

BRIGHT FUTURES: FAMILY MATTERS



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A CAREGIVER'S GIFT



It's December, a time of year when many cultures celebrate holidays and traditions. It's a time of reflection as well, looking back over the past twelve months. Our thoughts often turn to those we love and care for. Sometimes we are so busy caring for others that we forget to care for ourselves. This is especially true for those who care for children and adults with special health care needs or for aging parents.

November was National Family Caregiver Month, in honor of all those special people who devote so much of their time to seeing that the needs of family members are met. So it is fitting that in December we give those caregivers a special nod and thanks, and a reminder to take care of themselves.

According to the Family Caregiver Alliance (www.caregiver.org), about

44 million Americans provide 37 billion hours of unpaid, "informal" care each year for family and friends with chronic illnesses or conditions that prevent them from performing daily activities. These activities can include regular routines like bathing and meal preparation, but for many of these caregivers, they include dealing with medicines, treatments, and doctor visits.

FCA estimated the economic value of all that time in 2007 as at least \$375 billion. That's how much it would cost to provide paid caregivers for all those hours! It's a tremendous responsibility, borne out of love and respect for those they give care to.

For children and youth with special health care needs, the role of caregiver is often just an extension of the parent role. Mothers—and fathers—expect to take care of their child with a cold, or other minor illness. If that illness is more major or longterm, or if it is a disability, parents naturally extend their caregiving roles to include whatever medical assistance their child needs, to the limit they are able.

***What a gift that is! But who cares for the caregivers?
What kind of support do caregivers need to make sure their needs are met?***

In This Issue:

- A Caregiver's Gift
- Be Your Own Caregiver
- 8 Caregiver Self-Help Tools
- Other Resources
- Meet the Washington State Fathers Network: The Newest Member of the Bright Futures Family Network

Check out our new website!
www.fv-impact.org

"I encourage all Americans to pay tribute to those who provide for the health and well-being of their family members, friends, and neighbors."

—President Barack Obama, Presidential Proclamation, 2013 National Caregivers Month



Be Your Own Caregiver

“On an airplane, an oxygen mask descends in front of you. What do you do? As we all know, the first rule is to put on your own oxygen mask before you assist anyone else. Only when we first help ourselves can we effectively help others. Caring for yourself is one of the most important—and one of the most often forgotten—things you can do as a caregiver. When your needs are taken care of, the person you care for will benefit, too.”

—Family Caregiver Alliance, “Taking Care of YOU: Self-Care for Family Caregivers”

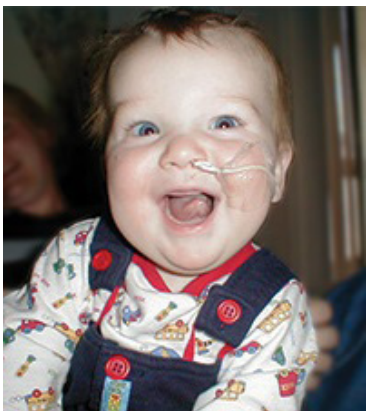
Caregiving is rewarding, but can also be very stressful. For the family caregiver especially, it can be a full-time, round-the-clock responsibility—in addition to juggling other responsibilities.

The Family Caregiver Alliance suggests eight “tools” for caregiver self-care. Use these as stepping stones—decide what you can do today, even if it is just one small step. Build on that step!

Tool #1: Reducing Personal Stress

That’s easier said than done, isn’t it? Fortunately, it isn’t an all or nothing goal. Start by identifying the specific things that are the most stressful to you. Some of those things are likely beyond your control. Are there some things that you could change to improve your situation?

Even if you can’t change the things that are causing you stress, you can take steps to reduce stress, such as eating healthy meals when possible, getting even ten minutes a day of physical activity, visiting with a friend, etc.



Your community may have cultural events and activities that can provide a change of pace—and a little stress relief. Check your local Chamber of Commerce for events in your area.

Resource: Check out the Family Voices IMPACT project website, www.fv-impact.org for health and wellness ideas.

Tool #2: Setting Goals

What would you like to accomplish as far as self-care goes over the next three to six months? Set a realistic goal, and then break that goal down into doable action steps.

If your goal is to be more physically active, your action steps might include walking three times a week for 10 minutes and then building up the time and distance you walk.

Tool #3: Seeking Solutions

What do you see as the major problems you face as a caregiver? Try to be as specific as possible. Not enough hours in the day? Maybe the real problem is that you are trying to do everything.

Once you’ve identified a problem to work on, brainstorm possible solutions. Don’t judge them to begin with. Brainstorm with a friend or other family member. Then pick a possible solution to try and go for it! If that one doesn’t work, try another.

Talk with friends or professionals about your strategies. Some problems may not be solvable today, but maybe another time. . . .

Resource: For a state-by-state listing of caregiver support resources, go to: http://www.caregiver.org/caregiver/jsp/fcn_content_node.jsp?nodeid=2083

Tool #4: Communicate Constructively

In order to get the help and support you need as a caregiver, you must present your ideas in ways that will be heard and respected. Be specific about what you need, and put it in terms of “I” messages—“I need this” or “I feel angry.” When you show respect for others, you’ll likely get it in return.

Tool #5: Asking for and Accepting Help

This is obvious, but it can be the most challenging. People want to be helpful but don’t necessarily know what to do.

Make a list of things that need doing and identify those that others could do for you. If someone asks how to help you’ll have specific tasks already figured out. You can use that list to match up with people you know who could do those things. Don’t be afraid to ask!

Tool #6: Talking to the Health Care Provider

An important skill to learn is communicating effectively with health care professionals. They can only help you if they understand your problems.

Resources: Kids as Self Advocates (KASA), the Family Voices project for, about, and run by youth with special health care needs, has a page of resources written by youth to help them learn to take responsibility for their own health: <http://fvkasa.org/resources/health.php>

See the Family Voices Health Care Checklist for All Children (Including Children with Special Health Care Needs): <http://www.fv-impact.org/files/4213/8342/8888/HealthCareChecklist.pdf>

Tool #7: Starting to Exercise

Physical activity will make you feel better—and it doesn’t take a lot of time or effort to be effective. Walking and gardening are great ways to get started! Look for ways to get your entire family moving, too—you’ll all benefit!

Resource: Check out the May 2013 issue of Bright Futures Family Matters: “Let’s Move!” http://www.fv-impact.org/files/7013/7572/9152/BFFM_April_2013-r.pdf This issue has tips for getting started exercising and eating healthy. You’ll find links for tips for involving children and adults with disabilities as well.

Tool #8: Learning from our Emotions

Listen to your emotions and the messages they carry. Let yourself feel what you feel—some days you’ll feel very good, and other days you might feel a sense of guilt, anger, or resentment. Talking it out with a friend or professional can help.

Depression is a common experience for caregivers. Recognizing when your negative or painful emotions are getting in your way can help you know when you need to seek help.

Resource: Check out the Fact Sheet on Caregiving and Depression from the Family Caregiver Alliance: http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=393

Read more about the FCA Tools for Caregiver Self-Care here: http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=847.



OTHER RESOURCES

- **Caregiver Action Network has resources for a variety of caregiving situations:**
<http://caregiveraction.org>
- **Teaching Families to Fish: How to Support Families as Caregivers:** This is an issue brief from the Lucille Packard Foundation for Children's Health: http://cshcn.wpengine.netdna-cdn.com/wp-content/uploads/2013/07/Family-centered_care-IssueBrief-final.pdf
- **Family-to-Family Health Information Centers (F2F HIC):** These federally-funded, parent-run centers provide information and resources to families of children and youth with special health care needs. They can help with health care financing, early and periodic screening, navigating community resources, transition to adult life, and parent/provider partnerships. To find the F2F HIC in your state, go to: <http://www.fv-ncfpp.org/f2fhic/find-a-f2f-hic/>

Meet the Washington State Fathers Network—The Newest Member of the Bright Futures Family Network!

“A powerful voice for fathers and families of children with special needs.”

As we explained in the January 2013 issue of Bright Futures Family Matters (http://www.fv-impact.org/files/7513/7572/9649/BFFM_Jan_2013_final-r.pdf), the Bright Futures Family Network (BFFN) is a group of family organizations

brought together by Family Voices, in partnership with the American Academy of Pediatrics. The organizations have different focuses and purposes, but all share the mission of providing support and encouragement to families. Improving health and wellness is a common goal across the organizations.

Greg Schell, Director of the Washington State Fathers Network, described this latest addition to the BFFN: “Even though we are called ‘Fathers Network’ we determined very early on that we were concerned about the ‘whole’ family. Dads, moms, siblings, grandparents, and friends all have unique things going on with them when an individual with special needs is part of the family. Addressing those needs takes unique approaches, specific knowledge, patience, tenacity, and a lot of compassion. We learn from moms, women, dads, men, children, self advocates, professionals, and our interactions with systems everyday. Adjusting to change is a major part of what we try to do. It actually is a lot of fun and often times makes a big difference for families, which is one of the core goals we highly value.” Check them out at: <http://fathersnetwork.org/>

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FAMILY VOICES MISSION

Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities.

Through our national grassroots network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

www.familyvoices.org

IMPACT

on HEALTH & WELLNESS for FAMILIES

With an Improving Understanding of MCH grant, Family Voices IMPACT works to develop ways to improve health and wellness for all children and families, and to encourage partnerships between families and professionals for children's good health. Share Bright Futures: Family Matters with your networks. Visit www.fv-impact.org

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