

A Thousand More
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Philly Mayer: First, I thought I was going to be a pilot.

Then, I was like that sounds kind of dangerous.

Once, I thought I would be like a garbage man.

Then I would think ehhhh.... it would get kinda messy, cause you're working with garbage!

Then, I thought, maybe I can be a farmer cause I really enjoy being around animals.

Beep, beep, beep, beep, beep, beep, beep.

Though farmers sometimes have to slaughter the animals.

So, I don't like that part.

I would probably be a cow milker so I wouldn't have to kill them.

And I like milk, so, that would be a good idea.

Therapist: Here we go, Philly.

We're going all the way. All the way, keep going. Keep going.

Come on, we're gonna touch that wall.

Oh, he's going back, he's turning.

Angela Mayer: He can move his legs freely in the water.

He just lets himself go.

Philly: I try and stay in as long as possible.

Floating...hard.

I usually sink without my floaty.

Angela: He challenges himself to hold his breath, that's part of his training.

Therapist: 80, 81, 82, 83, 84, 85!

Phillip Mayer: If he had his choice he'd be in the water twenty-four-seven.

I'd like to be right next to him, because I love being in the water too.

Philly: My mom and dad, they're good parents.

My dad is really kid friendly, because he actually acts like us.

Kind of weird.

My mom really just helps me a lot.

Angela: You need help? Is that better?

The pregnancy, everything was normal with Phillip.

It was a great pregnancy, perfect delivery. Everything was wonderful.

Voice: Put your hat on.

He was happy. Always happy.

And he was a chubby little guy, always smiling.

He was just a delightful baby to have.

Phillip: I remember Phillip being in a walker at your mom's house. And he's going all over the place.

I was amazed, I was like, and, I'm saying wow, this kid's my, this, he's my basketball center.

He's gonna be a brute.

And then, he just stopped pushing the walker around.

Angela: He was able to stand. And then suddenly he wasn't able to stand anymore.

Phillip: Poked, and probed, and this test, and that test, and they still couldn't figure out what was going on.

I just was to the point of saying, how much do you want to put this little baby through?

I asked God, I said God, why are you doing this to this little boy?

Angela: And at that point, that's when the doctors made the diagnosis.

Phillip: And she came in and she was talking all big words, and uh, all medical terms, and I caught something in there saying seven.

And she got up, and she goes okay, I guess to give us a moment.

And she walked out of the room and I remember looking at Angela and I says, she's telling me that I'm gonna have my, Phillip til he's seven?

That's it?

And I remember I wanted, I wanted to hit somebody.

Because I just thought right away it was a lie.

There's, there's no way that I'm not, I'm only gonna have him 'til seven.

Partygoes: Surprise!

Angela: I asked her, I said what can I do for him? She said, nothing.

I said, nothing?

As a mother, you tell me I can do nothing for my child?

There's no medicine to make him better.

It was something that we just couldn't fix.

Phillip: When they said what he had, SMA, I didn't even know what it was.

I had never heard of it.

Angela: What that means is that the motor neurons in the spine are not developing.

There's a portion of the gene that's missing.

And it's a recessive gene, so both parents need to have it for it to show up.

Most families, they'll have it in their first child.

But for us, our children are older, they don't have any signs of SMA.

Phillip: God's blessed us. He's strong, he's healthy and he's nine.

And he's gonna keep on going.

Philly: PlayStation 3 is cool because you can have a bigger screen and the games are usually a little bit more intense 'cause the remote literally vibrates.

Portable games don't vibrate, I don't get that.

Angela: As parents, our responsibility for Philly is to make his life as full as possible.

If he wants to do something, we make it happen.

Phillip: I've been diagnosed as being a hovercraft.

I watch over him a lot and Angela kinda tells me you gotta let him do things.

I'll do things but I won't be that far away.

I'll be right behind him and I'll be ready to do whatever I have to do to make it okay.

He's gonna do whatever he wants to do, and we're not gonna try to hold him back.

Angela: He uses a power wheelchair.

That's his mobility.

Phillip: It just lets him be involved with the games that the kids are playing.

It means that he's not excluded.

It gives him movement and freedom.

It's just the wind going past and he feels that.

Phillip: Does he want it to go faster?

I would say he wants it pushed up a notch.

He wants it as fast as it can go.

Philly: It says, see you later, man.

Really, it's not that easy to figure out but some people figure it out.

They're smart enough to figure it out.

Angela: He never wakes up and says,

Philip: No.

Angela: I wish I didn't have to go in my wheelchair today.

Philip: No.

Phillip: He wakes up singing.

Angela: He...he's annoyed about therapy, and physical torture, he calls it.

But he presses through, and he does what he needs to do.

Phillip: A tough day in Phillip's life is when he goes for surgery.

You feel helpless.

You feel like you don't know what to do.

I had just laid him on the operating table.

And he looked at me and said, Daddy, I'm not ready for this.

I don't want to do this.

I just looked at him I says, we have to do it bud, this is for you.

This is for you.

Angela: He's strong.

He hates to see anyone upset.

He's like you.

Phillip: I can come home, beaten up from work, beaten up bad 'cause that's what sometimes happens and I look at him and I just, I have to smile.

On your worst day, Phillip could put a smile on your face.

He makes the hard times easy.

Angela: Okay, ready?

Philly: Dad, just hold up my left side.

Angela: Hold his left side.

Phillip: Angela knows how to take care of Phillip.

Angela: Oh yeah, gotta get these toes, the little family.

Phily: Other foot.

Angela: Got the toes.

Phillip: You would say she makes it look easy.

I know it's not easy.

Philly: Dad, can I lean on your hand?

Phillip: Aren't you gonna hold your head up?

Angela: He's tired dad.

Phillip: I know.

Philly: Hands.

Phillip: It'll be over soon.

Angela: Almost there. OK?

Philly: Can I play my Zelda for ten more minutes?

Angela: Ten more minutes?

Bedtime is, uh...

Phillip: as late as he wants it to be sometimes.

Angela: He likes it to be late.

Phillip: Phillip's like the glue and e just glues everybody together.

Makes it all happen.

And everybody says it's supposed to be dad.

You're done?

Go to bed.

Philly: I'm not done.

Don't look at that thing!

Phillip: Dad just holds up the walls.

Angela: Ok, let's put your blanket on.

Ok? It's good?

Done.

Ah, ah, good job, Phil.

Excellent job, Philly.

I love you so.

Philly: I love you too mommy. Good night.

Angela: Good night.

Phillip: I can't imagine not being with him.

I, you know, I don't wanna think of it.

Angela: I know he would want us to know, that he would be with Jesus then.

He's not afraid of that and he wouldn't want us to be afraid of it.

And he wouldn't want us to be, be sad because he wouldn't be here.

He just inspires us to be together.

He wants all of us to remember that we're important to each other.

We would never lose what he gave us.

Phillip: I would take a thousand more children just like Phillip and I wouldn't wanna change, other than his condition, that I would change. But him himself, no.

I'd take a thousand more just like him.