**Example guide to personalize for your child --**

Every child with spina bifida is different. This is an example of a guide designed by one SBWIS parent for their child attending day-care. We encourage you to copy/cut/paste/edit as needed to develop the most appropriate guide for taking care of your child’s unique needs.

**A guide to caring for (insert child’s name)**:

We are so very excited that *Insert Child’s Name* will be in your care soon and have created this resource as a guide to help you to understand our child’s medical conditions and considerations that you should be aware of. We hope it will help you understand the conditions he/she is living with, when to contact us.

We realize that on paper, our child’s condition appears daunting to someone who may have little to no medical experience. Our child is just like any other child; but also has a few areas in their lives that they do it a little differently.

In general, our child is like any other. He/she has favorite toys, favorite activities, likes and dislikes. We want you to know that (child’s name)

Likes:

Dislikes:

Favorite books, games, toys, songs:

Most important to our child’s health, safety, and continued development, is **having daily communication between parent/guardian and care giver (babysitters, teachers, aides, and therapists).**

(insert child’s name) was born with a condition called:

SPINA BIFIDA

Spina Bifida is the most common permanently disabling birth defect in the United States. Spina Bifida literally means “split spine.” Spina Bifida happens when a baby is in the womb and the spinal column does not close completely. Helpful links:

<https://kidshealth.org/en/parents/spina-bifida.html>

<https://www.parentcenterhub.org/spinabifida/>

<https://www.youtube.com/watch?v=NMOSkmvw-54>

There are 3 main types of spina bifida.

(insert child’s name) is impacted by this type of spina bifida: (circle or highlight the appropriate type for your child so caregiver does not get confused).

* ***Myelomeningocele (Meningomyelocele), also called Spina Bifida Cystica:***
This is the most severe form of Spina Bifida. It happens when parts of the spinal cord and nerves come through the open part of the spine. It causes nerve damage and other disabilities. 70 to 90% of children with this condition also have too much fluid on their brains. This happens because fluid that protects the brain and spinal cord is unable to drain like it should. The fluid builds up, causing pressure and swelling. Without treatment, a person’s head grows too big, and they may have brain damage.
* ***Meningocele:*** This is a rare form of the condition where the protective membranes around the spinal cord (meninges)push out through the opening in the vertebrae. Fortunately, the spinal cord still develops normally, and these membranes can be surgically addressed with minor or no damage to the nerve pathways.
* ***Spina bifida Occulta*** This is the mildest form of the condition. In spina bifida occulta, there develops a small separation or gap in one or more of the bones of spine’s vertebrae. In this type of spina bifida, the nerves typically remain unaffected, so many people don’t even know they have the condition unless it is caught on an X-ray. Sometimes a small collection of fat or an abnormal tuft of hair is present on a newborn’s skin just above the spina bifida occulta location, but again, since it isn’t symptomatic, it doesn’t call for aggressive treatment, only monitoring.

In general, children with Spina Bifida must learn how to get around on their own without help, by using things like crutches, braces or wheelchairs. With help, it also is possible for children to learn how to go to the bathroom on their own. Doctors, nurses, teachers and parents should know what a child can and cannot do so they can help the child (within the limits of safety and health) be independent, play with other kids with and without disabilities, and to take care of him or herself.

SAFETY

Our biggest fear with our child being cared for by someone else is his/her safety. These are the most important concerns for our child’s safety:

* Communication: Our Child is almost entirely nonverbal, with a vocabulary of less than 5 words.
* **Body Awareness**: He/she does not understand gravity, and will happily throw himself/herself off of chairs, curbs, and try to throw himself/herself backwards out of someone's arms. Since he/she has little feeling in their legs they could severely hurt themselves without even knowing it.
* **Choking:** Due to damage that was done to his/her cerebellum before his/her Chiari malformation reversed, he/she is prone to choking on food or drink. He/she is not independently feeding himself/herself with utensils, and will always attempt to use his/her hands for everything. His/her eating behavior is more consistent with a one year old than a child almost three years old. He/she cannot sit at the table like a “typical” child, and will need constant visualization when eating to ensure he/she isn't grabbing a large bite of something.
* **Breath Holding:** Our Child does have a history of **breath holding** when he/she is hurt. He/she will inhale as a reaction, and forget to exhale due to being upset. His/her doctors are aware of this, and have monitored him/her doing this on numerous occasions. He/she **ALWAYS** recovers consciousness on his/her own after less than 5 seconds, though he/she sometimes does turn blue around the lips. These episodes are happening less and less as he/she ages and matures. **Please notify us** if this happens, but as long as he/she perks back up it isn't something we necessarily need to pick him/her up from school.
* **Walker Tipping:** Our child has been sitting on the back of his/her walker which then tips over and he/she could get hurt. We have been trying to help him/her understand that he/she cannot do this, and at times we do have to take the walker away for a few minutes.

**EMERGENCY SITUATIONS:**

Concerns that may arise related to (child’s name) **SHUNT** and when you should contact us.



**SHUNT:** a tube inserted to drain excess fluid from ventricles in the brain.

Symptoms of shunt issues and it could be malfunctioning. Call us if (child’s name) has:

* Headaches
* Vomiting
* Lethargy (sleepiness)
* Irritability
* Swelling or redness along the shunt tract
* Decreased school performance
* Periods of confusion
* Seizures
* Also contact us if (child’s name) is hit hard on the head, falls and bumps his/her head

Concerns that may arise related to **BOWEL/BLADDER INCONTINENCE,** and when you should contact us:



**Catheter** – a tube inserted to drain urine from the bladder.

Contact us:

* If urine produces stronger odor than normal
* If Child has any discharge or blood in Catheter
* If Child has a fever
* If Child becomes lethargic
* If Child vomits
* If Child has blood in diaper from urine or stool

**We do not anticipate our child will ever require a call to 911 emergency – in all concerns above we should be contacted.** As with any child we would understand if emergency personnel are contacted in the event there is a true **EMERGENCY**– such as:

* If child experienced a loss of consciousness
* If child stops breathing
* If child experiences a severe injury where his/her life is at risk.

**In the event of an emergency we expect to be contacted.**

**Best Contact Information:**

Hospital of choice:

Additional health conditions associated with spina bifida that impact (insert child’s name):

CHIARI MALFORMATION:

**Definition:** Chiari malformation happens when both the cerebellum and brain stem tissue extend into the foramen magnum (the hole at the skull base for passing of the spinal cord) and is present at birth.



<https://kidshealth.org/en/parents/chiari.html>

Child’s name, was born with a Chiari Malformation. The condition was treated with surgery and is being monitored by his/her doctor.

Contact us if:

* Child complains of neck or chest pain
* Child complains of headaches that are brought on by coughing, sneezing, or laughing
* Child has difficulty swallowing, which may cause gagging, choking, or vomiting
* Child has difficulty speaking
* Child complains of, or you observe a difference in, the weakness, numbness, tingling, or other abnormal feelings in his/her arms and legs

Child’s name, has scoliosis (spine curvature) due to this condition, and their spina bifida.

HYDROCEPHALUS

Definition: A complication that occurs with many cases of spina bifida is hydrocephalus, which is additional fluid that accumulates around the brain.

Impacts: *Insert Childs Name* was born with an extremely mild case of hydrocephalus that didn't require any intervention. However, after a spinal surgery in the summer of 2016, he/she temporarily developed an increase in fluid and it required intervention. His/her neurosurgeon placed a small hole in a part of Child’s brain, a place to allow the excess fluid to drain. There is always a possibility of repeating this spinal surgery, and needing to access that hole once again, so the neurosurgeon left a port under the skin of his/her head.

Caregiver: If you are looking at him/her, the reservoir is located on the front left of his/her head - You will feel a slight bump under the skin. This does not hurt to touch, but due to his/her history of surgeries, he/she does have PTSD, and does not like anyone or anything touching his/her head.

* Bumps to the head can impact his/her Hydrocephalus. Please report any bumps or hits to the head, even if they seem to be small.

**While it is unlikely that hydrocephalus will randomly onset at this age, it is important to report any neurological changes to us. Things to look out for would be extreme lethargy and projectile vomiting.**

LATEX ALLERGY

**Define:** Individuals with spina bifida are at a higher risk of having a latex allergy and are under precautions – meaning children are to be treated as though they have the allergy.

**Impact:** Our Child has a **LATEX ALLERGY PRECAUTION** and should avoid latex.

**Caregiver**: Latex free gloves should be used in cafeteria during food preparation, diaper changing and sunscreen application. Especially avoid latex band-aids and balloons. Please let us know if you would like a copy of a latex list. Common items in a daycare or school that contain latex and should be avoided: Nerf products, Koosh products, rubber bands, first aid items (ACE wrap, bandages, gloves), tape and adhesives.

<https://acaai.org/allergies/types/latex-allergy>

<https://www.mayoclinic.org/diseases-conditions/latex-allergy/symptoms-causes/syc-20374287>

If you have concerns about foods that contain latex that should be avoided, list them in this section.

Please inform us if he/she experiences any allergic reaction such as hives, difficulty breathing, swelling around lips or eyes, etc.

If medication can be administered, provide information in this section. Include name, dose and location of medicine.

OTHER ALLERGIES

Our child is allergic to bee stings and we have provided an EPI Pen for anyone to use if it appears he/she is having a reaction. If you need any training on how to use the EPI Pen please let us know.

BLADDER & BOWEL CARE

Define: Because of the damage to our child’s nerves – his/her bladder and bowel health is impacted, called neurogenic bowel and bladder.

Impact: He/she is not capable of urinating on his/her own, and at this time does require use of a catheter. Those with spina bifida are also at a higher risk of developing UTIs.

Caregiver: Please do NOT have potty training attempts made. Please do NOT expect our child to try to urinate on their own or make any comments that he/she should try to urinate like everyone else. We will provide any training on how to help our child go to the bathroom. It sounds very scary but you will quickly learn it is easy and not scary at all, just a different way to go.

UTI’s are unfortunately common and we would like to have open communication on any changes you notice while helping with potty time. It is important to note if his/her urine smells strong or foul, if there is any blood while going to the bathroom or in his/her diaper, if he/she has a fever, if you notice low flow, or wet diapers between cathings.

We manage *Insert Childs Name* bowel care at home nightly by using a cone enema system. We do not anticipate *Insert Childs Name* to have problems in this area while at school – but realize it may impact him/her and want to be sure we help faculty and staff understand his/her condition.

Typically, we only see bowel accidents when we have had inconsistencies in doing his/her care (if we miss/skip a night), if they have a stomach bug, or if they are on antibiotics. If we see any changes in his/her function or warning signs that would make us believe he/she might be more likely to have an accident we will be sure to let those helping with his/her care know so they are aware.

**When to call:**

1. **Blood in Diaper/on Catheter**
2. **Foul Smelling Urine**
3. **No Urine**
4. **Fever**

MOBILITY

Even though our child has movement throughout his/her legs, he/she has extremely low muscle tone in his/her legs and trunk, and very little feeling in his/her legs. At this time (October 2018), he/she is able to pull to stand, cruise on furniture, and he/she has a walker and wheelchair that he/she uses for mobility. We encourage him/her to walk, either independently or with his/her walker in the home. All of his/her doctors predict that he/she will walk independently one day, however, while he/she is still learning it is important that he/she be given every chance to use his/her muscles by crawling or walking.

Our child will need help washing hands as it is hard for him/her to stand and wash at the same time, also getting in and out of chairs is still a work in progress.

**His/her wheelchair is NOT to be used for anything other than transportation to / from the cafeteria and car to/ from home**.

Because of the lack of feeling in his/her legs and trunk instability*, insert child name* likes to do the “w” sit. We do not want him/her doing this and always need it corrected by saying “feet in front” or “check your legs”. This is a very bad position for our child to be in as it causes unneeded strain on the knees and hips. Please correct the “w” sit as much as possible.

WHEELCHAIR

Our child learned how to use a wheelchair with a homemade toddler wheelchair at 18 months old, and graduated to a full-size pediatric wheelchair at 2 years old. His/her wheelchair currently has an “anti-tipper” on the back – which helps prevent him/her from falling backwards.

Childs Name doesn't understand gravity, and needs to be closely monitored at all times, especially when in his/her chair. He/she will gladly roll straight off a curb and slam his/her face into the cement.

He/she doesn’t understand how big the wheelchair is and accidentally will run into corners and other children. We are working on awareness but he/she will need help.

He/She has become very independent with his/her chair and operates it on his/her own about 90% of the time. Our child’s wheelchair seems to attract a lot of questions and attention. People who do not know him/her may ask “what is wrong” or ask why he/she doesn’t walk. It’s okay to let strangers know that he was born with spina bifida and the braces/chair help him/her get around better and faster.

It is also common for people, especially kids, to want to help him/her or push his/her wheelchair. We encourage him/her to be independent and usually *Insert childs name* does not like when children come up to him/her and try to push his wheelchair. We try to teach others that they need to ask before touching or pushing the wheelchair.

 At this time *Insert child’s name* is unable to get in or out of his/her wheelchair by himself/herself and will need assistance.

**His/her wheelchair is NOT to be used for anything other than transportation to / from the cafeteria and car to/ from home.**

Other ideas for this section: Describe your expectations about wheelchair seating, straps, seat-belts, tray/no tray, how long in or out of wheelchair, use of wheelchair brakes, safest way to transfer and assist your child.

WALKER

*Insert child’s name* is in the beginning stages of learning to use a walker. It is equipped with a harness to prevent him/her from falling if his/her legs give out, or if he/she decides he/she would rather crawl. He/she is still building up endurance with this and should be allowed time to crawl or cruise around the classroom when it is an appropriate time to do so.

He/she loves to sit on the back the walker, which does make it fall over and he/she could get hurt. We do give him/her 2 warnings and on the 3rd one we take the walker away (for 1 minute) to discourage this behavior.

We are currently working on helping *insert child’s name* step over small steps, especially with the left foot and taking side steps. By encouraging him/her to “take steps” versus “hopping”.

ORTHOTICS

To help with his/her endurance he/she uses AFO braces and cables. This helps give him/her more support with walking.

While our child can walk barefoot, with socks, or with shoes – it is physically exhausting for him/her to keep that up for long. **HE/SHE IS TO WEAR THESE DURING ALL WAKING HOURS**.

When he/she naps they should be removed, and if you notice any extreme redness or bruising we should be notified. Those with spina bifida often have issues with circulation, and a slightly mis-fitting braces can result in pressure sores. **We need to be notified** so adjustments can be made. If he/she does develop a pressure sore then he/she needs to remain out of bracing until it heals **completely.** If you notice redness, please keep an eye on it. If redness is still present 30 minutes after bracing has been removed, we need to be notified.

We can show anyone who would like to learn the best way to put on the AFOs to avoid sock rubbing and make sure they are fitting correctly.

NOISE SENSITIVITY

Child’s name is very sensitive to loud noises. He/she sees a private OT for SPD (sensory processing disorder), however know that he/she covers his/her ears for loud noises, but also as a defense mechanism for anything he/she deems scary, upsetting, or overwhelming.

**We've reached the end! We appreciate your time, and for taking an interest in getting to know our sweet little man/lady.**