

# Building the Team at Home

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# Outline

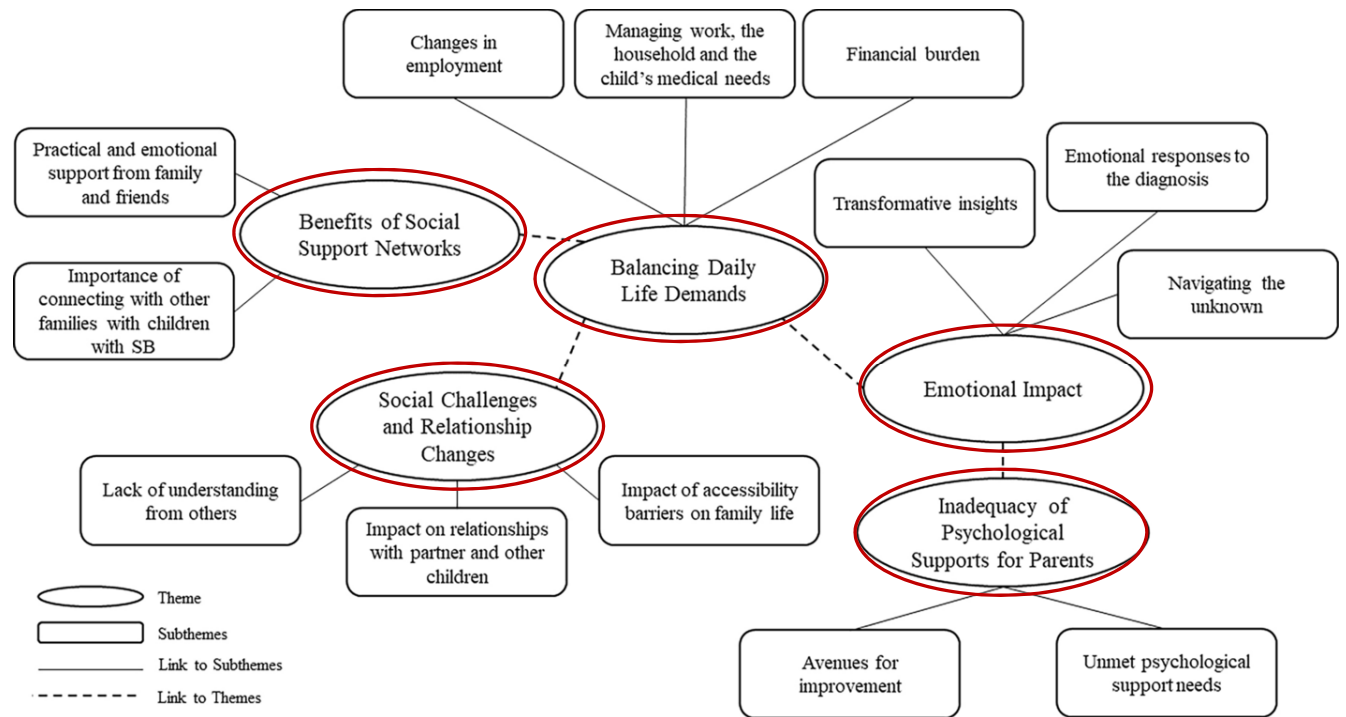
- Impact on whole family
- Impact on sibling
- Positive aspects of having a sibling with SB
- Negative aspects of having a sibling with SB
- Supporting siblings
- Maintaining family well being
- Resources
- Family activities
- Discussion and open the floor for questions

# Impact on the Family

## Having a child with Spina Bifida

- Parents of children with SB experience **more stress** than parents of typically developing children
- However, there is **considerable resilience** in these families as well
- Parents of children with Spina Bifida show few differences in **marital function** compared to families of typically-developing children.

# Family Stressors



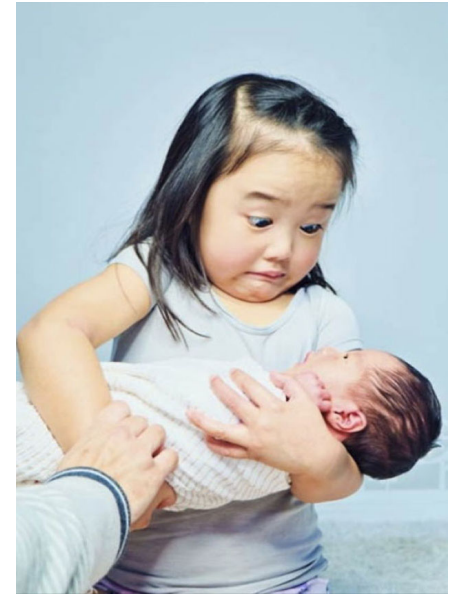
## Impact on the family

- Feel less satisfied and competent as parents
- Lower quality of life
- Smaller social networks
- Less optimistic about the future
- Feel more isolated
- Parental adjustment
- Sleep and anxiety – especially in mothers
- Mental health – PTSD and depression
- Lower family quality of life

# Impact on the Sibling

## Impact on the Sibling

- Children experience new externalizing and internalizing symptoms
  - Anxiety
  - Acting out
  - Challenges with routines
  - Impact family dynamic
  - Differences between boys and girls
  - Considerations for other disabilities outside of Spina Bifida.



# Positive Influence on the sibling

- Empathy and Compassion
- Maturity
- Resilience
- Advocacy
- Foster open conversations and connectivity within the family
- A sense of purpose
- Positive Life Experiences
- Modeling behaviors



# Supporting Siblings

# Supporting siblings - Providing Education about Spina Bifida

## Parent-Child Conversations:

- Can help develop self-esteem
- Strength bond between parent and child
- Teaching children how to cope
- Every child is different

## Focus on:

- Age-appropriate explanations
- Match the sibling's developmental
- Provide honesty and transparency

## For Parents

- Take care of yourself
- Model positive emotional responses

# Strengthen Bonds Between Siblings

## **Involve Siblings in Therapy Including siblings in therapy sessions can:**

- Help them feel helpful instead of jealous
- Make therapy "fun" for the sibling with CP
- Build understanding of what their sibling is working on
- Create shared experiences and goals

## **Give Siblings Minor Caretaking Tasks Assigning appropriate responsibilities:**

- Helps them feel useful and involved rather than "shut out"
- Can increase self-esteem and sense of pride
- Takes some pressure off parents
- Builds confidence in their abilities

## **Find Accessible Activities Siblings Can Do Together**

- Music and dance
- Engaging with pets
- Crafts and art projects
- Adaptive sports
- Games and shared hobbies
- Technology and video games

# Give Siblings Their Own

## **Pursue Individual Interests**

Make sure siblings have opportunities to develop their own identity: • Devote attention to the sibling outside of therapy and "CP time"

- Schedule regular "one-on-one" time with each parent
- Allow time for siblings to develop their own hobbies and interests
- Support activities that are just theirs

## **Encourage Community Participation**

- Encourage joining clubs and teams
- Foster socializing with peers

- Help build an external support network
- Promote age-appropriate independence

## **Be Aware of Additional Stressors**

Pay special attention to siblings' needs during times of increased stress, such as:

- Surgeries or hospitalizations
- Medical emergencies
- Major therapy or treatment changes
- Transitions in the family

# Family Wellbeing

Caregivers and siblings need to maintain emotional, mental, and spiritual health as well as physical well-being.

Remember:

Therapy can be for everyone, even you!

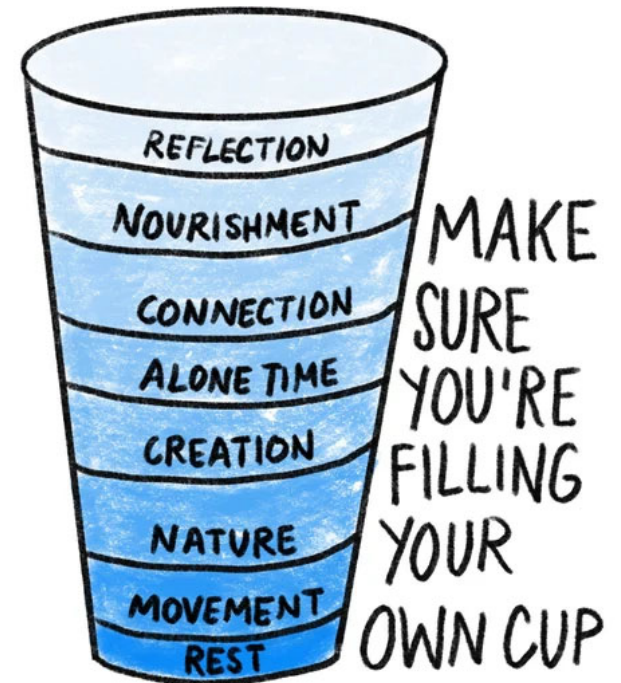
Take breaks

Self-Care looks different for everyone

Validation and Connectivity

Don't be afraid to celebrate

Acknowledge hard/difficult feelings



It's important to take care of yourself.

- Ask for support
- Remember to eat
- Get rest
- Take breaks
- Take time to deal with your own feelings

## Routines help children and parents feel safe, organized, and in control.

- ❑ **A morning routine.** Keep the same wake-up and breakfast time each morning. This can make it easier to start the day.
- ❑ **Family check-in routines.** A quick check-in each morning gives parents and children a set time to talk and to plan the day.
- ❑ **A playtime routine.** Set aside time for your children to have fun. This can include playing games, drawing pictures, watching movies, or playing sports with friends or family.
- ❑ **A dinner routine.** Eating together most nights allows families to talk about their day and helps them feel closer.
- ❑ **A bedtime routine.** Keep the same routine at night — everyone will sleep better. Do something relaxing before bedtime, like take a bath or read a story.
- ❑ **A “me time” routine.** Set aside a brief time to check in with yourself every day. Relax and breathe. Think about what is going well in your life at the moment.

# Remember

Every family's journey with Spina Bifida is unique. There is no "right way" to navigate these experiences.

What matters most is:

- ✓ Open, honest communication
- ✓ Recognizing and validating all family members' feelings
- ✓ Seeking support when needed
- ✓ Celebrating strengths alongside challenges
- ✓ Fostering connections between siblings
- ✓ Maintaining balance in family life

All of your children deserve attention, support, and the opportunity to thrive.

# Family Activities

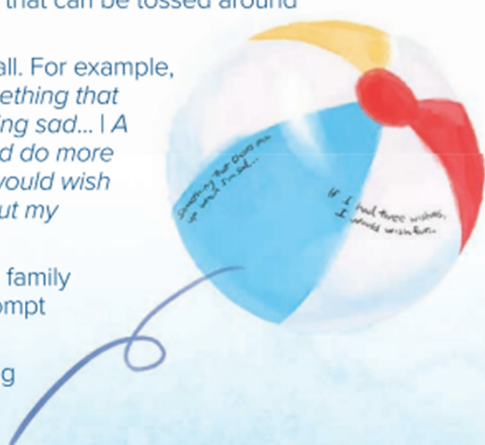
## Family mailbox:

- Make a family mailbox using a jar or shoebox.
- Family members write questions, thoughts or ideas they are wondering about on strips of paper to be placed inside the mailbox.
- You can decorate the mailbox together.
- Thoughts and questions can be explored during regular family meeting times.



## Thumb-ball:

- Find a beach ball or any ball that can be tossed around easily that you can write on.
- Write prompts all over the ball. For example, some prompts may be: *Something that cheers me up when I'm feeling sad...* | *A family activity I wish we could do more is...* | *If I had three wishes, I would wish for...* | *A question I have about my parent's illness is...* (etc.).
- Toss the ball around to each family member and answer the prompt where a thumb lands.
- Keep the game going as long as all are engaged.



## Shared family notebook:

- Find a notebook (lined or not) to begin a shared family journal.
- This can be a book to share thoughts and feelings through writing and/or drawing pictures.
- Questions can be written down for family members to answer or it can be a place to write freely about any thoughts/feelings.
- For younger children, it may work best to primarily use pictures to communicate information.

# Family Activities

## Favorite place collage:

- Create a collage of your favorite place. This place could be a place you have been to before or one you are dreaming about.
- Find a piece of paper, glue, markers, and cut-outs from magazines.
- Glue cut-outs on the page or write in favorite places, things, people, about the place that helps bring it to life.
- This can be an individual activity, or a family can create a collective "favorite place collage."

## Family Coping kit:

- Find a bin or basket to create a "family coping kit."
- Search around the home for coping items that all can use when having trouble coping. Some ideas may be favorite books, simple activities, stress balls, bubbles, and any items that bring a sense of calm.
- Regularly assess as a family how the coping kit is working for all and change out items as you see fit.



## Family Name Poem:

- Use your last name or other word that represents your family.
- Write the word on a piece of paper with room underneath or to the side of the word.
- For each letter of the word, think of a descriptive word that represents your family.



Steady  
Together  
Rowdy  
Orderly (sometimes)  
Nice  
Grateful

## Resources

- Sibling Support <https://siblingsupport.org>
- The Arc <https://thearc.org/get-involved/siblings/>
- Navigate Life Texas <https://www.navigatelifetexas.org/en/family-support/siblings-of-children-with-disabilities>
- A Sibling's Guide to Autism <https://www.autismspeaks.org/tool-kit/siblings-guide-autism>
- Family Functioning Guideline – Spina Bifida Association <https://www.spinabifidaassociation.org/blog/family-functioning/>
- Family Fun and Activities Resources <https://www.cookchildrens.org/health-resources/family-life/family-fun-and-activities/>

Thank You!

**Discussion:**

- How do you relate to this situation? What has been your experience?
- What have been your challenges?
- Do you have tips or ideas to share with other families?

# References

Fleary, S. A., & Heffer, R. W. (2013). Impact of growing up with a chronically ill sibling on well siblings' late adolescent functioning. *ISRN family medicine*, 2013, 737356. <https://doi.org/10.5402/2013/737356>

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<https://health.ucdavis.edu/media-resources/children/documents/patient-education-A-to-Z/ParentingThroughIllness-English.pdf>

## Example of Conversations and Things to Say

- Hailey (15 year female):
- Alex (7 year old sibling): "Its not fair, you spend more time with John!"
  - Parent responses: "I hear you, Alex. I do spend a lot time with your brother. That does not mean he is more important. His body needs more medical care. He needs more help going to the bathroom and he has a lot of doctor appointments. Would you like to plan an evening where you and I can do something together?"

## Positive aspects – OG

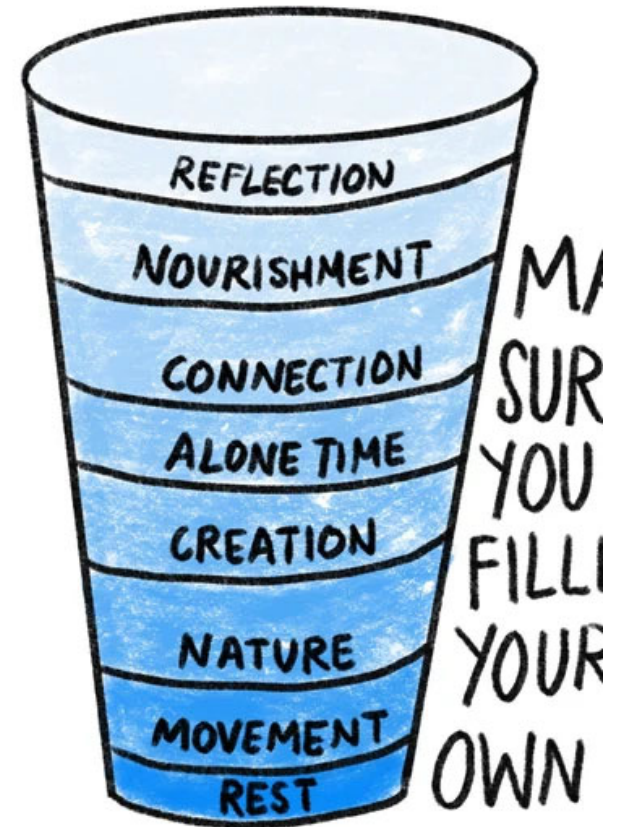
- **Empathy and Compassion** Growing up with a sibling with a disability often fosters a greater understanding and appreciation for people with disabilities. Siblings learn to see beyond differences and recognize the inherent value in every person.
- **Resilience** Siblings can develop strong coping skills and resilience in the face of challenges. They learn to adapt to unexpected situations and develop problem-solving abilities that serve them throughout life.
- **Advocacy** Many siblings become powerful allies and advocates for their brothers or sisters, championing their rights and needs. This advocacy often extends beyond their sibling to supporting disability rights and inclusion in their communities.
- **Strong Family Bonds** The shared experience can create deep and lasting bonds within the family, promoting a sense of unity. Families often develop unique strengths and communication patterns that bring them closer together.
- **Sense of Purpose** Siblings who are involved in their sibling's care, even in small ways, can experience a greater sense of purpose and contribution. They develop confidence knowing they make a meaningful difference in their sibling's life.

# Family Wellbeing – OG

Caregivers and siblings need to maintain emotional, mental, and spiritual health as well as physical well-being.

Remember:

- Seek respite care when needed—taking breaks is essential for long-term sustainability
- Connect with other families who understand your experience
- Celebrate all family members and their individual accomplishments
- Acknowledge that difficult feelings are normal and seeking help is a sign of strength



# Supporting siblings -OG

## 1. Educate Siblings About Cerebral Palsy

Age-Appropriate Explanations Explain cerebral palsy in ways that match your child's developmental level. Be honest about the extra time demands and don't hide or downplay CP's possible impacts.

### Open Communication About Feelings

- Talk honestly about their feelings
- Understand that jealousy and resentment are natural emotions
- Allow normal sibling squabbles to occur—do not overprotect the child with CP
- Give siblings control over some family choices (what's for dinner, weekend activities, etc.)
- Seek professional support if needed

## Negative aspects -OG

- **Emotional Stress** Siblings can experience stress, anxiety, or frustration related to their sibling's needs. The demands of medical appointments, therapies, and caregiving can create emotional strain on the entire family.
- **Added Responsibilities** They may have to take on caregiving roles or other responsibilities, which can be overwhelming. Some siblings may feel they grow up faster than their peers or have less freedom in their daily lives.
- **Guilt and Resentment** Siblings may experience:
  - Guilt for being able to do things their sibling cannot Sibling Session (for parents) The Sibling Experience: Creating Space for Connection, Support, and Sharing Confidence
  - Resentment about the extra attention their sibling receives
  - Conflicted feelings about the demands placed on parents
  - Confusion about why these feelings exist These feelings are natural and normal, but need acknowledgment and support.
- **Social Challenges** Siblings may feel embarrassed or angry when peers ask insensitive questions or bully them or their sibling with CP. They might struggle with explaining their sibling's disability to friends or dealing with uncomfortable social situations.