

## 16. Going to School

- Advice on working with the school
- Emergency care in school
- School, classroom, medical, and transportation



Many children with Progeria attend school with their peers, and require special accommodations so that they can comfortably participate in regular classes. This section includes recommendations and some examples of practical accommodations for the children.

### Advice on working with the school to accommodate your child's needs

It is highly recommended that parents have meetings with the principal, school nurses, therapists, and all teachers involved with your child. It's a great opportunity to inform everyone about what Progeria is and what your child's needs may be. It's also an opportunity for the staff to help each other and parents by sharing strategies and advice about how to best serve the child. Start-of-year meetings allow staff to ask questions that pop up unexpectedly, and help staff to see that parents are available for continued discussion and questions. Throughout the year, parents may also choose to incorporate a "communication book" in which teachers, teacher's assistants, and other helpers can enter observations which can then be discussed with parents. End-of-year meetings allow sharing between current teachers and the following year's teachers. Often the parents or the current teachers can choose the following year's teachers. Choices may center around emergency preparedness training, demeanor of a particular teacher, and classroom proximity to the nurse's office or building entrance. Bring copies of this

*Give copies of this handbook to your child's school staff; it may help answer many questions.*

handbook to meetings; these are available from PROF. Everyone will be appreciative of the shared communication and optimal preparedness.

## Emergency care in school

Any child who develops dyspnea (shortness of breath), angina (chest pain), or cyanosis (blue discoloration of lips and skin) during exertion should stop immediately. If symptoms do not rapidly resolve, the child should receive emergency medical care according to the school or facility's emergency plan. If oxygen is available it should be administered. Due to the risk for cardiac events, it is also desirable for school medical personnel to be trained in cardiopulmonary resuscitation (CPR) and to have access to an automated external defibrillator (AED) with pediatric capability. For more information on CPR training, emergency care in the schools, and automated external defibrillators, refer to the American Heart Association website at [www.americanheart.org](http://www.americanheart.org).

## School, classroom, medical, and transportation

- Ensure proper seating height with feet touching the surface. If feet are hanging, legs become uncomfortable. Most desks and chairs can be lowered, or smaller desks and chairs can be brought in.
- Supply a soft cushion to put on hard chairs or supply a support and multi-position orthopedic chair.
- Allow the child to sit, stand, and move around at will. Sometimes for comfort, the children need to stand at the desk intermittently instead of sitting and can do this without interrupting their work.
- It often becomes difficult for children with Progeria to sit cross-legged or on a hard floor. Provide a rolling stool chair in each class.
- Stools in bathrooms are needed to reach sinks. Doors to bathrooms should be easily opened or remain open throughout the day.
- For younger children, supply a stroller to the school. For older children, access to a wheelchair may be useful, especially if the child has joint problems.
- Two sets of books should be supplied, one for home and one for school.
- Monitor writing fatigue in the classroom.

- Writing suggestions:
  - Scribe or keyboarding as needed for longer writing assignments.
  - A sloped drawing board to place on the desk can be far more comfortable than writing on a flat surface.
  - Large pencils or pencil grips similar to ones supplied to arthritis sufferers may be more comfortable for writing.
  - A laptop or AlphaSmart can reduce fatigue or “writer’s cramp”.
- A rolling book bag is advised.
- Assign a lower locker on the end so there is no student to at least one side next to him/her.
- Allow the child to wear a hat in school. Most schools do not allow children to wear hats, but it’s important to allow children with Progeria to wear caps or hats if this makes them more comfortable.
- Accommodations for standardized and state testing:
  - Arrange for the test to be administered in short periods with frequent breaks.
  - The child can use a word processor, Alpha-Smart, or similar electronic keyboard to type long composition and/or answers to open-response questions as needed.
  - Another option is Scribe ELA Composition, wherein the child dictates the compositions to a scribe or uses a speech-to-text conversion device to record the composition as needed.
- For physical education class, it is optimal if the teacher allows the child to try things that he/she wants to try, but also let the child rest whenever needed. Making sure the child is always involved (not feeling left out) with the activity is very important. The teacher should monitor cardiovascular activity closely. This can be self-limiting, as the children should play with peers as much as possible. Often the child can serve a central “important” role such as scorekeeper or “designated quarterback” so that contact is minimized but involvement is maximized.
- The physical education teacher should provide accommodations in gym class and the locker room as needed. If the class goes outside, monitor temperature. If the child is not going out due to severe temperature, he/she can stay in with a buddy.
- Children with Progeria should not be picked up by other children. Children love to pick each other up but because they often squeeze too tightly or fall with the child, this is never recommended.

- Arrange for physical therapy 3 times per week in school, for 20-30 minutes per session, and for occupational therapy 1-2 times per week in school, for 20 minutes per session. PT is often provided as part of the school day, and it helps to avoid after-school PT and OT appointments which can detract from quality of life.
- Allow the child to carry a lunch box with him/her to eat or drink at will. Often the children need small, frequent drinks and snacks, but school usually limits eating and drinking times. Children with Progeria should be allowed to eat and drink at will without disrupting the classroom. Make sure substitute teachers are aware of this as well.
- The child may need to go to the front of the lunch line so that he/she has enough time to get food and eat it. Children with Progeria often eat more slowly than their peers, but they need to maximize food and drink intake. Also, taking a “buddy” to the front of the lunch line helps with carrying trays and with comfort level. Be sure the lunch room attendant can help them carry trays or reach food items if necessary.
- Have an adult or student escort carry the child’s backpack at the beginning of the day and assist at dismissal.
- A student or adult should also assist in transition from class to class. A one-on-one teacher’s assistant to escort your child from classroom to classroom and dining areas, carry heavy items such as backpacks and books, and reach items on high shelves as needed depending on the child’s age, health status, and school regulations. As the children get older, their peers can assist with these types of tasks, thus avoiding the need for an assigned adult assistant in school.
- The child should leave class 2 to 3 minutes earlier than the regular dismissal time in between classes and for the bus. Backpacks become “head height” and can easily hit the child. Also, hallways become crowded and unruly between classes. Early transition time is optimal.
- The child should have a parent or other school-approved adult accompany the child on all field trips.
- Arrange for a mini-bus for transportation to and from school, if possible. The regular school bus is the least well monitored area of school. Special bus accommodations are optimal.

- Seating in the classroom should be in close proximity to the teacher and near the door. All children with Progeria develop a low tone hearing deficit. Though this does not generally affect the speech tones, sitting at the front of classes is optimal. Sitting near the door also helps classroom to classroom transition without disruption.
- Classrooms should be chosen so they are close to the elevator, if the school has one.
- Allow the child to use the elevator with a buddy whenever traveling between floors.
- In the younger years, have a warm “quiet area” with a blanket and pillow where the child can relax if they feel tired. Rest periods at the nurse’s office may be needed as she/he gets older.
- Nursing staff should be directed to call parents whenever the child is seen at nurse’s office.
- Nursing staff should have a defibrillator available for treatment.
- In case of ambulance transfer to a hospital, arrangements should be made to be taken directly to a pre-determined hospital where the hospital staff knows the child best and/or is best equipped to take care of a child with Progeria. Progeria is rare and in most cases the staff will not know how to treat patients with Progeria. Ambulance staff will determine if the medical situation warrants transfer to the nearest hospital, regardless of whether they have experience with the child.
- Having close friends and reliable assistants to help in school is KEY to making everyone feel comfortable and happy.