10 Essentials For Prepping With A Special Needs Child

Do you have a family member with special needs? I do. My oldest son, Owen, was born with Angelman Syndrome. It's a deletion on the maternal $15^{\rm th}$ chromosome.

He's completely non-verbal, globally developmentally delayed, has hard to control epilepsy, and eats anything he can get his hands on as a result of Pica. He's also one amazing kid with a cheerful personality. He's a fighter—surviving more in his short life than most people have to in a lifetime.

That's how I know that prepping with a child with special needs is a bit different. It requires some serious thought, and some creativity. Read the following article, and you will see what I mean.

Special needs is sort of a catch-all phrase. It doesn't mean exactly the same thing from one individual to the next. That means we won't prep exactly the same way. We all have to do what's best for our individual family.

Regardless of your loved one's diagnosis, here are ten things to consider when prepping:

1. Make an Accurate Inventory of Needs

What does your loved one need each day? Take time to make an accurate inventory of these needs. On a piece of paper or your computer, list:

- Daily meds (including dosage)
- Rescue meds
- Self-Care needs (diapers, wipes, gloves, etc.)
- Durable medical equipment (wheelchair, stander, walker, etc.)

- Other medical supplies (feeding tube supplies, bags, catheters, etc.)
- Special food (formulas, etc.)
- Anything else your loved one needs on a regular basis

Now that you have a list, you can use this information to help you prep. Look over your list. What are essentials to life, and what are niceties instead of necessities? Prioritize your list in order of most essential to least essential. That way you can start with the essentials.

2. Talk to Your Loved One

As <u>you start prepping</u>, be sure to talk to you loved one. I operate under the belief that my son understands a lot more than I realize. When I talk to the other kids about what we're doing and why, Owen is there too.

I explain it in as age-appropriate terms as I can, and reassure them all. We talk about our fire escape plans, our family meeting place, why we're stockpiling certain things, and everything else we can think of.

I explain to Owen that one of the reasons his bedroom is on the ground floor is so that he won't have to try and jump through a window. It's not something he could physically do. I let him know that we've thought about his needs, and will always do our very best to meet them.

Include your loved one in conversations and planning so they have an idea of what you're thinking and can ask questions if possible.

3. Prepare for the Most Likely Event First

I live in the middle of nowhere surrounded by miles of timber in every direction. <u>Wildfire</u> is the most likely event I should prep for. <u>The odds</u> of having a fire come through my land are greater than other natural disasters.

I know that in a wildfire event, we'd have to bug out. It'd be much easier to stay put with all of Owen's equipment, but it wouldn't be safe to do so. So we make sure we're prepared before wildfire season rolls around.

Owen's wheelchair stays on our family's minibus when we're not using it inside. So does a dose of each of his emergency medications. Each year, I repack a plastic tote with clothes for everyone. I also include a couple days' worth of meds for Owen, diapers, wipes, and disposable gloves.

There's also some bottled water and storable food. It's everything we'd need to survive somewhere else for a few days. And it's already packed on the bus and ready to make a quick exit.

What event is most likely in your area? If you haven't yet started getting prepared, prep for that event first. Think through it in your mind, and start gathering what you'll need.

Start by getting a 3-day supply built up of all your loved one's essentials. It's a baby step, but an important one.

Bug Out or Bug In?

Medical equipment is heavy. It's bulky. And it certainly doesn't move quietly through the woods. Depending on your child's mobility, leaving might be very difficult.

When you're making plans for a crisis, you might find it makes more sense to stay put. That way you don't have to leave all of your equipment and medical stockpiles behind. If we don't absolutely have to leave the farm, we're planning on staying here.

4. Stockpiling Meds

I've heard that some doctors are understanding and will help you stockpile meds to be better prepared. I haven't yet found this to be true. Unfortunately, doctors are at the mercy of

insurance companies, and most of modern medications are very expensive.

The insurance companies don't want to shell out more than they absolutely have to. They carefully monitor dosages, when medications are being refilled, and do everything they can to prevent paying for too many.

But, there are still ways to stockpile meds. Using these techniques, I've successfully gotten a couple week supply built up of most of my son's medications.

Auto Refill

Simply by switching to auto-refill, the medication is refilled as soon as the insurance company will allow it. I've found this is usually a couple of days before the medication runs out. Owen's meds are automatically shipped to us thanks to a mail order pharmacy, and I'm slowly building a reserve.

Refill On Time Even When Just Starting the Medicine

Almost every med my son has started required a slow start. He started with a half-tablet, or just one instead of two. As his body adjusted to the medicine, we slowly increased the dosage.

He didn't use the entire bottle before it was time to refill. I refilled it anyways. Just like that, a small stockpile was created.

Save Meds

Each time my son has surgery scheduled, he doesn't take his meds in the morning. They have such a long half-life that it's easier to just skip the dose than to mess with trying to make him take them without food or drink.

If your loved one has to miss a dose for some reason, hang onto that pill. Each time you save a pill, you're adding one additional dose to your stockpile.

5. Learn Alternatives to Medication

My son's seizures are controlled well on a low-carb, high fat diet. Unfortunately, this diet takes a toll in other ways, especially in his behavior. That's why we're relying on meds currently.

But, if I ran out, I know I could keep the majority of his seizures away by changing his diet. With a milk cow for cream, and chickens for eggs, I have a steady supply of ingredients for a high-fat, low carb diet.

Not every medication can be replaced by a <u>natural alternative</u>. But, many of them can. <u>This Survivopedia post</u> shares some excellent points about medication alternatives that are easier to stockpile. Do some research and see what you can try as a replacement.

Know What Each Medication Does

Before you can think about replacing a medication, you have to know what it does. Ensure that you know the purpose behind every drug your loved one takes. You can see if there are over-the-counter meds that might work in a pinch.

You should also research the half-life of each drug. That's how long it'll last in their system.

I'm not a doctor, but in a crisis situation, you may be able to increase the amount of time between each dose. That'll help stretch your stockpile. You can also experiment with dosage and see if you can offer a lower dose and still get the desired result.

<u>Have a Medication Weaning Plan</u>

Going cold-turkey off of some pharmaceuticals can cause many problems. It's often too much of a shock for the body. That's why having a weaning plan is imperative.

When you can no longer pick up meds, take a count. Inventory everything you have and see how many doses that is. Then, work backwards to slowly cut the doses down. That way instead of going from a full dose to nothing when you run out, you already have a plan in place for stepping off the med.

If you've found a natural alternative, be sure to slowly introduce this during the weaning period. It'll be a smoother transition for your child than changing it all at once.

6. Think Through Dietary Changes

If your loved one requires a special diet, or is fed by formula, it's essential to think through alternatives. Do you have a way to meet nutritional needs without the actual formula?

Could you stockpile infant formula? It won't have the exact same nutrients, but its readily available and will provide some nutrition.

Could you create a homemade formula out of goat's milk and supplements? Start researching recipes and learning from other parents in similar situations.

Having a backup plan for meals will help you know what to store.

7. Stockpile Medical Supplies

In addition to meds and dietary needs, what else does your loved one need? My son struggles with incontinence since he can't tell me when he needs to go to the bathroom. As a result, we need to keep diapers and wipes on hand.

By receiving as many packs as the insurance will allow, we've built up a nice supply of diapers. We are working with Owen on toileting, so our supply lasts longer than it otherwise would. Every diaper not used is one we can store.

I've also used the subscribe and save feature on Amazon to stockpile supplies we purchase out of pocket. I just have an order shipped a little sooner than I really need it. Over time, a nice supply has accumulated. You can try this for:

- Over the counter meds
- Disposable gloves
- Baby wipes
- First aid supplies
- Anything that's shelf stable

8. What About Power?

Is your loved one dependent on electricity for any reason? From powering feeding pumps to using oxygen, many medical devices require constant access to electricity.

Do you have the ability to power your house off the grid? If you aren't able to completely unplug currently, consider investing in a generator. Or ensure you have what you need to build your own.

It's a small step towards preserving your loved one's quality of life while you gain more self-sufficiency.

9. The Marvel of Modern Science

Many children with special needs, my son included, have had their lives saved or extended because of modern science. Owen has used life-saving emergency seizure medications more than once. He also has a battery operated device implanted in his chest keeping many seizures at bay.

In addition to seizure rescue, other medical advancements have kept him alive. He's used rescue medication for a severe reaction to a wasp sting. He's had emergency surgery to pull foreign bodies out of his throat.

Without modern society, he most likely wouldn't have survived many of these events. Before advancements in science and

pharmaceuticals, the infant and child death rate was higher. Society simply didn't have the medicine and medical training necessary to save those lives.

Unfortunately, there's not always a suitable replacement for modern science when a crisis occurs. I simply won't be able to perform the surgery needed to replace the battery in his VNS implant. I will run out of meds at some point. He will likely continue to eat objects that pose a threat to his life.

You have to be mentally prepared for the worst. All of the prepping and stockpiling of meds can only go so far.

As author William Forstchen discusses in the novel *One Second After*, the chronically ill and the elderly are at a distinct disadvantage in case of an EMP or solar storm. They're also at risk in many other SHTF situations. As hard as it is to admit, not everyone will survive a crisis despite your best efforts.

10. Today Isn't Necessarily Your Future

Because of the high risk for people with special needs, it's easy to get caught thinking about what will happen to your child if society changes. Depression and a sense of despair are common. But, there's one essential component we haven't covered yet.

<u>Life Changes</u>

When my son was first diagnosed, he couldn't swallow liquids properly. He was diagnosed with failure to thrive. Eventually, he had a g-tube installed surgically.

For a couple of years, he got almost all of his nutrition through his tube. Any liquids he took by mouth had to be thickened. He was hooked to an electrical pump at night, and drip fed for several hours. We assumed he'd be using his tube forever.

But we were wrong. Today, we only use the tube to keep him

hydrated in times of intense illness. He eats everything else by mouth, and can swallow liquids without aspirating. As he grew and got stronger, he outgrew some difficulties.

I share this because you can't accurately predict what the future holds. None of us can. Just because your child requires certain medications or treatments today, it doesn't mean that's what is in store forever.

So prep for today's needs. That's all we can do. But know that as life changes, your child's needs will change. As each change occurs, take time to reevaluate your prepping plan. Update your gear, change out meds. That way you're always as ready as you can be.

How Are You Prepping?

What special needs do your loved ones have? Please share in the comments how you are prepping for these needs. As a community, we can all learn from each other, and be better prepared for whatever tomorrow brings.



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This article has been written by **Lisa Tanner** for <u>Survivopedia</u>.