

### **Coping with Caregiving** ready, set, accomplish!

This is Part Two in a series of articles dealing with the stresses that come along with caregiving.

In the last article we discussed the reasons for and signs of caregiver stress and burnout. In this and the coming articles we will look at some solutions. First up is:

#### Setting Realistic Goals and Forming Realistic Expectations

We all want the best for our family. Having a child or relative with a disability doesn't change that. But it is very easy for caregivers to fall into the trap of setting unrealistic, unachievable goals for themselves and their loved one, which can cause unnecessary stress and disappointment. To learn how to avoid these pitfalls and keep your sanity, you, as the caregiver, must learn to plan achievable goals and have healthy expectations. So...

#### What are the basic goals of caregiving?

To ensure your loved one's...

quality of life physical comfort safety

That sounds simple enough, but is commonly taken to an extreme. Saying to yourself, "I never want my son to feel pain" is impossible whether or not he has a disability. Even the goal "I want my son to be happy." can be overwhelming.

There are six measures you must take if you want to see results from your goals:

Plan for the short term Be specific Focus on an exact problem Understand yourself Understand your loved one Understand their disability

It cannot be stressed enough that to see results you need to plan specific and achievable goals. They need to be short term and



### "How will what I want to achieve affect the other areas of my life?"

focused on an exact problem. This problem could be a part of your long-term goal.

Your long-term goal for your daughter may be for her to have a fulfilling life. But keeping it so broad and open-ended will fill you with a sense of failure at not doing enough at any given point. Instead, try to focus on an aspect of your long-term goal, like her social network. Instead of saying my goal is for my daughter to have a fulfilling life, say my goal is to make sure she spends at least two hours a week active in the community. Specific and attainable. This is something you can achieve right now.

Next, are the three things to understand when setting caregiving goals. The first and hardest thing to understand is you. Ask yourself these questions:

How will what I want to achieve affect me and the other areas of my life?

How will it affect my job?

How will it affect my spouse and/or my children?

What other demands do I have on my time? Being honest with yourself and accepting the limitations of what you can accomplish will

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# In the Community got determination?

Self-determination is defined as the ability of individuals to make the choices that allow them to exercise control over their own lives, to achieve the goals to which they aspire and to acquire the skills and resources necessary to participate fully and meaningfully in society.

From September 15-17, 2009, Imagine Enterprises working with the Texas Council for Developmental Disabilities, has planned for a statewide conference on self-determination principles, practices and effective implementation strategies. This conference is for self-advocates, families, professional, advocates, agencies & organizations.

The first two days feature intensive exploration of issues from national experts, federal and state staff, self-advocates and family members. The third day of the conference, September 17th, is dedicated to employment and small business solutions to generate

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help prevent burnout down the line.

The other thing to understand is your family member and their disability. Ask yourself these questions:

How will this goal affect him/her behaviorally?

How will it affect them physically? What about emotionally?

This is important – and not always easy. You must be objective about the disability and its affects and limitations. For example, your husband had a traumatic brain injury and now becomes easily enraged. It is hard to remember when he is screaming that this is not your husband, this is his disability.

Distinguishing between intentional and unintentional behavior will help you keep your expectations for him reasonable and realistic. If your goal for your husband is to have him get more exercise, but children yelling set him off, then you probably

income and expand opportunities for self-determination. The Self-Determination for Texas project advances the principles of self-determination in the lives of Texans with disabilities.

For more information on the conference and self-determination go to:

selfdetermined.org nconsd.org sabeusa.org



shouldn't take him for a walk in a park with a playground.

Being aware of all aspects of his disability will help you avoid stressful situations and make your goals more attainable. Know your loved one and know their disability.

Perhaps the hardest part of all of this is addressing what you expect of yourself. "If only I could do more, then things would be better." Ever said or thought that? This may be difficult to digest, but that type of thinking is unhealthy and will only cause you more stress. Self-expectation is a balancing act between what you want and what you realistically can do. Expecting too much will leave you with constant worry or guilt. Expecting too little will leave you without progress and hope. A healthy and realistic expectation of you as a caregiver will create satisfaction and reduce stress.

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Do you love your attendant? Nominate him or her for Attendant of the Year! Email your nomination (including why you think they should win) to caretx@dsswtx.org or mail them to:

DSSW Attendant of the Quarter 6243 IH-10 West, suite 375 San Antonio, TX 78201

## Morgan's Wonderland where everyone can play

This is just plain wonderful. The Gordan Hartman Foundation, a non-profit in San Antonio, will open the world's largest special needs park this fall. It is a 21.5-acre oasis of fun designed especially for individuals with disabilities. One of the greatest parts about this venture is that it will be a place where the whole family can play and relax together. Morgan's Wonderland has the potential to bring about community integration on a grand scale by appealing to everyone, regardless of disability.

There will be so much to explore at Morgan's Wonderland and every effort was made to make is safe and fun. All visitors will be assigned special wristbands that will identify their family or group. These bands provide state of the art security through RFID (Radio Frequency Identification) technology. The park will have several monitors throughout it, so if a family or group member becomes separated – any other member of their group can scan their own bracelet and see where everyone is. These bracelets guard against the possibility of someone becoming lost, leaving with a stranger, or leaving the park alone.

Once you are in the park you are greeted by the 31' sculpture of hands releasing a butterfly to remind you of the parks theme – the freedom to soar. And soar you will, maybe first you will soar to the Sensory Mini Village. It's a small town with a theater, country vet, hardware shop, and grocery store. Not only does it inspire imaginative play but also offers interactive sensory stimulation through the use





of colors, lights, sounds, and textures. After that you might feel the need for speed, so you can head over to the accessible go-cart racetrack and burn rubber for a few laps. Then it is naturally time to cool down in the water play area or relax on a train ride around the 8-acre lake. Of course we have only explored about an eighth of the park so far. There are too many activities and amenities to cover, so here is a list:

Large restrooms 3 Accessible Playscapes

Train Rides Amphitheater

Gymnasium Catch-and-Release Fishing
Ball Field Special Event Center

Water Play Area Go-Cart Race Track

Music Garden Sand Spiral
Sensory Mini Village Garden Sanctuary

2,000 square foot indoor small event & play area

Walk and Roll path around lake

Swings (several types including wheelchair swings)

Over 25 Picnic Areas & Pavillions 2 First Aid Stations & Feeding Room

Did we mention it is free admission? Yep, this is just plain wonderful. For more information on Morgan's Wonderland and the Gordan Hartman Foundation visit these websites:

soarsa.org hartmansa.org

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But how do you do it? Here are a few tips:

- 1) Remember that you have control over what you expect from yourself as a caregiver. By setting realistic goals and expecting to meet those goals you can create a pattern of success.
- 2) Don't degrade the little tasks and goals that you successfully complete, be proud of yourself because those little things add up over time. Putting them down as "not enough" will only make you feel disappointment and disappointment in yourself will not help you become a better caregiver. Disappointment will not help you "do more."

Goals and expectations. They can be dangerous or they can be fulfilling. It all depends on how realistic you are about them. Giving yourself and your loved one attainable goals and healthy expectations is an integral part to coping with the stresses of caregiving and avoiding caregiver burnout.

In our next article we discuss the second solution to caregiver stres, "Establishing Your Limits."



Don't degrade the little tasks and goals you complete.

