

17. Living with Progeria

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Parents and siblings of children with Progeria have shared the following insights on how they have dealt with the challenges of living with Progeria.

You are not alone. Families help each other by sharing experiences.

General thoughts about daily life

“In the beginning, prior to and just after our son was diagnosed, daily life was very difficult. We didn’t know how to “deal” with our first-born’s diagnosis because we couldn’t even begin to assimilate it, much less share it with the rest of the family. We dreamed that our son’s pediatrician would call to tell us they’d made a terrible mistake and misdiagnosed our son. Now, having received nothing but support and love from so many, and love from our son, we would do it all over again if we had to. Our son is now 11 years old. He has touched our lives and the lives of others in ways I cannot explain.”

“As the parents of a 3 year-old boy with Progeria, we try very hard to treat him as if he doesn’t have Progeria. At times, this is difficult. He does get to eat whatever he wants and he does get more attention than his big sister. We don’t discourage his waking up at night wanting Pediasure. We do try to make sure he gets the same experiences we provide his older sister.”

Talking to your child with Progeria: what to tell them, when, and how

“There is no right or wrong answer for when and how to discuss Progeria with affected children and siblings. Decisions will be based on each child’s personality, and the different cultures we all live in.”

“Generally, children hear and understand what they are ready to understand. They ask what they are ready to hear about. As a rule, we answer what is asked and assume that our child wants to hear only what he asks. We don’t go any deeper than that, because we believe that in time he will make it clear that he is ready to hear more. Also, things are changing so quickly because of the trial that we don’t actually know if what we are saying is accurate about his future.”

“She knows she’s shorter, no hair, thin skinned, and it’s called Progeria – that’s it. We are not sure how or when the time will come. We believe she already knows, but we just don’t talk about it.”

Dealing with the outside world

“Be prepared for stares and even rude comments; have answers ready but don’t get into arguments. Your child may not be aware of the stares and comments, but you will. Siblings may be upset by strangers’ stares and questions; prepare them for it.”

“You will experience a lot of whispering, stares, and questions. When the child is younger it’s easier – he/she doesn’t understand. Remember, you are the parent, you can say ‘NO’ or say ‘not now’ if someone approaches you. Sometimes it can be annoying, but most times they are just concerned, so just smile and they will smile back.”

“The most difficult thing for us at first was not the medical issues. It was the psychological and emotional challenges we feared that our child would have to face. His happiness was the first thing on our minds. We made sure we made strong friends within our community. Real friends don’t think about how a person looks or what they CAN’T do. Real friends only see their friend in front of them and want to play and have fun. Friends and family are the core to our child’s happiness. The rest of the world with their stares and comments have only a minor effect on ego and self-confidence.”

“Incorporate cousins and neighboring children in your child’s circle to build long-term friendships.”

“Getting the word out in our local community has been very helpful in two ways: It helps with fundraising activities and it will help our son and family better deal with the differences in appearance. With awareness, we have gotten tremendous support from our community. That has helped us as parents and we hope that as our son gets older it will help him to feel comfortable [about] looking different.”

“It would be very helpful to meet other children with Progeria and, at some point, children with other health problems.”

Siblings

“Give all your children special attention; don’t neglect siblings for being normal. Siblings-jealously issues will arise. Try to have a day just for brother or sister, so they feel special.”

“What to tell siblings depends on the child’s place in birth order, but we don’t tell siblings anything we haven’t told our child with Progeria.”

“Our older children know what the diagnosis is, and our child with Progeria does not.”

“Our 11 year-old child with Progeria has a 3 year-old sibling and so far we have tried in the clearest way possible to explain to the 3 year-old that he must be careful and not be too rough with his older brother. We believe the 3 year-old understands his brother is special.”

“Siblings can participate in PRF activities, work at raising funds, and would enjoy meeting other children with Progeria and their siblings. We believe all this is very positive for them.”

“Growing up in a household with a child who has special needs can give rise to challenging issues for siblings. The need for extra attention given to the child affected with Progeria may cause a sibling to feel that he/she is not as special or valued by their family because he/she does not have an illness. When the identity of the family centers around caring for a child with Progeria, siblings may have difficulty developing their own independent roles and sense of self within the family. Make sure to be extra vigilant that siblings do not feel that they are any less special because they do not require a special diet, special accommodations, or special visits to the doctor. This form of logic may seem preposterous to

an adult, but it is not to a young child. A sibling child may feel guilty about his or her own good health and physical abilities. Support for siblings can come in the form of friendship with other children who are living with a 'difference' in their family. There most likely will not be other families with children with Progeria in your vicinity, so you might want to look for this support in the form of families who are dealing with another type of disability. Make sure that all children in the family have the opportunity to explore their own interests and unique talents."

Sports

"We give our child plenty of exercise, up to his/her capacity. We have a lowered basketball hoop at home. Miniature golf and candlepin bowling are sports he can share with friends. Water play is excellent but we make sure adult supervision is constant. Also, we have balls, hoops, etc. for play inside the home."

"Introduce children with Progeria to sports as early as possible. This not only allows them to be an active part of the community early on, but also it is the best time to ensure accommodations are made to enable their participation. Over the years, we have dealt with changes that have affected his participation by introducing our child to other types of sports that do not require extreme amounts of endurance and aggressive competition."

"Swimming: The baby wetsuit never fit his odd-shaped body, and therefore didn't keep him warm. He would turn blue after 5 minutes in the pool. We recently purchased a 3mm full, custom-made wetsuit from Harvey's Dive Suits."

"A regular session at a hydrotherapy pool promotes relaxation, relieves pain, assists movement, and is good exercise. It's also pretty good fun!"

Clothing and footwear

"You may have to make some clothes by hand, or have them custom-made. Favor cottons and materials that don't irritate their sensitive skin."

"Pants with adjustable waist bands are extremely helpful as the waist remains much smaller than the usual pant length needed."

“If sneakers – perhaps with orthotics – are comfortable, don’t worry about fashion or formality.”

“Use soft, padded insoles in shoes – leather, if possible.”

“In winter, your child’s fingers and toes may get very cold easily, so thick gloves or two pairs of gloves can help.”

Religious affiliation

“This can be an excellent source of acceptance and companionship. Discuss with your family’s clergy your understanding of why this is happening to your child. Religious youth groups and/or scouting programs can be good. Involve your child in helping others; he/she will find it empowering.”

“Church youth groups are extremely important and vital to our children because they establish fundamental faith and belief that there is a higher being, and we firmly believe God will take care of our son and guide us to raising him to be all He intends him to be.”

Pets

“Pets can be a wonderful source of companionship and unconditional love, but large and/or strange dogs can be a hazard.”

“Animals are extremely important! Our kids need to feel as though they have the ability to watch over and be responsible for something.”

Practical accommodations around the house

- Install lever type taps (faucets) to baths and basins
- Lower coat hooks, light switches, and door handles, and ease door closers so they are not so stiff – this will make it easier for your child to enter rooms and cupboards
- Fit smaller hand rails below the normal ones on stairs
- Use a memory foam mattress (like Tempur) on the bed; an occupational therapist may be able to help with this
- Keep small step stools or boxes handy for reaching counters, basins, and getting on and off of the toilet
- Arrange for furniture in which the child will be comfortable

Travel

“Use a car seat made from memory foam instead of the normal hard plastic seats.”

“Be aware of how easily your child may tire.”

“When flying, ask for a seat upgrade to make long flights more comfortable. Also, ask if it’s possible to use the airline lounge to avoid waiting in busy departure areas. If you travel with your child regularly – such as to Boston for the clinical trials – try to find a good contact with the airline in a senior position. This can be very helpful when asking for assistance.”

“Make sure your child gets lots of rest the night before a trip, and lots of fluids before and during the trip.”

“When checking in before flights, tell staff that you have a disabled child so that you can avoid long lines.”

“Arrange for a wheelchair to be waiting for you at your destination so that your child doesn’t have to stand in (the immigration) line or walk through the airport.”

“Some airlines will put a ‘disabled’ sticker or tag on your luggage so that it comes off of the plane first with the first class luggage.”

“Pack all necessary medications in your hand baggage in case your checked luggage gets lost.”

“Ensure hospitals are within close distance.”

“Don’t be afraid to embark on new adventures. Although some cultures are a little more alienated and/or accepting of people who appear different, you will be OK!”

Other thoughts

“Make allowances that the child may have to snack at otherwise forbidden times, for energy and to stave off headaches, but otherwise try to treat him as normally as possible.”

“Let them eat what they crave. They need the calories and energy sources and may not be able to handle ‘regular’ food the rest of the family is eating. Be aware that this may cause problems with siblings.”

“The child may act out at times as he becomes aware of his differences.”

“Provide plenty of stimulation such as sports, art, music, drama, and a variety of social situations.”

“Physical therapy: We were surprised at how quickly his joints started to become less flexible. One day he only had slightly bent knees, the next he had tight arms (at the elbows), wrists, ankles, and hips. This seemed to happen overnight around the age of 3. We also noticed he wasn’t standing up straight about the age of 3. His shoulders were hunching over. To remedy this, we do stretching every day. He sees a physical therapist once a month to check his progress.”

“Have regular visits to a chiroprapist to help with nail cutting and removal of hard skin areas. Watch for in-grown nails/toe nails, since their fingers and toes are so narrow.”