exciting and creative Events Committee who have created the vision for our future fundraisers & awareness campaigns.

For a detailed list of volunteers and contributors please visit our website www.therewithcare.org

Mark your Calendars! TWC Upcoming Events

- February 2, 2007 - Look for There With Care's Annual Event at The Boulder Theater - "All The World Is A Stage" - Stay tuned for details!
- November 3rd - Volunteer Appreciation Party
- November 22nd - Delivery of Thanksgiving Meals to our Families.
  Sign up now to volunteer for this project.
- Fall Fundraisers are happening in your neighborhood - contact the TWC office to attend or host one.
- Summer of 2007 - Exciting Film Event - Details to be announced.