



Things to Think About!

Check it Out

By Karen Morgan

Visit our website at...



www.snproject.com

and go to "research links" for a list of services, support groups, and other useful resources in your state.



www.caringtoday.com

Disability Information
& Resources



www.makoa.com

If you have any contact info for similar services available in your home state we'd love to add them to our web listings. Anything you would like to see added can be sent via the email address listed below.

Also, if you have a topic you would like to see covered in our newsletter, or have a specific question that we can answer directly, please feel free to contact us anytime through the following email address...

snproject@hotmail.com

Avoiding Parent Burn-Out

By Linda Jorgensen

In an ideal world an infant is born after an uneventful pregnancy and delivery. 24 to 48 hours later that same normal, healthy infant is discharged from the hospital to go home with its mother. But this scenario doesn't always occur. Some infants are born prematurely, others are born with birth anomalies, and not all infants that go home with their mothers remain problem free. Illness, injury, and disabilities can arise and the next thing a parent knows they are providing skilled nursing care at home for a child that is totally dependant on them for all their care. What happens next? Often it's Parent Burnout.

Caring for a chronically ill loved one is stressful and problematic. It can be tough on you physically, emotionally and financially. But there are many things a parent can do to become a more effective, less stressed, and informed caregiver.

Here are some tips on how to become a better "C-A-R-E-G-I-V-E-R":



Consider and Communicate needs. That includes your own, those of your special needs child, and other family members living in the household. Weigh what needs to be done versus what can wait. Ask your child's Physician what daily routine care your child will need and then discuss this routine care, and how it will impact the household, with family members. It is important to allow other members of the household to help especially siblings. When much of the attention is now on the child with special needs, involving siblings allows them to feel they are a part of what is going on and have not been forgotten. Enlist their help in caring for the household and your special needs child. Simple, age appropriate tasks such as helping pick up clutter, taking out the trash or reading a story to their sibling can give you a moments respite and make the sibling feel needed and useful.




Ask For Help. Do not expect that others will ask if you need help. It is up to you to do the asking. Accept help from friends, family members, church friends, neighbors, etc. Prepare a list of tasks for anyone who may offer assistance. The list may include: running an errand for you, preparing a meal, taking other children after school one day, assisting with general housework or yard work, etc. Think of tasks that would be most helpful to you and then ask for help when you need it.


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Recognize Your Limits.


Providing care for a child who is ill or has special needs is probably only one of many conflicting demands on your time. It is important to be realistic.


Recognize what you can and cannot do, define your priorities, and act accordingly. Turn to family members or friends for emotional support. They can help you feel less alone and better able to deal with care giving responsibilities. In some instances it is perfectly acceptable to say "No".


 **Exercise.** Get out and get moving! Being physically active can provide you with an outlet that is relaxing and make you feel good. Walking, stretching, swimming, or taking an exercise class once a week are examples of invigorating exercises that can help reduce stress levels, lift your mood and improve your overall health. Talk to your doctor and enlist him in building an exercise program that is appropriate for you.

 **Group Support.** Join a parent's support group. In addition to offering useful information, such groups provide a unique forum for parents and caregivers to come together and share their feelings and frustrations in a supportive environment. Groups can help parents feel less isolated and can create strong bonds of mutual help and friendship.

 **Inform Yourself.** Learn the skills you will need in caring for your child at home from the professionals. If your child spends any time in the hospital observe the nursing staff as they provide care. Ask questions. Have them "show you how it's done". Seek information from reliable sources. Contact your hospital's Parent Resource Center or Outreach Program. Investigate community resources that may be of help to you. Consider using in-home services or housekeeping services to assist you in keeping up with your heavy workload. Contact your local Department Of Health and Human Services and enquire about services for children with special needs. Apply for Medicaid. It may be necessary to apply for both the traditional program and a state Medicaid Waiver Program, if your family income does not meet the required level. Apply for Supplemental Security Income. Help is available but you have to locate it!

 **Vacation.** Yes! You need to take breaks! Disengaging from the day-to-day care periodically is important. Although spending the summer at the beach may not be realistic a long weekend can provide a much-needed get away. If you are unable to take a long weekend then take shorter, less lengthy "mental health" breaks. Indulge yourself in a haircut or manicure. Read a book, take a nap, or go for a walk at a local park or window shop at your local mall. Taking a break for even a few hours at your favorite destination can help recharge your battery.

 **Eat Right.** Food is fuel for your body. Skipping meals, eating poorly, or drinking lots of caffeine is not good for you. Learn to prepare and eat simple, nutritious, well-balanced meals. Eat three balanced meals daily, drink plenty of fluids and avoid large amounts of sugar and caffeine.

 **Rest.** Sleep refreshes and enables you to function throughout the day. Studies have shown that most American adults do not get the full amount of needed sleep each night. For a parent taking care of a special needs child this problem is compounded by their needs as well. If your child is restless at night or requires care every few hours around the clock consider outside help in the evenings to allow you to sleep. Becoming sleep-deprived is a mistake far too many people make when caring for someone. If you are not adequately rested, you can't take care of someone else. If you are unable to sleep because of tension or worry, practice relaxation exercises. Deep breathing or visualizing pleasant scenes can be helpful. Continued sleep disturbance may be a sign of major depression, which needs medical attention. Remember. If you are not adequately rested, you can't take care of someone else. And if you become ill, that makes TWO to take care of. If you don't take care of yourself, who will?



"Realizing that the care of an individual with special needs must be a team effort is your first step to avoiding burn out."