

Have you thought about..

What NOT to say to parents
with medically complex kids



children's healing center®

Sickness affects everyone – rich, poor, old and, yes, even young.

Chances are you know someone whose child has been diagnosed with a life-threatening or life-altering disease. From kidney, blood and heart disorders to arthritis, cancer and autoimmune conditions, these medical diagnoses upend a family's life.

Loved ones often reach out to ask how they can help. Or perhaps to offer helpful "advice."

The problem is these well-intentioned people can leave the family feeling worse. What seems like an innocent conversation starter may be a trigger for families experiencing medical trauma.

Of course, most don't intend to offend – they just don't know what to say. And that's OK – sickness is scary, confusing, sad and complicated. By taking a few minutes to think before you speak, you'll likely find a way to be helpful – rather than pile onto the family's difficult reality.

This short booklet shares some common phrases families experiencing medical trauma hear that are less than helpful – and offers suggestions of what to say instead.



DO NOT SAY

“How is your child doing?”

A casual conversation starter, this phrase can be complicated for a parent with a sick kid. Generalizations are almost impossible to answer because parents often have a day-to-day – or even minute-by-minute – outlook.

Instead, try:

“Did you learn anything new at Mia’s doctor visit this week?”





DO NOT SAY

“Have you thought
about trying XYZ?”

Families have likely exhausted every resource available to them. They've consulted Western and Eastern medicine, Google, specialists, books, other families in similar positions – and probably looked to a deity or two. Asking if they've heard about the latest craze you read on a blog is not helpful.

Instead, try:

“I did some research to better
inform myself about what
Aiden's sickness entails.”

DO NOT SAY

“They don’t look sick.”

Not every sick child has visible symptoms. Diseases attack the body differently and have varying impacts on quality of life. A medically challenged kid may be able to run, jump and do other things a kid who isn’t sick can, but it may require greater recovery time, for instance. Find something positive to say about the child.

Instead, try:

“Sophia has the best smile
– it’s really lovely to see.”





DO NOT SAY

“This worked for my friend; why isn’t it working for you?”

A treatment plan is as unique as the individual. Just because a certain treatment works for one person does not mean it will work for another. Parents are working with their care team – and child – to find a solution. They don’t need another consultant.

Instead, try:

“Has Noah’s care team provided any new treatment options?”

DO NOT SAY

“Will they ever get
back to normal?”

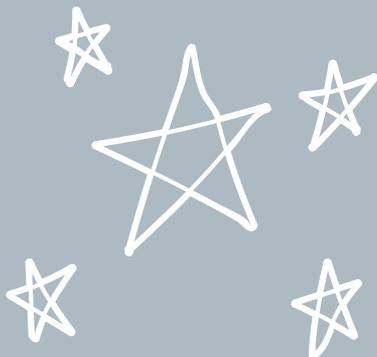
What is normal anyway? By asking this, you imply the child is “other.” Every kid is special, unique and loved. Normal is just a setting on the dryer; it has nothing to do with life.

Instead, try:

“Have you found ways for
Benjamin to have some fun?”



DO NOT SAY



“We’ll stop
inviting you since
you never come.”

A medical diagnosis is an isolating incident. Families often shelter away from the world so their child can stay safe. Friends and neighbors may understand this in the beginning and think they’re trying to take the pressure off. But when kids stop getting invited to activities, it can dig a deeper hole of despair.

Instead, try:

“Even if Noah can’t join,
we wanted to let you know
we’re thinking about him
and look forward to seeing
him when he’s able.”

DO NOT SAY

“At least it’s not X”

No matter what, a serious medical diagnosis will negatively affect a kid’s life. Comparing a diagnosis to a more severe disease is insensitive, even if you are “trying to make them feel better.” Families are figuring out a way forward – one disease is no easier to navigate than another.

Instead, try:

“What would you like me to know about Harper’s diagnosis?”





DO NOT SAY

“What can I
help you with?”

Truly, a nice gesture, but it is not helpful. By saying this, you put the responsibility back on the person dealing with sickness instead of lifting a weight from their shoulders.

Instead, try:

“Can I come clean your
house, drop over a meal
or run an errand?”

DO NOT SAY

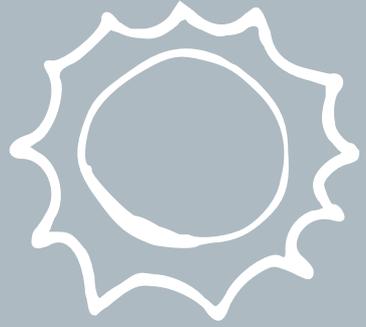
“God won’t give you anything you can’t handle”

A frequent statement in faith communities, this is often painful to hear. Families all respond differently when they receive the diagnosis, and many even question their faith. Do not trivialize their grief – no matter how devout they may be.

Instead, try:

“I will keep Malika and your family in my prayers.”





DO NOT SAY

“I don’t know how you do this.”

While meant to compliment a parent’s strength in handling their child’s diagnosis, this phrase can be very triggering. Most people have no concept of how a medical diagnosis changes day-to-day life. Some parents, while outwardly strong, may be crumbling inside.

Instead, try:

“What is one obstacle in your way today?” Then remove it.

DO NOT SAY

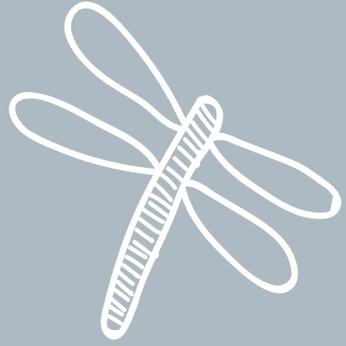
“All kids get sick.”

While true, it's beside the point. Healthy children who get sick usually don't land in the hospital fighting for their life.

Instead, try:

“Has Mason had any changes to his condition?”





DO NOT SAY

“Look at the bright side...”

Here's the thing, sickness sucks. There's no way around it. By telling someone to look on the bright side, you're telling them their pain doesn't count.

Instead, try:

“I'm here to listen
– whenever you need an ear.”

NEVER SAY

“God only takes the
best ones.”

Absolutely never.





Listen, Listen, Listen!

When you put your foot in your mouth, which you likely will, acknowledge, apologize – and learn from it.

It's OK to have realistic conversations with these families – they have already faced conversations most of us never will. You won't ask them a question they haven't heard or express a concern they haven't felt. They are often ready to talk about their child's diagnosis, but you should let them lead – and be respectful.

Most importantly, always LISTEN – and don't try to fix. You really can't. A support system is what families experiencing medical trauma need more than anything. Just being there is the best way to help and support.

The Children's Healing Center

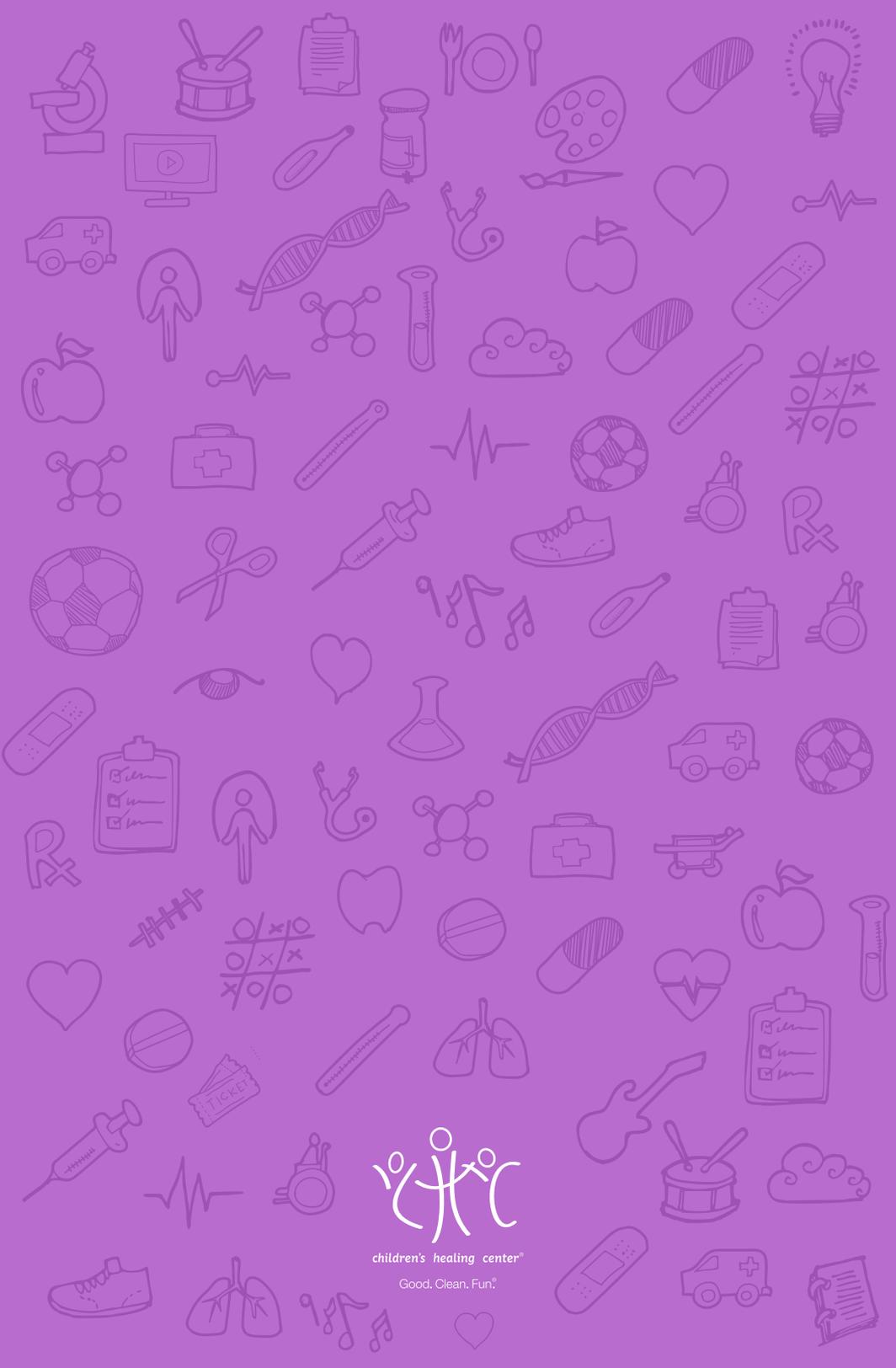
The Children's Healing Center is the first year-round daytime recreation facility for kids with weakened immune systems and their families. Open to ages 0-26 who are immune-compromised and their families, the Center is an oasis for members to step away from the stress of a complex medical diagnosis to experience the healing power of Good. Clean. Fun.® With a focus on socialization, play therapy, recreation and education, kids, young adults and families have a safe space to express themselves, interact with others and feel a sense of belonging.

Learn more at [ChildrensHealingCenter.org](https://www.ChildrensHealingCenter.org)



About This Booklet

A group of parents led by Danyle, Dawn, Lee and Sara, whose children are medically complex and utilize the Children's Healing Center, were consulted to compile this advice. They shared real – and sometimes hurtful – stories of interactions they've had over the course of their child's diagnosis. They all hope to help create a world that is more aware, compassionate and considerate.



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