

Looking after yourself and your family (cont')

- ❑ Raising a child with a chronic situation calls for specialist knowledge. Reading, seminars and consulting with professionals in parenting will avoid extra concerns and help in difficult decision-making. In the early stages of parenting, parents should avoid excessive reading as it is difficult to check what is relevant and the mind is already overwhelmed.
- ❑ Siblings will do well with regular special attention and paced information about their brother and sister. Back-up plans for how they can handle times of upheaval and questions from their peers will decrease anxiety.
- ❑ Remember that grandparents will be subjected to shock also. Try to reduce your expectations of empathic, helpful feedback, especially in the early stages.
- ❑ Advise family and friends of the nature and intensity of your trauma. Often they have no idea how to relate to the situation. Parents have found it useful to send information about the child's condition to others.

Checklist for getting support

- ❑ Are any symptoms described above persisting with the same intensity over time?
- ❑ Do you have consistent support from family and friends?
- ❑ Have you been able to express the depth of your emotions to someone?

Checklist for getting support (continued)

- ❑ Have you been given opportunities to express your feelings about the diagnosis?
- ❑ Do you express your feelings often?
- ❑ Do you find yourself "stuck" thinking about a particular incident during diagnosis, or word(s) used during diagnosis?
- ❑ Are there certain experiences that you can't get off your mind?
- ❑ When you look back to diagnosis or thereabouts, do you think that the depth of your feelings are getting harder to manage?
- ❑ Do you spend more than 8-10 hours without adult company for more than two days in a row?
- ❑ Does your partner generally support you?
- ❑ Do you feel increasing anxiety in being able to manage your child's condition
- ❑ Have you been able to shake-off a feeling of "what's the point?"
- ❑ Do you avoid talking about your thoughts and feelings?

Resources

The book *Through Loss* (Bruce, E.J. & Schultz, C.L. 2004) may assist you to understand your feelings more. It is available from the Emotional Health Centre, Cheltenham. 95537127.

INFORMATION & TIP SHEET

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When your child has been diagnosed with a disability or chronic condition.....

Overview

The diagnosis of a chronic condition or disability in a child represents a serious personal trauma for parents. Typically, parents feel isolated and question "why me, why my child?" Naturally, mothers and fathers experience a deep sense of painful grief that is often expressed very differently and at different points of time. Sometimes the loss or its extent is not as apparent to one parent. Perhaps one parent has not been exposed to as much information specific to the child, or they have been shielded from comparisons with other children the same age.

This difference in response can easily lead to misunderstandings and disconnection between partners and it is common for relationships to be under great strain. Often partners feel they cannot successfully support each other. The severe stress caused by trauma and grief can create physical symptoms: appetite change, nausea, abdominal pain, changed bowel habits, alteration to normal period pattern, headaches, dizziness, palpitations and chest pains. There may be efforts to reduce distress and find emotional relief by seeking distractions.

Overview (continued)

Research indicates that many parents will experience post-traumatic symptoms. Such symptoms include flashbacks to the words or situation surrounding diagnosis, preoccupation and fear with how the future might unfold, a feeling of not being entirely present, for instance, feeling remote from one's child or other children, friends and places. Sometimes parents feel that their bodies are on alert; things they did not worry about before now create fear. Naturally, there are difficulties concentrating.

Post-traumatic symptoms are often more evident in mothers because they are more likely to be at home isolated with their thoughts and being responsible for managing during the day. The workplace may allow fathers, but not all fathers, to avoid the intense thinking that mothers' experience. There are fathers who find that no amount of work distracts them from worrying. While trauma symptoms generally decrease over time, they can be resistant, particularly when traumatic information about one's child continues. Within this psychological climate, depression is not uncommon for parents.

Symptoms

Symptoms of depression will include a range of thoughts and behaviors including a sense of "dragging" yourself around – a difficulty facing the day, disinterest in previously enjoyed activities, quick feelings of agitation or irritation, problems relaxing, a loss of personal goals, change in appetite, feelings of helplessness, becoming locked into routines wherein you feel mindless, feelings of detachment from loved ones, sometimes hostility towards them. Of course there are degrees of depression, but you will have noticed some consistent changes in you.

Over time, generally parents move towards adapting to their child's condition – a possibility that seems impossible in the beginning! It is typical for parents to often feel that they have gone backwards. However, it is a steep learning curve. It is normal for a sense of grief in varying intensity to parallel the child's life.

Looking after yourself and your family

- ❑ In the early period, post-diagnosis, parents need to be mindful of the trauma and the huge adaptation surrounding it. Try and guard against: too much reading, too many questions, being exposed to images that create fear of the future, or talking to individuals who are ignorant of the depth of your feelings. Pace yourself if possible. You will know when you are ready to take any next steps.
- ❑ Try not to run out of energy and vital nutrients by eating small meals or snacks throughout the day. Keep up fluid intake. Alternate with your partner in taking short exercise.
- ❑ Long periods of isolation with your own thoughts intensify negative thoughts and should be avoided if possible, if only broken up by talk-back shows at home or a brief walk.
- ❑ Mothers and fathers need regular support to work through aspects of this trauma. Counseling should be considered vital to emotional and physical well-being.

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- ❑ The well-being and longevity of the relationship between mother and father is the greatest asset amidst this trauma. Relationship counseling early on is vital in respecting each partner's unique approach to managing loss in their lives.
- ❑ Suffering from continuing traumatic symptoms or depression is common. In these situations the natural chemicals in the brain have become depleted through ongoing stress. Finding relief through prescribed antidepressants or naturopathic means is crucial to well-being and healthy parenting. Medication may be short term. Some parents return to medication at different times. In tandem with counseling, parents continue to learn ways to manage.
- ❑ Sleep deprivation is normal. As it can easily lead to depression, relentless sleep deprivation should be tackled early. Typically respite is difficult. Parents may need to alternate sleeping arrangements, usually away from the home environment. Sometimes parents find that prescribed medication or naturopathic substances help with gaining sleep when the opportunity arises.
- ❑ Joining a support group of other parents in similar situations reduces perceptions of isolation. Discussion in these groups will normalize your feelings.