

Homeschooling with a Chronically Ill Child

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Most people don't realize that when a child is diagnosed with a chronic illness, the family is diagnosed with the chronic illness. No one escapes. When our son was diagnosed, the doctor informed us that 70% of the marriages in his practice end in divorce, and the teen pregnancy rate is significantly higher than the national average. I was shocked.

Homeschooling is challenging. Homeschooling with a chronically ill child defies description. The time, energy, and financial resources dedicated to the management of the illness can be staggering. We have not only the normal, every day challenges of cleaning, laundry, grocery shopping, and child training, but we also have the added challenge of doctor appointments and medical crises. In the first four months of this year, I drove 5,600 miles to 52 doctor appointments in Richmond as well as out of state. The constant physical, financial, and emotional strain takes a toll.

Before my son was ill, I would read through those "how to help" articles and think, "Got it: make dinner, pray, occasionally help with a daily chore." When people started asking *me* how they could help, I generally had this "deer in the headlights" look because I just didn't know how to answer. The list is huge; the needs are great. My goal is to help you understand *why* that list exists, and give you some practical ideas on how to come alongside these families.

Encourage us

Every "how to help" list suggests sending a card. Now I understand why—I can put a card on my desk. When I see it sitting there, I remember that someone out there is praying for my family and loving me even when I have no time to return a phone call or an e-mail. It is a tangible reminder that I am not alone. E-mail is great, but I don't see that e-mail when I walk past my desk.

When Job lost his family and material possessions, his friends came by and sat with him for a week and said nothing at all. They just sat with him. You have no idea how much it means to someone grieving (and we do grieve over the health of our children) to let them know that they are not alone. Pray for the family, and then drop them a note that tells them you prayed for them. The card on the shelf is a reminder that we are loved, not only by our friends, but by our Heavenly Father.

Remind us

Remind the family of what is true. We often hear, "God won't give you more than you can handle" or "God doesn't make mistakes." We know that God is sovereign and that He has a plan that we just don't understand. We need to be reminded that God loves us and our children and that even in *this*, God is showing Himself to be faithful. He has not abandoned us. Send a scripture verse with a note that explains why that Scripture is important to you.

Come alongside us

Help us avoid our isolation. Doctor's offices and hospitals are lonely places, especially when we are out of town. At home, the needs are so great that we just keep plodding forward. There is no time to do anything else. We would love to go out for coffee or visit for an afternoon, but school and housework are already incomplete. How do we afford the time?

If you would like to visit, suggest working on a job together. That bathroom that is half painted can be finished in an afternoon with a friend. Not only do we get to see a friend, but we get to complete a task that never leaves the list. There are many jobs that two can do... weeding a flower bed or ironing together while we chat. If you simply want to visit, offer to come over for an hour and bring a snack to share. It is a manageable amount of time for both, and your snack removes the panic of "how to be hospitable."

Include our children

Homeschooling brings monumental pressure. Older children are able to manage because they can work independently, but younger children are a whole different ballgame. We have a family friend who volunteered a couple of days a week to keep my younger children moving forward academically. We would have lost the majority of this school year if not for Erlene.

Another family invited my older children to their home for a science and world geography class. We were able to keep that one afternoon a week available for that class, and my older children were able to see their friends and complete two classes that I did not have to manage at all.

The child that is ill gets the vast majority of the attention. He also gets to escape household chores because he is either ill or at a doctor's office. The other children, therefore, carry a heavier load, and they do so with less supervision and attention. They are just as isolated as I am. Consider including them when your family does something fun like going for ice cream or visiting a museum. If your child is playing a team sport, ask if you can transport our children too. My children would love to play sports or take ballet, but I simply don't know how to make it happen.

Pray for our marriages

When the family is assaulted by a chronic illness, the strain on the marriage is truly unbelievable.

I am utterly swamped trying to keep up with daily life as well as all of my son's diagnoses, medications, and how he feels each day—any change in the morning could have consequences for the afternoon. He has multiple issues and two of them are rare and little understood.

My husband is swamped at work and feeling the pressure of excelling at his job while still maintaining a relationship with me and the children. Changing jobs takes on a whole new perspective when you have to consider the health insurance issue and whether or not your son would be insured by a different company.

Add in financial pressures from medical expenses and just the traveling (36,000 miles per year driving to out-of-state physicians), and the marriage struggles. Time is what we don't have but what we need to nurture the relationship. How marriages survive without Christ is truly an enigma to me. Please pray for us.

Families with chronically ill children struggle in unique ways. Below is a list of ways you can come alongside these families and show them the love of Christ in real and tangible ways. This list is by no mean exhaustive, but I hope that a greater understanding of the struggle will help you think of creative ways to help.

1. Send a card. Really. It is fairly painless for you and provides immense encouragement to the recipient.

2. Put flowers with a card on the porch just to brighten their day. These can be wildflowers in a Mason jar. Just the fact that you took the time to do it is appreciated.

3. Provide meals. Don't underestimate the help of a meal. Not only do we not have to think about what to prepare, but we don't have to go to the grocery store to get the ingredients. Just be sure to check with the family regarding food allergies.

4. Offer to go to the grocery store. We need groceries too, but sometimes just getting to the store seems like a monumental task.

5. If you do call or send an e-mail, feel free to talk about the mundane. Our identity tends to become the illness. Not talking about it is amazingly refreshing and reminds us that there is more to life than "the illness."

6. Be patient when we are slow to respond to phone calls or e-mails.

7. Visit.

Offer to help complete a job that the family is struggling to complete.

Offer to bring a snack.

Offer to stay for a specific, short period of time.

8. Offer to keep the children for a weekend so the parents can have a complete conversation that doesn't revolve around the illness, the children, or what needs to be done next.

9. Offer homeschooling help
Teach a class for the family for the school year.

Include one or more of the family's children in a class you are teaching to your own children.

Substitute teach for the family when the sick child needs to go to a doctor appointment.

Come one day a week to assist with schoolwork in whatever form is helpful.

Offer to include the children when you go on a field trip or visit a museum.

Offer to help transport children for team sports or ballet.

10. Help financially

Give restaurant gift cards that can be used by the parents for a date or by the family when they are out of the area at a doctor appointment.

Buy gasoline gift cards for doctor appointments. Last year when gas was so expensive, our gas budget exceeded our mortgage.

Offer tickets to an aquarium or museum when the family has to go out of town. Generally, just parents go with the child, so it may not be as expensive as purchasing tickets for the whole family. Our son was blessed with a trip to the aquarium and the Coke Museum in Atlanta this

past winter. It was a huge gift for him and it helped ease the stress of the reason for the trip. He has a great memory of that trip because of the aquarium.

Purchase a museum membership for the family. It provides “fun” outings for them for a full year.

Surprise the children with small gifts. Recently, someone in our church specifically asked what each of the children enjoyed and gave them each a gift to encourage them. It doesn't have to be expensive.

11. Make hospital and doctor visits

Don't underestimate the loneliness of hospitals for the child and the parents. Be aware that everyone is tired. A hospital is not a place of rest. Keep the visits short.

Bring food. The child may or may not be able to eat, but the parents can, and the cafeteria gets old really quickly. You could even offer to bring a meal for you and the parents to share. Healthy food is a mystery at the hospital so consider fresh fruit or a homemade treat. Even a beverage can be a welcome treat.

Give or lend a book or movie to the child. He is bored and stressed, and a book or movie allows him to “escape” for a little while.

Bring balloons. Balloons are a reminder to everyone that they are loved and are being prayed for. Again, don't underestimate the isolation of the illness...even on a good day.

Enlist your friends or relatives. A friend's mom who lives in Toledo helped us navigate the hospital there and find a local restaurant. She was a voice of home when we were far from home.

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