

Special Children Need Special Care

A Child Safety Guide for Parents of Children with Special Needs

Every child deserves the chance to be safe.

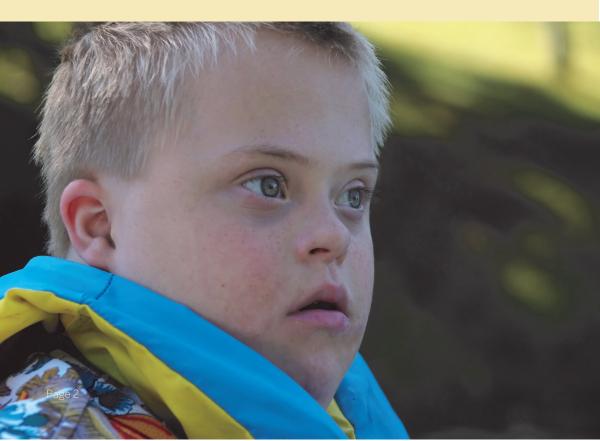
You can help your child with special needs from being injured by doing three things:

- 1. Be informed
- 2. Practice safety daily
- 3. Use products to help keep children safe

Only small changes may be needed to keep your child with special needs safe. Please visit *safetystore.pediatrics.iu.edu* and view the Riley Red Wagon child safety series to help your family learn about safety together.

This information can help you plan for the safety of a child with special needs in the hospital, at home, at school, and during travel.

Everything you read here has been written from a child's point of view. See the world from a child's eyes to help shape how you keep children with special needs safe every day.





Take part in the care I receive at the hospital.

Speak up for me if you have questions, concerns, or don't understand my care. Tell my nurse or doctor if something doesn't seem quite right. Some things you can do to help:

- Know the name for and reason why I am given any medicine
- Tell medical staff:
 - Every medicine, vitamins, herbs, or supplements I am taking
 - About any allergies I have, including how I react to medicine and food
- Make sure medical staff knows how I can take medicine (liquid, pills, shots, etc.)
- Know when the medicines are ordered and when you get them at the hospital or pharmacy. Some things to think about:
 - Are my medicine labels clear and easy to understand?
 - What is the best way to measure my liquid medicine?
 - If you are not sure how to use any of my supplies . . . ask
 - What are the side effects of my medicines?
 - Is it safe for me to take more than one medicine at the same time including over-the-counter drugs, herbals, and vitamins?
- Make sure that you know what my medicine looks like, that it is correct, and that it is for me
- When you pick up my medicine from the pharmacy:
 - Is my name on the prescription?
 - Is this the medicine and correct dose that my doctor ordered?
- Are my medicines being given on a schedule that works and makes sense for me?

Think about safety and my health care providers.

Know who people are and what they are doing for my care. Speak up if you have questions or concerns. Here are some questions to ask:

Who are you?

Look for an identification badge. Ask the person who they are and what they are there to do. Call my doctor or nurse if you have questions or concerns or do not get the information you need.

Did you wash your hands?

Hand washing prevents the spread of infections. Ask all hospital staff and visitors who touch me if they washed their hands. Remind everyone to wash their hands and remember to wash your hands, too.

Do you know my child's name?

Make sure the nurse or doctor knows my name before giving me any medicines or treatment. Speak up if you think someone thinks I am another patient.

What is my child's medicine schedule?

Know the times of the day I get a medicine. If I do not get my medicine, tell my nurse or doctor. Tell the nurse or doctor if you think I am going to get the wrong medicine. When medication is being given, ask the nurse or doctor to give you medicine and dosage information.

Why are these tests being done?

Ask why each test or procedure is being done and how it can help me. Ask when the results will be ready.

When does the IV get replaced?

Ask how long it should take for the liquid to "run out" of the IV. If the IV looks like it's dripping too fast, too slow, or not at all, tell the nurse right away.

What should I know about my child's surgery?

Ask questions and ask for written information so you know and understand what will be done during my surgery. Know what to expect immediately following surgery, recovery time, and for the future.

Learn how to prepare me for going home.

Here are some Riley Hospital for Children at IU Health services for families that can help you:

KIDS (Kiwanis in Direct Support) for Riley provides support to families by helping with transportation, meals, lodging, or tasks at home. For more information, call Riley Social Work Department at IU Health at 317-944-8312.

For more information about the Ronald McDonald House, located on the Indiana University medical campus in Indianapolis and also within Riley Hospital, call 317-269-2247.

Go to The Safety Store at Riley Hospital for Children at IU Health to learn about safety. You can buy child safety products at low-cost. Call 1-888-365-2022 toll free for more information.

If my special needs do not allow use of a standard car safety seat when I am ready to go home, call the National Center for the Safe Transportation of Children with Special Health Care Needs (at Riley Hospital for Children at IU Health) at 1-800-755-0912.

Visit the Edward A. Block Family Library at Riley Hospital for Children at IU Health to learn more about my medical condition or surgery. Buy a notebook and write down what you learn or any important information my doctor tells you. Ask for written handouts that you can keep. For more information about the Block Family Library, call 317-948-1645.

Know how to use any equipment that will go home with me. Make sure you

understand instructions for my discharge and follow-up care. The Riley Family Education Center at IU Health offers instruction classes prior to hospital discharge. For more information, call 317-944-8845.

Plan ahead for my safety at home.

Use child safety products and practice safety daily to help keep me safe, no matter how old I am.

- Have adults watching inside and outside our home, especially the kitchen and bathrooms. Put door locks (at the top of the door) or door knob covers on doors to rooms or closets that you don't want me to enter.
- Put safety locks or latches on cabinets, drawers, doors, windows, toilets, ovens, stove knobs, and fencing.
- Put safety gates at the top and bottom of stairways. Do not use pressure gates at the top of stairs because they can fall over when I push against them.
- Put corner guards on sharp edges of furniture, remove rugs, and remove anything lying on the stairs.
- Put on door alarms to let you know when I go outside.
- Keep all medicines, cleaning products, firearms, matches, lighters, and alcoholic beverages out of my reach and stored in an upper locked cabinet. In a poison emergency, call the Poison Control number, 1-800-222-1222.
- Keep electrical cords, computer cables, telephone wires, and drapery and mini-blind cords out of reach.
- Put in outlet covers to keep me from touching electrical outlets.
- Be sure the smoke detectors work. Test the batteries once a month and replace the batteries every 6 months to make sure they are working properly.
- Set our water temperature no higher than 120° F. Put anti-scald devices in bathroom and kitchen faucets.
- Test my bath water before putting me in it.
- Let hot foods and liquids cool, especially after being microwaved.
- Practice a fire escape plan so I know what to do and everyone who
 takes care of me knows what to do in case there is a fire or other
 emergency.
- Teach me what I can and cannot touch. Repeat what I need to know, use pictures, and practice safety rules regularly to help me learn about being safe.

For more information about home safety and low-cost products for all children, including children with special needs, call The Safety Store at Riley Hospital for Children toll-free at 1-888-365-2022.

Learn how to keep me safe when we travel.

Remember these tips to keep me safe when we travel.

- My car safety seat, booster seat, or safety belt should be right for my age, weight, height, and disability, or medical condition.
- Put in and use my car safety seat or booster seat by following manufacturer's instructions and the vehicle owner's manual. Remember, the back seat is the safest place for me.
- If I can't hold my head up or can't sit on my own, I may need a car seat that offers me extra support. If I'm an infant or toddler, I should ride in a rear-facing car seat until I am 2 years old or until I reach the highest weight or height allowed by the manufacturer of my car seat. If I am 2 years or older, or younger than age 2 but have outgrown the rear-facing weight or height limit for my car seat, I should use a forward-facing car seat with a harness up to the highest weight or height allowed by the car seat manufacturer. A therapist may be able to add additional support for my head and sides, or at the car safety seat buckle to keep me from sliding forward.
- Medical equipment should be secured on the floor of the vehicle or anchored securely on the vehicle seat.
- If I've just had surgery, or have a cast and can't bend at the hips, I may need a special car safety seat or special vest to make safe travel still possible. If I must travel in a wheelchair, secure my transit-certified wheelchair facing forward and at four points on the floor. Buckle me up with a separate lap/shoulder belt. I may require a special restraint or wheelchair on the school bus. The school officials should include my transportation needs as they develop my Individual Education Plan (IEP). Also, the bus driver should be trained to take care of my special needs.
- Never leave me alone in a car.

For more information, call the National Center for the Safe Transportation of Children with Special Health Care Needs (at Riley Hospital for Children at IU Health) at 1-800-755-0912.



Help keep me safe at home.

Make a plan for me to go home easy and safe. The plan might include:

- Telling local emergency services, including the fire department and electric company, about my special needs and where I usually am during the day (school, child care, etc.)
- Checking to make sure ventilation systems, including the air conditioning and heating are working
- Medical equipment, special devices, and supplies that are needed at home
- Devices I may need to sit, walk or move which include: baby carriers, strollers, highchairs, and play pens
- Ramps for a wheel chair
- Larger doors so I can get in, out, and around our home
- Nursing care in the home
- Keeping our home and car smoke-free
- Adding more and back-up electrical power



Help me make a safe escape in an emergency.

Be ready for any emergency. Fires, storms, tornados, hurricanes, and earthquakes can happen anywhere and at any time. Put our local emergency numbers by all telephones, on the refrigerator, in the car, in all cell phones, and other easy to find locations.

Have a family emergency evacuation plan to keep me safe in any emergency. Put this plan where all caregivers can see and use it, including in the car. My written emergency plan should list:

- How to find you and get me the right medical care in case I have an emergency
- My medicine requirements, how I need to travel, and what to do for me during travel
- How to move my medical equipment and medicine
- How to use medical equipment if the electricity is out
- If there is flood, earthquake, tornado or other damage and streets and sidewalks cannot be used, how will you get me around?

Other questions to think about:

- How do I get out of our house? To child care? To school? To work?
 To other frequently visited places? Is a plan in place and practiced by people who care for me?
- Do I know what an emergency means? Do I know what to do in an emergency? Can I dial the local emergency number? If not, could we set that number on speed dial so that I only have to push one button? Will the operator understand me? Can we set a code word so the operator knows when I need help?
- Will the local emergency system call our house if there is an emergency in the community?
- Have you called local emergency agencies to update information about my special needs?
- Will people help me more quickly if you put in an alarm system that lets the local emergency number operator know there is an emergency in our home?

For more information and to obtain a free Family Emergency Evacuation Plan, contact The Safety Store at Riley Hospital for Children at IU Health at 317-944-6565 or toll-free at 1-888-365-2022.

Help me stay safe in case of a fire.

Let's practice fire safety as a family. Make and practice a fire escape plan for our home.

Our fire escape plan should include:

- Two ways I can escape out of every room
- A place to meet once outside

All family members should know what to do to help me escape safely in a fire. Include me in our regular practice of our fire escape plan. Do you know . . .

- If my bedroom or classroom at school or place of work is on the second floor, can I get down the stairs safely?
- Who will help me?
- How will medical equipment that I need be carried out in a fire?
- If an escape plan has been developed and is it regularly practiced at home, my childcare, or school?

Put in smoke alarms and carbon monoxide detectors inside every sleeping area and on each floor of our home, including the basement. Test smoke alarms monthly to make sure they work and replace the batteries twice a year. If I can't see or hear, contact The Safety Store at Riley Hospital for Children at IU Health for information about special smoke alarms to help alert me in a fire.

Practice stop, drop, and roll. If I am in a wheelchair, help me practice lock (the wheelchair), drop to

the floor, and roll. If I can't get to the ground, have a fire-proof blanket nearby or in my wheelchair pouch to help put out the flames.

Practice staying low under smoke. If I cannot get to the ground, someone will need to put me on a blanket and drag me to get away from a fire. Contact The Safety Store at Riley Hospital for Children at IU Health for more information about products and how you can help me make a safe escape.



Community support is important to my safety.

My siblings, our family, babysitters, teachers, employers, and other care providers need to be active partners in planning to help keep me safe. Talk to them about:

- How my medical needs and other challenges might affect how I react or am cared for in an emergency
- My essential medical records and emergency contact information
- How to make and practice an emergency plan that helps me to escape safely
- How to best communicate with me

Safety is a lifelong practice that needs to be talked about with everyone who has contact with me as I grow up.

- Talk about safety and be an example for me and my siblings regularly so we know that safety is important to our family
- Include me in everything that our family practices for safety
- Have a first aid kit in the car and at home that can help anyone respond to my medical needs if I am hurt

Maintain my updated medical Passport by visiting this website: www.earlychildhoodmeetingplace.org/docs/WellnessPassport/index.html

Help me be a safe bike rider and pedestrian.

Bike riding helps me make new friends and gain confidence in my physical abilities. Ask my therapist if I'm ready to ride a bike.

- Get a tricycle or bicycle that meets my needs. If I can't use a standard bike, check with The Safety Store at Riley Hospital for Children at IU Health for information on adapted bikes, bike carts, or tandem cycles for children with different abilities.
- Make sure you and I always wear an approved and properly fitted bike helmet when riding bikes. Ask my therapist for help finding a bike helmet that fits me properly.
- Practice with me often so I am able to use hand turn signals and follow traffic safety rules.
- Ride along with me. I may fall or not know what to do and need your help. Let me practice in a safe place with you.
- Ask my school, youth group, church or neighborhood to present a bike safety course for me and other children to learn and practice bike safety together. Visit the *Racing for Safety* website at *racingforsafety.pediatrics.iu.edu* for information and resources to plan and present a Racing for Safety bike safety course for all children, including children with special needs.

Walking is a good way for me to exercise, meet people, and learn about my neighborhood. I may use a wheelchair to "walk," but I should still follow these rules to be safe:

- Look left, right, left again and behind before crossing a street, and obey all traffic lights and signs. Let me practice when we are walking together.
- Use hand signals so I can let drivers know when I am turning or stopping in my wheelchair if we walk in the street.
- Always use sidewalks. If there are no sidewalks, we should walk facing traffic and as far to the left as possible.
- Take walks where there are crosswalk signals, crossing guards, and sloped curbs.
- Hold my hand when we cross the street.
- Wear bright colored clothing and add reflectors or flags to my wheelchair to help drivers better see me.
- Wear sunscreen and have drinking water available for during walks. Begin with short walks and take breaks to help build my strength.

Help keep me safe on playgrounds.

Speak up for me and my needs for safe, playgrounds that I can visit and use. See the Americans with Disabilities Act Accessibility Guidelines (www.access-board.gov), the American Society for Testing and Materials International (www.astm.org), and the Consumer Product Safety Commission (www.cpsc.gov) for more information.

When we visit a playground or help develop a new one, look for:

- A flat playground surface for me to play on, especially if I'm in a wheelchair or have difficulty walking. Rubber matting also protects me if I fall.
- Play areas connected together with a flat surface so I can move freely and easily between the areas. Look for parts sticking out that may catch my clothing, special device, or medical equipment.
- A playground that lets you get to me quickly in case of an emergency.

Here are some other ways to help keep me safe:

- Apply sunscreen with at least a 15 SPF before going outside and several times during the day. Give me breaks and plenty of water during the day.
- Check that the playground equipment is not too hot from the sun.
- Watch me at all times. Teach me not to talk to or leave with people I don't know unless you have told me that they are going to pick me up and they use a code word known only by you and me.

Help keep me safe at school:

 Talk ahead of time with my school or preschool administrators, my teachers, aides, and other children in my classroom. Help everyone prepare for my return from the hospital and for a safe education setting that allows me to fully participate and learn.



Help keep me safe from intentional injuries.

Keep me from being abused physically, emotionally, or sexually by taking the steps below.

Talk to me about:

- My body and how to protect it
- How to not let anyone touch or talk to me in ways that can hurt me, or give me harmful drugs or medicines
- How to tell you, my doctors, nurses, therapists, teachers, and other adults when I have been hurt in any way or if I think something is not right
- **Know who takes care of me.** Help them to understand my special needs, personality, and behavior. Give them your contact information so they can find you in an emergency or if they have questions about caring for me.
- **Talk to me.** Ask me questions about any bruises on my body. Find out what happens to me during the day. If I don't want to go or stay somewhere with a family member or care provider, listen to me and find out why.
- If I have been hurt physically, emotionally, or sexually, please get me medical care immediately. Provide as much information as possible so that the medical care providers can make good decisions about my care.
- Take out time for yourself, when possible. Find a sitter or respite care agency who can watch me and care for my needs when my parents need a break.



If you need help or information, call Prevent Child Abuse Indiana at 1-800-800-5556.

Do your part to help keep all kids safe.

Safety is important for all children.

Practice safety everywhere and every day. Include children with special needs in your efforts to keep all children safe.

Knowing how to keep me safe is important for you and everyone who cares for me. To learn more about community outreach programs and education materials on child safety and information about child safety products, call The Safety Store at 1-888-365-2022, or email safestor@iu.edu.

Other Links:

Fire Safety and Burn Prevention for Children with Special Needs, Safe Kids USA www.safekids.org/safety-basics/special-needs/fire-burn-safety

Keeping Children with Special Needs Safe in the Home, Safe Kids, USA www.safekids.org/safety-basics/special-needs

National Fire Protection Association www.nfpa.org, and search for I Know My Fire Safety Plan



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The Riley Hospital Family Centered Care Program and

The Riley Hospital Family Advisory Council

For more information, visit safetystore.pediatrics.iu.edu

