**Emergency Preparedness for People with Special Health Care Needs**

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**I know you’re thinking, “Its king cake season not hurricane season yet!”** Now is a good time to start making a plan, funding the plan, and building your Geaux Kit. Emergency Preparedness is your responsibility and it takes a bit of forethought to prepare for those with special healthcare needs. Isn’t the state supposed to do that for us? Nope!

Medical Special Needs Shelters are a last resort for the most critical patients. Families are not allowed to accompany the patient. There is a strict triage or qualification assessment. Your family member with special needs may not meet the criteria in which case you will be turned away to seek alternate shelter elsewhere. Mass shelters do not provide medical supplies, adequate power sources for medical equipment, privacy, or a controlled environment for CYSHCN. In short, you don’t want to go there!

We’re not just talking about hurricanes here either. Preparedness applies to many types of emergencies. An emergency could be anything from an unexpected emergency department visit; a change in insurance companies which alters payment for supplies or supplier provider changes; natural or man-made disasters. Know the types of potential emergencies in your area.

Preparedness should include plans for sheltering in place and evacuations.

Contact your parish Emergency Preparedness and Homeland Security officials to register for priority notification of emergency news briefs and so they can check on your family during an event. Arrange a pre-need introduction with local first responders so your child and the providers can become familiar with each other, your home/school settings, and emergency transportation vehicles.

Ask your physician to write a justification letter to your Energy Provider for Priority Service Restoration for those who depend upon electricity to operate medical equipment.

Ask your physician to provide complex patients with an emergency health information form or a set of hospital orders (See Resource Links). Patients should keep both written and electronic copies in multiple places for optimal access, i.e. with the patient, in the kit, at school, in the vehicle, in an alternate emergency rendezvous location.

**What Goes in the GEAUX KIT?**

**Supplies**

What does your family member with special health care needs require on a daily basis to live and thrive? Multiply by seven for week’s supply or more. Think about things that would not be readily accessible “off-the-self” at a local Walgreens/ Wal-Mart or items that would be costly, both financially and time- wise, to acquire in an emergency evacuation. “Latex-free is important to me!”

* Feeding supplies- formula, bags, extension tubes, vent tubes, buttons, syringes, split gauze, tape, power strip, ready-to-eat recreational foods as appropriate, etc. The feeding pump and charger would go with the patient at the time of evacuation, if possible. Back-ups of these machines usually would not be available for a kit.
* Trachea supplies- trach tubes, collars, omni-flex connectors, gauze, lubricant, betadine, speaking valves, cleaning kit, suction catheters, etc.
* Oxygen, BiPAP, or Ventilator Supplies- copy of settings/rates, portable O2 tanks, circuits, tubing, connectors, cannulas, filters, power strip, distilled water. O2 Concentrator, BiPAP, Ventilator, Suction Machine and chargers would go with the patient at the time of evacuation, if possible. Back –ups of these machines usually would not be available for a kit.
* Nebulizer supplies- nebulizer, mask, tubing, chamber, aerosol meds, saline, charger, inhaler, spacer, power strip, etc. Nebulizers are inexpensive ($25) so a back-up is reasonable.
* Urological supplies- catheters, lubricant, irrigation syringes, betadine, chux/underpads, gloves, diapers, wipes, urosotomy pouches and barriers, etc.
* Bowel Program supplies- cone-tipped enema kit, ACE irrigation kit, ostomy pouches and barriers, gloves, etc.
* Wound Care supplies- barriers, tape, ointment, etc.
* Glucometer supplies- glucometer, test strips, lancets, alcohol wipes, batteries, glucose, etc.
* Vital Signs Assessment Kit- thermometer, blood pressure cuff, stethoscope, pulse oximeter, batteries, etc.
* Personal Hygiene supplies- Aloe Vesta Cleansing Foam (no-rinse perineum, body, & shampoo cleanser), battery-powered razor, deodorant, toothpaste/brush, etc.
* Medications- Always include a pharmacy print-out of current prescription drugs. Include any medications for which you are able to acquire an advance supply. This is not as easy because of payer source limitations, protocols, and expiration frequencies. Include those that can be acquired such as EPI Pens, OTC meds, etc. Consider using a nationwide pharmacy so prescriptions will be in their system accessible from any location in case of evacuation. In declared emergencies, state Medicaid regulations often authorize advance refills for evacuation or ease prior authorizations for emergency resupply.
* Labels- Include at least one manufacturers’ label for each product for correct name, size, stock numbers, and basic descriptions of products for comparable substitutions for resupply, i.e 12 fr hydrophilic plastic catheter with a coude tip vs a Rusch Hydro12.
* Comfort items- Include personal items to occupy or comfort your child such as an eye shade for sleeping, a favorite stuffed animal or toy, noise-cancelling headphones, earbuds and MP3/ iPod, batteries, chargers, etc.
* Important Documents – Copies of birth certificates; social security cards; legal information including copies of power of attorney, continuing tutorship, or guardianship paperwork especially for those 18+ years old; medical information. Be sure to protect these documents in a waterproof container such as a ziplock bag. Electronic documents can be stored on a flash drive but may not be accessible in a power failure.
* Funds for evacuation –Secure a designated credit card for emergency evacuations only; and cash. Cash works during power failures and nationwide.
* Clothing- Just a few sets. Space is precious. Most clothing can be laundered and purchased anywhere. These are easily located and often donated in evacuation situations.
* Don’t forget the regular stuff for yourself and other members of your family! Lay in an appropriate supply of water, ready-to-eat food, batteries, flashlights, cell phone chargers. [www.getagameplan.org](http://www.getagameplan.org) , etc.

Finally, remember to check expiration dates and rotate stock routinely.

**Information**

Families should include a Care Notebook which accompanies their family member always and is included in the kit also. The Book (as we call ours) conveys intimate patient knowledge to providers in the absence of the primary caregiver. I like to say, “Anyone could take my son and The Book to the nearest provider and he could receive informed emergency care.” This tool is invaluable for multiple reasons- providing documentation for providers, insurance, plans of care for school, home health providers, and support agencies. As youth transition into independence, having a written medical history and plans of care become invaluable to the teen and young adult. Not to mention supplementing a mama’s memory!

Ours is a WORD document which can be updated as needed. There are several on-line care notebook templates. Google ‘care notebook’ to find the model that serves your needs best such as this one from the National Center for Medical Home Implementation <http://www.medicalhomeinfo.org/for_families/care_notebook/>

We keep printed copies in our son’s wheelchair bag, our vehicles, and in the emergency kit. We keep an electronic copy on a really cool Batman flash drive on his wheelchair, in my purse, and in my husband’s wallet.

**The Book contains**:

* Medical History including diagnoses organized by body system or subspecialty, dates, surgeries, idiosyncrasies, etc.
* Medications and Supplies including doses, administration routes, sizes, stock numbers, recipe for mixing enteral formula, etc.
* Allergy Information including type of allergens (foods, drugs, environmental), type of reactions and corresponding treatments, and safe alternative foods, drugs, and products. “Latex-free is important to me!”
* Daily Plans of Care including routines and instructions for medications, catheterization, tube feeding, glucometer checks, nebulizer treatments, respiratory support (settings/rate), how to use equipment, etc.
* Physicians including subspecialty, names, addresses, phone/fax numbers, and email addresses.
* Vendors including names, addresses, phone/fax numbers, and email addresses for pharmacy, enteral supplies, DME, respiratory supplies, orthotics, urological supplies.
* Insurance Information including policy and ID numbers, contact numbers, copies of cards, contact info for waiver services and case managers.
* Legal Information including copies of power of attorney, continuing tutorship or guardianship paperwork especially for those 18+ years old.
* Copy of our son’s neuropsychological exam. It helps explain him to others.
* A brief Biographical Sketch including his likes/dislikes; hobbies/interests; triggers-things that upset him; and how he communicates best. This makes our son a real person to the provider –not just a list of diagnoses and issues. We like to say, “He presents much differently than he ‘reads’ on paper!”
* Emergency Evacuation Response Plan includes primary caregiver contact info, alternate emergency contact info both in- and out- of town, designated evacuation locations respective to threat, plans specific to hurricane, fire, tornado, flood, hazardous materials, terrorist threat, individual evacuation needs (a packing list) and location of the GEAUX KIT. Sounds complicated, right? However, these plans are required by waiver service providers. Therefore, the family can secure a copy for the patient’s records from their case manager. Done!

**Tips for Building and Maintaining an Emergency Supply Kit**

* Formula- Ask your physician to write prescription for 2 more per month to build an extra month supply over the course of 10 months. Example: 22 cans formula versus 20.
* Feeding Bags- Wash and reuse 1 bag every other day for 30 days to build an extra two-week supply per month.
* Catheters- Ask your physician to write prescription for 1 more per day per month to build an extra weeks supply per month. Example: 5 catheters per day versus 4. Contact your vendor who may offer sample supplies or “go kits”.
* Ostomy supplies- Ask your physician to write prescription for 2 more pouches and barriers per month. Search for a local support group at United Ostomy Associations of America [www.ostomy.org](http://www.ostomy.org) . Many of these groups offer supply exchanges or can put you in touch with vendors who have sample stock. Let local suppliers know you will accept any returned or partial boxes. Those cannot be re-sold and are kept as sample stock.
* Respiratory Supplies- Ask your physician to write prescription for 1 more tube, cannula, connector, circuit, etc. per month to build an extra supply. Ask for an extra set up when hospitalized or in the Emergency Department. Often times it will be given to you.
* Look for equipment exchanges such as:
  + Oley Foundation maintains an exchange list of enteral equipment and supplies which people are willing to mail sometimes you pay for shipping.  The details are here: <http://www.oley.org/equipexchange.html>.    The current supply list is here: <http://www.oley.org/EquipExchage_completelist.html> . Also, there is a list of links to similar resource exchanges and general insurance resources on the same page.
  + Host an equipment/supply swap a during a local peer-support group event. Families often have overstock due to product or size changes which they are willing to give away or exchange.
* Check expiration dates and rotate stock routinely.
* Get a generator. Waiver plans will pay for one if the patient is dependent upon electricity. Take advantage of tax-free holidays to purchase items like this. Remember, generators require general maintenance both during operation and inactivity.
* Stash cash. Visit 52 Week Money Savings Challenge plans for charts to save $1,378 or lesser amounts per year.

<http://lifeasyouliveit.blogspot.com/2013/12/52-week-money-savings-challenge.html>

* Stash a week’s supply kit in multiple locations for optimal access, i.e. with a relative, neighbor, school, in vehicle, etc. Check expiration dates and rotate stock routinely.
* Work with local, regional, state, and federal peer-support organizations to develop emergency re-supply and equipment replacement plans in the event of disasters. For example in the aftermath of Hurricane Katrina, Spina Bifida of Greater New Orleans partnered with Spina Bifida Association of America and state chapters to locate our folks displaced and scattered throughout the country and help them secure supplies and replace lost or destroyed equipment. SBAA networked with national vendors and suppliers as well as state chapter equipment closets to meet these needs. Post-Katrina, the SBGNO board of directors learned to make contact with members ahead of hurricanes to find out evacuation locations, cell phone numbers, and to make sure they have our best contact numbers during and after the event. The advance of social media outlets like Facebook and Twitter have been very useful tools in staying connected during and after these events especially when phone and electric services are unavailable.

**Emergency Preparedness means peace of mind for families! Ready? Set? Geaux!**