

# I am Me

*A Book about Garrett*



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My family...Mommy (Ma), Me (Me), Daddy (Da), Chloe (Coe), Ethan (E), and Sam (Am)

## What makes me happy

Lots of things make me happy. Trains. Music. Teddy Bears. Stuffed animals. Stories. Hugs. Milk. Pop Tarts. Cereal. Playing in the Sand. Playing in the water. Taking bike rides. Playing in the park. Watching movies. Taking walks. I like to be with people. I like giving hugs. I like touching things. I like it when you hold my hand while we walk. I like being tickled...a little bit.

Music is a wonderful part of my life. I like to listen to music. Anything from Queen to Gershwin to Charlie Daniels and Kate Perry. There really isn't any kind of music I don't like. When I get mad, you can usually calm me down with music. It might take 3 or 4 songs, but I always calm down when you play music.



Every night before I go to bed, I get a cup of milk, a little cereal, and a story. Then I like to snuggle in bed with my teddy bears and doggy (with the light on, of course!). I don't sleep well.

I go to bed at 7:00 pm and sleep through the night sometimes (rarely). Usually I wake up at 10:00 with a bad dream. Sometimes I wake up at 2:00 and play until the sun rises.

I really enjoy playing in outside. In the sand or in the water—it doesn't matter. I just like to be outside. I have a little wading pool where I get to splash around in. Sometimes I forget what toy I'm allowed to use in the water and I take something in the pool that doesn't belong there. But then I also like to take my story books outside and bury them in the sand too.

I like hugs. I will hug anyone and everyone. I like to say hi to everyone. There is no such thing as "Stranger Danger" to me. If someone offered me candy (or even just smiled) I would happily get in their car or walk away from school with them. Sometimes I'm too touchy—I think my classmates don't like me hugging them, but I can't seem to help myself...I get so happy to see people.

I like to take walks. I like to hold your hand while we're walking—I'm unstable on my feet and that hand really helps me out. I sometimes have problems on uneven surfaces. I especially have trouble on ice and snow. I just can't see that the ground is slippery!

## What makes me sad

Change. Unexpected change. Loud noises. Making me do things I don't want to do. Throwing up. Things not happening the way I think they should. Scary movies. Scary books. Too many people moving too fast around me.

I don't like loud noises. We went to see the Muppet Movie and nobody warned me there was going to be a loud explosion in the movie. Daddy spent 20 minutes with me in the lobby before I stopped crying and would go back in the theater. Even something as simple as music that starts suddenly can frighten me.

I don't understand all of the scheduling that goes on at school, but I do understand that certain things happen at certain times. If you change that on me, I will get upset. Your best bet is to warn me of the change. Give me lots of time to prepare and I'll transition better.

I get scared from scary books—I'll let you know if something is scaring me...please don't make me continue doing it.

If we have to go to a crowded area, I will get anxious without someone to hold my hand and help me out. I think there is just too much noise, too many people, too much moving and jostling around.



## When I get sick



I get sick a lot. Usually every 3 months or so, I get sick. It doesn't really matter how it starts, the scary problem to watch for is it progressing to my lungs. Just about everything ends up as respiratory distress.

You can tell I'm having trouble breathing because:

- I wheeze
- I retract (suck in the skin between my ribs)
- I turn pasty-pale
- If you have a pulse oximeter, my saturation will drop

The key is to keep me oxygenated (with oxygen), give me nebulizer treatments (to open my airways). If it gets bad enough, a couple of days on oral steroids will generally give me the boost I need to kick the infection.

Don't be afraid of calling an ambulance. My pulse ox can drop really fast and if you aren't ready for it, we'll both be in an awful pickle! I've been in so many ambulances, I've lost count. I can't

begin to tell you how many hospital admissions I've seen. Heck, the doctors at the Urgent Care Clinic recognize me and my Dad now.

If you don't get me the help I need, I have shown that I will go into full respiratory arrest. That wasn't fun either! I got addicted to Methadone and spent 10 days trying to get weaned off of it.

My parents will keep me home when I'm sick, but it can come on really fast. One time last year, I went to school looking and feeling fine, but by early morning, the school called my mom. That night, I was getting nebulizer treatments and breathing Oxygen. I didn't have to go to the hospital that time because everybody reacted quickly to what was happening.



Just keep an eye on me. If I'm not acting right, then something is probably wrong.

Please, let's avoid getting sick if we can. Keep me away from sick people, especially sick kids. I don't understand things like washing hands, not sharing snot, or covering my mouth when I cough and sneeze.

## What I want from you

Love. Patience. Understanding. I don't want you treat me like I'm stupid. I may not be living at the same level as other kids my age, but that doesn't mean I don't have feelings. I want you to talk to me on my level...get down and look me in the eyes. I want you to talk to me in a way I can understand...use simple sentences with simple words. Don't pontificate to show your mental prowess...all I hear is a bunch of jumbled sounds! I like choices....simple, distinct choices. Things like A or B. Don't put me in a library and tell me to pick a book, rather, show me two books and ask which one I want. Don't walk me through the cafeteria line and ask what I want. Give me 2 choices: chips or fruit. I can't understand when you present me with too many choices.



I want you to help me. Not do everything for me, because then I won't learn, but I want you to help me do things that are difficult. For example, I find it hard to use utensils at the table—my



dexterity just isn't good enough for me to balance food on a spoon and actually make it to my mouth. My sister was awesome during our summer vacation because she would help me eat my fruit cup. It still made a mess, but not nearly as big a mess as if I had tried to do it myself.

I want you to learn to speak like I speak...using sign language. I don't know a lot of sign language, but that is still my primary method of communicating. Please make an effort to learn the few words I know. It lets me know that you really do care.

Play with me, color with me. Sit with me while we listen to music. Hold me when I'm sick. Pray with me when I'm scared.



## What you need to know

You need to know that I wander. I don't see boundaries like the rest of the world. In my mind, I can go anywhere, do anything. That means that if I want to walk out a door, I will. Crosswalks mean nothing to me. I will walk and wander until I find something interesting to look at. There are a lot of really cool squirrels for me to look at! This means that if you are responsible for me, you need to know where I am all of the time. I move slow, but when you aren't looking, I can be out the door and in serious trouble really, really fast!

I want you to help me eat. I don't understand that I can't eat big bites. I don't understand that I can't stuff my mouth with yummy food without choking. If you don't cut my food for me, I will try to eat it and I will probably regurgitate it back for you.

There are times when I get mad. When this happens, I will hit myself, throw myself on the floor, hit you, bite you, and throw things. It's bad for everyone all the way around. What's really dangerous though is that I lose control and hurt myself.

So, if I get mad (or rather, when I get mad), the best thing to do is to get on my level. Look me in the eye. Find out why I'm mad—it's usually because a) you aren't letting me do something I want, or b) you are making me do something I don't want.

Once you tell me to do something, you need to stick to your guns. Don't let my behavior cause you to cave. All that does is let me know that I can get whatever I want by getting mad. It is best to avoid this situation in the first place. My Dad does this by giving me choices (2 choices) instead of telling me to do things. If you emphasize those two choices, I will usually calm down and make a choice. It's only when you tell me to do A without letting me be involved in the decision.

For example, if it is time to go from the car into the house, Dad will say “let’s go in the house, Garrett.” If I get mad and throw a fit, he will say “You can either walk into the house or I will carry you into the house.” That gives me a choice without letting me out of the original instructions.

I also will calm down if you play music for me. Sometimes it takes 3 or 4 songs, but so far, music has always been able to calm me down. I will most likely tell you I don’t want music if you ask while I’m mad, but in the end, it will win me over.

I understand that sometimes there isn’t a choice. When these times occur, you need to prepare me for the change. I can’t simply stop one activity and move to the next when you say to. I need to be prepared mentally to make that change.

What you see is what you get. I don’t have an agenda. I don’t know how to tell a fib. I don’t hide my feelings. I’m not afraid of hurting your feelings. I’ll tell you what I think. I’ll act out according to how I feel. You really shouldn’t take things I say and do personally when they hurt your feelings. I really do love you, just sometimes you do things that I don’t like—and I’ll tell you so. If there’s anyone who is without guile, and with pure love, it’s me.



Slow down...take your time...I live at my own speed—Garrett speed. Most likely you live way too fast for me to keep up with you. Take some time and enjoy life at my level. Don't try to force me to do things faster than I can...it just won't work. Don't treat me like a typical peer...I'm not. Don't treat me like I'm stupid...I'm not. Don't expect too little out of me...I can learn. Don't expect too much out of me...everything takes longer for me.

There will be times when I act in a way that makes you uncomfortable. You need to realize that it probably doesn't make me uncomfortable. I act the way I act because that's what I know. It isn't because of any great, deep, in-depth ploy. When I throw a tantrum, you shouldn't be embarrassed, just be patient. When I throw up, you shouldn't be ashamed, you should just help me clean up and move on. Things will happen...that's ok.

The world looks so different from my level. It really is a simple place—it's a place of goodness and beauty and I love to explore it...all of it. Come and experience life with me!



## The Medical Stuff

Inevitably, people ask the question “so, what’s Garrett have?” ...or something similar.

My dad thinks that all of my problems are based on my underlying genetic anomaly. It really comes down to the fact that, while I may be physically almost 8 years old, my mind still functions like a 3 year old.

- Low Muscle Tone (Hypotonia)
- Difficulty swallowing (Dysphagia)
- Weak windpipe (Tracheal malacia)
- Adenoidectomy/tonsillectomy
- Holes in my heart (ASD / VSD [both closed])
- I sort of have three atria (Cortriatriatum)
- Problems with my tricuspid valve (Ebstein's Anomaly)
- Itchy, irritated skin (Eczema)
- Something called Asthma
- Allergies (grass, trees, dust, cats, mold, and so many other things I can't list them all here)
- Atypical Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)
- Problems with my genes (Supernumary chromosomal material—18/22 skin cells have extra markers)
- Everything about me is delayed—physically, mentally, socially (Global Developmental Delays)
- Problems with my ears (Eustachian tubes)
- Trouble walking (Pediatric leg braces)
- Different eyes (Epicanthal Folds)
- Small & low-set ears (dysmorphic or hypoplastic ears)
- Small hands & feet
- Broad nose
- High arched palate

## My Sign Language Dictionary

<u>Known Signs</u>	<u>Description</u>
Alligator	arms in front of you bring hands together like a biting alligator
Apple	make fist with right hand, twist knuckle on right cheek
Ball	make ball with two hands
Balloon	pretend hands are a balloon being blown up
Bathroom	make fist, thumb between 1st and 2nd finger and twist or make fist and twist
Beads	make "p" and bring it across neck like a necklace
Bear	cross arms on chest and claw at collarbone
Blue	make a "b" and wave
Book	make a book shape with your hands
Boy	pretend you're grabbing a baseball cap bill
Brown	make "b" and slide it down the right side of your face
Bubbles	pretend your hands are popping bubbles
Bus	both hands in front of your face palms toward you, then open right hand like a bus door
Candy	point pointer finger beside mouth and twist
Car	pretend you're driving a steering wheel
Cat	make whiskers on your face with your hand
Cereal	slide whole hand under your chin from left to right
Chair	left hand 2 fingers out, right hand pretend you're sitting down on left hand
Chloe	make a "C" under your chin
Close	bring 2 hands together like you are closing a book
Cookie	left hand out palm up, right hand make cookie cutter shape
Cow	pretend you're milking a cow
Cracker	make "C" under right elbow
Crayon	wiggle 4 fingers in front of chin, then write with finger on table
Dad	thumb to head fingers, out (or fist)
Dog	slap leg like calling dog
Drink	Stroke your throat like water going down
Elephant	make trunk motion with right hand
Ethan	Make "e" with right hand and wag it like a tree
Fish	make hand swim in front of you like a fish
Game	two thumbs up, bring fists together
Garrett	make "G" on thump over heart
Giraffe	run hand up your neck like a long neck
Girl	pretend to tie a bonnet under chin using thumb
Green	make "G" and shake it
Hat	pat head where a hat would go

Home	make house shape with hands
Horse	put hand by head and flick 2 fingers up and down like horse ear
Hot dog	make bun with left hand, lay right pointer in like a hot dog
House	make house shape with hands
Ice cream	pretend you are eating ice cream cone
I'm sorry	Rub palm on chest
Jump	make 2 fingers jump in your palm
Lion	show lion mane around head
Marbles	like you're flicking a marble
Milk	squeeze fist beside head
Mirror	hand flat and twist it (arm up at 90 degrees)
Mom	make fist, thumb on chin
Monkey	pretend you are a monkey
More	Tap fingers together in front of you
Movie	palms at 90 degree like a movie screen and shake the screen
Music	stroke your left arm out and back
Necklace	draw a necklace on your neck
No	Close fingers and thumb (like a mouth closing)
Off	make "F" and slide it out or snap fingers to thumb in a "hush" sign
Open	like you are opening a bag of chips or a bag
Orange	fist on chin and pump fist open and close
Paint	like crayon, only use all fingers on table
Pancakes	pretend you're squashing a bumble bee
Pants	pretend you are pulling up your pants
Penguin	walk like a penguin
Phone	make a phone and put it to your ear
Pig	open and close hand under chin to side
Pink	make "P" and flick it down your lip
pizza	make "Z"
Please	rub chest with open hand
Push	make push sign with two hands
Puzzle	both hands make knuckles and interlock knuckles like a puzzle
Raisin	bounce fingers up arm
Red	make an "R" and flick it down your lip
Sad	Run finger down face like a tear
Sam	Run fist down side of face (like you're combing your hair)
Scissors	cut with your hand
Shirt	grab your shirt and pull it
Shoes	bump two fists together on the side
Slide	hold left hand out, pretend right hand is slide
Stop	left hand flat, right hand flat on side (thumb up) brought down on left

Swing	both hands 2 fingers together and swing them out
Table	2 arms in front of you on top of each other (like yoga pose)
Thank you	Put open hand on chin/mouth and move it away from you toward person
Toy	make "Y" and shake it
Tree	right elbow on left hand and shake hands like leaves of tree
White	pull hand out from chest
Yellow	make "Y" and shake it