



This guide was developed primarily by parents of our youngest members with spina bifida. Allowing others to care for your child can be scary. As the expert, you can share what you know about your child's condition to create a more successful and safe experience for the care provider, you and most importantly, your child.

We hope you find this outline and guide helpful. The intent is to provide a format that may work for you when communicating about your child to caregivers (babysitters/day care providers/pre-school staff). As you think about your child's needs and modify this guide, know that everything you include will be helpful for easing the transition from your care to someone else's.

You will be creating a guide specific to your child. We'd like to see your completed guide, so we can improve this tool for future parents. You can share your personalized guide by emailing it Kathy at [sbwis@sbwis.org](mailto:sbwis@sbwis.org). Your child's personal information will be kept confidential, while your ideas and topics included will be added to this example for use by others. Thank you for completing your child's personalized guide to providing the best care possible when away from parents/guardians.

Please read the following outline and sample guide to create and present to a daycare/preschool facility/baby sitter or any person caring for your child with spina bifida. This is intended to be a helpful reference of areas that you might want to include in a similar guide about your child with spina bifida.

1. Use this outline to create your own child specific guide.
  - This a sample guide for ideas.
  - If you choose to use the sample guide, you can read through and delete any areas that do not apply to your child. Also, add any items that are relevant to your child.
  - This guide should be customized for your child.
2. If you choose to use sections from the sample guide in your final guide, please edit it to reference the correct gender and child's name as applicable.
3. We suggest giving this to a care provider during a one-on-one meeting and read through it together. This gives the care provider an opportunity to ask clarifying questions and take notes.
4. Remind all care providers that this guide may / will change as your child's health changes. It is to be used as a guide and you encourage their questions and frequent communications about your child.

Good luck while creating your child's personalized guide for caregivers.

## Suggested outline:

SBWIS parents suggest including these topics in your child's personalized guide to care. Remember when writing your guide, keep descriptions informative and short – not too overwhelming. Emphasize with care giver that not everything can be included on paper and open communication is necessary.

1. What is Spina Bifida
  - Define
  - Child Specific traits
2. Main Concerns
  - Safety – discuss top safety concerns briefly for quick reference  
Examples: language, mobility, eating/drinking, behavior, latex sensitivity
3. Medical Concerns
  - Emergencies - discuss **TOP** concerns and symptoms and when the caregiver should call the Parent/ Legal Guardian
  - Chiari II - define what it is, how it impacts your child, what caregiver should know
  - Hydrocephalus / Shunt - define what it is, how it impacts your child, what caregiver should know
  - Bowel/Bladder Incontinence - define what it is, how it impacts your child, what caregiver should know
4. Mobility
  - Describe how your child gets around, feeling in legs/feet, etc.
  - Walker/Wheelchair/Canes - describe when they should use, how caregivers can help, child's capabilities and where they need help, any areas teachers should be aware of
  - Orthotics - describe what they are, when/how child wears them, skin care, areas caregiver should be concerned about
5. Other concerns
  - Breathing needs, sleep apnea, eating/drinking, noise sensitivity, learning disabilities

General tips when caring for a child with spina bifida:

1. Observe – look for clues
2. Use common sense
3. Add variety when teaching (auditory/visual/tactile)
4. Be flexible
5. Be consistent
6. Have a plan. And a back-up plan.
7. Be positive!

