

# FACTSHEET



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## Dealing with Anxiety, Grief and Loss and Spina Bifida

### What causes anxiety, grief and loss?

Finding out that your child has Spina Bifida can cause mixed emotions and may lead to many lifestyle changes. There will be changes that you will need to make to areas of your life to help you raise your child. These changes may disrupt your current family routine and can cause stress to other family relationships. You may have some anxiety about dealing with change. You may have worries for what the future may hold for you, your child and your family.

Another common reaction to learning your child has Spina Bifida are feelings of grief and loss of what could have been. You may have a range of different emotions such as shock, guilt, anger, sadness, fear, blame and loneliness. You may grieve the loss of your original plans as parents and your child's future.

Feelings of grief and anxiety are a normal part of adjusting to caring for a child living with Spina Bifida. These feelings are not just for this situation. All big changes in life can bring with them a loss of comfortable and predictable routines, as well as the fear of what is not known.

### How to manage?

#### Be Informed and Organised

Some fears and worries are unfounded and occur due to a lack of accurate information. Having a good understanding of Spina Bifida will help create a feeling of control. Being informed reduces worry due to "not

knowing." Knowledge about Spina Bifida will help you cope with the uncertainty of the condition and explore options to help your child.

Write down questions you have to discuss with your doctor and ask for information.

You may have lots of new information, medical appointments and things to remember now. Think about what type of organisational skills you already have. The use of calendars or diaries may help you feel more organised and in control.

#### Focus on the Positive

Children living with Spina Bifida have many strengths and abilities. With the right medical care and follow-up, they have opportunities for a great quality of life.

Children may have challenges in areas of mobility, bladder and bowel control.

Families with a positive approach to raising their children will experience less anxiety. They will cope and adjust with challenges and adversity when faced.

#### Accept Support

Accept the support of trusted family and friends. Work with your child's treating health team and remember it is difficult for everyone in new situations.

Accepting support will help you create a network to lean on during hard times. Feeling like you are on your own may lead to higher unnecessary levels of distress and

anxiety. This will affect the whole family unit. Some families find being involved with parent support groups very useful and a helpful forum for gaining skills and sharing experiences.

Social workers, psychologists and your treating team are available to talk through issues with you. A support network in the community can help to strengthen your family and help you adapt to change.

Whilst anxiety, grief and loss are normal reactions when you find out your child has Spina Bifida, these feelings should reduce with time. If you experience prolonged anxiety, feel overly worried or sad, it is best to seek support to help you overcome these feelings and try new or different strategies to manage.

### **Maintain interests outside of caring**

Research has shown families who maintain their own interests outside of a “caring role,” report high levels of resilience, and long-term ability to adapt and cope to all of life’s challenges. It is important not to ignore your own physical and mental health needs and create balance in your family life.

### **Remember:**

- Caring for a child living with Spina Bifida can be both challenging, and also very rewarding as long as parents are:
  - informed
  - realistic
  - positive
  - maintaining their interests
  - accepting of support.
- There are many people to support you and your family and lots of information for you to read and improve your understanding.
- Anxiety, stress and grief are all normal responses to an initial diagnosis of Spina Bifida. If these feelings are prolonged you need to seek support and counseling to assist you in adjusting to your new family situation.

### **You can find further information about managing anxiety, grief and loss at:**

- Beyond Blue is a not-for-profit organisation with a lot of information about depression and anxiety: [www.beyondblue.org.au](http://www.beyondblue.org.au)
- Relationships Australia provides individual and family support: [www.relationships.org.au](http://www.relationships.org.au)
- Spina bifida tween to teen: [www.sbtween2teen.org](http://www.sbtween2teen.org)
- Northcott provide a range of services for families. [www.northcott.com.au](http://www.northcott.com.au)
- Livewire is powered by Starlight and is aimed at teens with disability and illness: [www.livewire.org.au](http://www.livewire.org.au)