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TIES THAT BIND

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SOCIAL SECURITY

How to keep your food-allergic child from feeling left out pg. 4

MEET KFA'S LATEST RISING STAR:

3-year-old **MEGAN LADEWIG**



president's message

Lynda Mitchell
President, Kids With Food Allergies

A diagnosis of a food allergy can be an overwhelming experience for both parents and children. Every aspect of day-to-day living is often affected, which challenges our ability to keep our children safe. Learning to balance fear, acquire new skills and plan ahead can feel overwhelming. It's normal to go through all the different stages of grief—denial, anger, bargaining, depression, acceptance—when your child is diagnosed with a food allergy. Realize that children can go through the same emotions too, trying to deal with a restricted diet and the frustrations of feeling left out of activities other children are able to do.

Not all families deal with a food allergy diagnosis in the same way. Some parents and children, by their nature, adapt to change well and have healthy coping mechanisms. Others need to learn to take care of themselves better and acquire a healthy coping mechanism. Learn how to help yourself and your children deal with challenges in a healthy, rather than harmful way in this issue of Support Net.

We've interviewed three professionals who work directly with parents and their children with food allergies. I thank Michael Miller, M.Ed.S., LCSW, of National Jewish Health, Denver, Colo.; Jennifer LeBovidge, Ph.D., of Children's Hospital Boston; and Joy Hogge, Ph.D., licensed psychologist, for conveying their expertise with all of us. Both Miller and Dr. LeBovidge share their insights on the emotional repercussions a diagnosis of a food allergy has on children. Dr. Hogge and Miller discuss the impact food allergies have on parents.. This information benefits us all—whether it's affirmation that we are doing things right or teaching us how to approach situations differently and offering new skills to try.

I hope you find this issue insightful. Raising a child with a food allergy isn't easy, but with the right coping skills, we can improve the quality of life for our children and for ourselves.

Warm regards,

Lynda Mitchell
President



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OUR MISSION

The mission of Kids With Food Allergies is to foster optimal health, nutrition and well-being of children with food allergies by providing education and a caring support community for their families and caregivers.

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Imagination Helps 3-Year-Old Rise Above Food Allergies

By Tanya Bumgardner

Rock-a-bye baby in the treetop. When the wind blows the cradle will rock...

As parents, we often sing this familiar rhyme to our children. But Megan Ladewig likes to imagine she's a parent, singing it to her little sister to calm her crying. At 3 years old, she has already decided she wants to be a mommy when she grows up.

Of course, Megan's active imagination lets her switch from "mommy mode" to a neighing horse or a purring cat at a moment's notice. Her imagination has also proved to be a blessing when coping with her food allergies. According to her mother, Jennifer Ladewig, Megan also likes to "imagine rice bread to be a yummy pizza."

A positive outlook is necessary for a preschooler like Megan when dealing with anaphylactic allergies to eggs, peanuts and tree nuts, along with potato, tomato, wheat and soy. Plus, Megan also has Celiac Disease. "You have to constantly read labels and worry about coming into contact with foods that can cause an anaphylactic reaction," Jennifer says of Megan's situation.

But despite her allergies, Megan remains outgoing, energetic and happy. She loves to have books read to her, play with her Schleich animals and spend time with her five siblings: Hannah, Emily, Joshua, Karis and Phoebe. "She fully accepts her limitations. Megan will tell people that eggs and peanuts will really hurt her. She can tell you everything she can't have," says Jennifer.

When Megan was diagnosed with food allergies at 12 months old, her family was faced with a daunting challenge until a friend referred Jennifer to KFA. In KFA, she found support and "the ability to not dwell on and always fear Megan's food allergies."

When looking back on the past two years of Megan's life, Jennifer is grateful for KFA. "KFA has been a wonderful lifeline for our family. A food-allergy diagnosis is a life-changing event for the whole family, and it takes time to adjust. Awareness, education, acceptance and diligence is key to living with food allergies." Now, thankfully, with the help of online friends, Megan can focus on who her imagination will let her become next, instead of her food allergies.

Tanya Bumgardner is a freelance writer and the parent of a food-allergic child.





How to keep your food-allergic child
from feeling **LEFT OUT**

SOCIAL SECURITY

BY BETH PULITI

It's three o'clock in the afternoon and your little one has just been delivered home from school safe and sound. He barely makes it out of the big yellow bus before he breaks into a run at the sight of you. You outstretch your arms, but he thrusts a card into your hands instead, hardly able to contain his excitement. Peering down at the childish scrawl, your heart sinks. Another birthday invitation.

"Momma, can I go?"

How do you respond? There isn't one right answer. Depending on your child's age and allergy severity, he may not be able to go to the party. Or, he may be able to go as long as you attend to make sure he isn't served birthday cake or reaches for some off a friend's plate.

Restrictions in foods and social activities can lead children to experience feelings of sadness, anger, frustration and self consciousness—particularly when they feel safety precautions make them stand out from their peers, explained Jennifer LeBovidge, Ph.D., a psychologist at Children's Hospital Boston. These emotions are normal for children with and without food allergies, and children can develop skills for managing them.

Michael Miller, M.Ed.S., LCSW, put it another way. "Children and their families are dealing with a loss—whether it's a loss of body integrity, for instance, or not being able to eat foods that others are enjoying," he said.

"They go through all the different stages of grief even though they might not be aware of it. Children can get angry, can get sad—they can't believe it's happening to them. Children need to be helped to recognize these different feelings, helped to understand that these feelings are normal and taught to express them in ways that are appropriate. In time, these feelings can weaken and children can learn to accept and live with their allergies, like avoiding what they need to avoid," said Miller, the director of psychological services in The Pediatric Outpatient Clinic at National Jewish Health, Denver, Colo.

As a parent, you know all too well that birthday parties simply scratch the surface of socially-ostracizing events. Your food-allergic child may have to sit at an allergen-free table at lunch. Sleepovers or parties could be banned if there is concern about whether the supervising adult can be trusted to follow safety precautions and take action in an emergency. Children might even pose a risk to themselves, particularly as they move towards adolescence.

"They can feel embarrassed asking questions about ingredients or asking others to wash their hands before eating if they feel their allergy makes them stick out or is a 'big deal'," said LeBovidge. "Some adolescents may feel uncomfortable with dating situations that require them to talk to romantic partners about issues such as safety practices around kissing."

Although some children with food allergies experience teasing about their allergy, or even bullying, it is important to remember that most children with food allergies have supportive friends and can participate in most social activities with some advanced planning, she stressed.

HOW TO CONTROL EMOTIONS

Younger children who may not yet know how to express their feelings appropriately might take their feelings out on parents or siblings, which is often anger. Miller suggested that parents dedicate a "feelings corner" in their home for this very reason.

"A feelings corner is a specific area that is precisely for your child to go to when he's upset. 'Here's another birthday party I can't have birthday cake at!' he might yell, to which you as the parent would reply empathetically, 'You look really upset, and I don't blame you for being upset. Why don't you go to the 'feelings' corner, and punch that pillow (or do jumping jacks, or rip paper, or journal, or draw)?" explained Miller.

FIVE STAGES OF GRIEF

Finding out your child has food allergies can be emotionally devastating to both you and your child. It's common for your child (and yourself) to go through the stages of grief before accepting the situation.

1. Denial: "I feel fine. I can eat this."
2. Anger: "Why me? My sister doesn't have it!"
3. Bargaining: "I will give my life savings if only..."
4. Depression: "What's the point? I'd just as soon die."
5. Acceptance: "It's going to be OK. There are other things I can eat."

Depending on your child, their temperament and the way they handle certain strong emotions, this corner of your home can serve as a spot where children can learn to put words to feelings and then actively get them out.

“They’re not hitting anyone, throwing things across the room or breaking windows. Rather, they’re retreating to a place where it is appropriate, acceptable and actually encouraged to blow off steam or to cry,” said Miller. “Try to encourage your child to bring it upon himself to say, ‘I’m so upset I’m going to the feelings corner.’ Once they do, the parent can just put another check on the calendar as a reward for handling the situation so well. Depending on the age, these checks can earn rewards.”

HOW PARENTS CAN HELP

When your food-allergic child feels left out of a social situation, what should you do to help?

Listen. Empathetic listening should take place first and foremost—because it does feel bad, and your child has to have their feelings validated, listened to and understood, said Miller.

Problem solve. “Parents can also involve children in problem-solving how to handle social situations—for example, attending a birthday party or extracurricular event where food will be served—to help them feel more in control. Typically there are different options for how to handle a situation and having some say in the matter can help,” suggested Dr. LeBovidge. An alternative treat to bring might help them feel more involved at the party.

Role play. Helping children rehearse and role play language to use for common situations that may arise (such as when a friend asks them about their allergies or when someone offers them food in a social situation) may help them feel prepared.

DEPRESSION VS. ANXIETY

The following signs indicate depression:

- Persistent sad or irritable mood
- Less interest in activities that were once enjoyed (Younger children might complain of feeling “bored.”)
- Social withdrawal
- Trouble concentrating
- Physical complaints (e.g., headaches, stomachaches, muscle aches)
- Trouble sleeping or sleeping more than is typical
- Appetite or weight changes
- Non-compliance with the medical regimen
- Impairment of functioning (A teacher might express worry about the child zoning out or not turning work in.)
- Peer-conflict
- Guilt
- Morbid thoughts

The following signs indicate anxiety:

NOTE: Some anxiety about food allergies is normal and can be very adaptive in promoting the vigilance and caution necessary for food allergy management.

Signs that anxiety may be more chronic or impairing include:

- Frequent worried thoughts that are difficult to control
- Constant need for reassurance about what is safe (which does not seem to help to reduce the anxiety level for long)
- Physical symptoms of stress (e.g., accelerated heart beat or palpitations, feeling of choking, trembling, or nausea)
- Separation anxiety or school refusal
- Frequent trips to the nurse
- Trouble sleeping
- Fear of dying (because of a history of anaphylaxis)

Symptoms that are getting in the way of daily activities or that are generalizing to more and more situations also signal that children may need support from a mental health professional to learn skills to manage their anxiety and cope effectively with their food allergies.

Educate. Take steps to educate others (e.g., school personnel, relatives, other parents) about food allergies. "While food allergy management is second nature to many families of children with food allergy, it is not so for most people. Providing education, not only about what food allergies are, but providing concrete examples of simple steps that people can take to include children with food allergies in social situations, can be extremely valuable," Dr. LeBovidge explained. The more information others are armed with, the more supportive they can be.

Instill trust. Explain to your child that he should always tell you if he is being teased or bullied because of his food allergy. Let him know how important it is to tell you his feelings and that it is not tattling; it is standing up for himself and being responsible for his health and well-being.

Behavioral health professionals can help with the tasks mentioned above. They also provide a safe space for divulging feelings, planning for events, devising strategies for behavior management, grieving, etc. But remember, children take their cues on how to handle challenging situations from their parents.

"So when parents project a calm, matter-of-fact approach to allergy management, focusing on safety routines and model use of coping strategies themselves, children will benefit from the underlying message that food allergy is manageable," explained Dr. LeBovidge.

Positive attention and praise for children's use of coping strategies (whether it's going to the feelings corner, problem-solving or taking an active role in allergy management) can also help build children's sense of self-efficacy and confidence.

"It's also important that parents remember—and remind others—that children are not defined by their food allergies," said Dr. LeBovidge. "Helping children identify their strengths and pursue their interests will increase their self-confidence overall."

RESOURCES FOR PARENTS

- The No Biggie Bunch Children's Book Series: www.nobiggiebunch.com
- **Understanding Children and Chronic Illness** booklet:
<http://www.nationaljewish.org/pdf/Understanding-ChildrenChronicIllness.pdf>
- Find a local food allergy support group: <http://www.kidswithfoodallergies.org/groups.php>
- Read more about emotional and social issues in food-allergic children:
http://www.kidswithfoodallergies.org/resourcetopic.php?topic=emotional_social

Beth Puliti is a professional writer for a national healthcare trade magazine.

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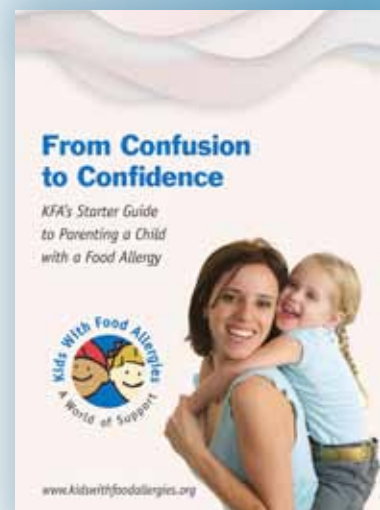
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The **EMOTIONAL** repercussions food allergies have on parents—
and how to **MANAGE THEM**



SPONTANEITY THAT FEBIND

BY BETH PULITI

When your child is diagnosed with a food allergy, spontaneity often becomes a thing of the past. You must now balance safety and normalcy, which isn't always easy. While allergists can help define safety parameters, it is frequently up to families to find normalcy within those parameters on their own.

"Your family's life can eventually feel much more normal than it did right after the diagnosis, but only when you accept that more planning and thought must go into routine things," explained Joy Hogge, Ph.D., licensed psychologist and mother of a food-allergic child.

Losing spontaneity can feel like someone died—and, really, life as you knew it did. It's OK to grieve that loss, said Hogge. "That's better than trying to ignore how much planning is needed, and put your child at risk, or to keep waiting for things to get 'back to normal' and build up resentment that it's not happening."

Michael Miller, M.Ed.S., LCSW, concurred and noted that parents, just like children, can go through all the different stages of grief—denial, anger, bargaining, depression, acceptance—when their child is diagnosed with food allergies. Learning to identify these feelings and express them in an appropriate way will help parents accept that they must take extra steps to accommodate their food-allergic child.

If the thought of additional planning for your food-allergic child becomes unbearable, recognize this can be a normal reaction, but with proper support you can manage and plan accordingly for your food-allergic child's well-being. Take action before you emotionally "blow up," suggested Miller. Make it a point to call your spouse or mother, visit with your therapist or connect with others across the country who are in the same situation. This can help you move on toward acceptance.

"We also teach parents of food-allergic children to do diaphragmatic breathing to relax the body and anchor the mind. All irritating thoughts that keep intruding fall away when the parent focuses on just the sound of their breath," he said.

Relaxation techniques such as belly breathing may not be for everybody. Exercising or chatting on the phone can be just as therapeutic to some. After 15 minutes of a relaxation exercise, parents may be able to face the extra planning it now takes to go to the store, an often daunting responsibility.

If cooking safe foods for your child is what intimidates you, Miller suggests alternating cooking with your spouse. Perhaps whoever does most of the cooking can take a break on the weekends. Making a variety of food in volume and freezing it in advance or having safe popsicles at the ready can also help alleviate some stress. Or, if your child is old enough, invite him or her to help prepare safe foods and entrees for the week.

For parents of multiple children, helping everyone in your family learn how to support your child with food allergies—without that child becoming the central focus of the family—may be challenging. Even routine tasks take on an added gravity when done for the child with food allergies.

"Making lunches, dealing with school parties, planning play dates, participating in sports are all possible for children with food allergies, but can

take an inordinate amount of time and planning," said Hogge. "For example, your child without food allergies might want a birthday dinner at a restaurant that isn't safe for your child with food allergies. It helps to think those things through beforehand, and find a balance that makes sense for you and your family."

Balancing the needs and desires of children without food allergies with the safety and emotional well-being of a child who has them isn't easy, but it is possible. While a certain level of worry is inevitable, try to take charge of your worrying by using it to help you think through details and make safe plans instead of letting your worrying take charge of you and your life. Constantly worrying about your child's food allergies affects the mental and physical health of everyone in your family.

"It [worrying] exhausts the family, allows food allergies to become the family's central focus, and keeps all members from being as supportive and available to others as they could be," explained Hogge.

If you become too preoccupied with your own fears and worries, you are setting an example that food allergies are the determining factor in your life. Yes, food allergies are serious, must be dealt with and always kept in mind. But they do not have the right to take away the basic happiness and independence of your children, yourself or your families. As parents, work to ensure that doesn't happen.

It's normal to also feel isolated from your friends, family and even your spouse because you are afraid to leave your child in other people's care—and rightly so, said Miller. Gain a bit more freedom by finding people who take your child's food allergy as seriously as you. It might take a long while, but even finding a trustworthy babysitter so you can go on a date with your spouse can give you peace of mind. Also, making sure both parents are equally involved and learned is crucial.

Becoming too preoccupied and worried keeps parents from being emotionally available for the support, love and guidance all children need. How can you avoid falling into the anxiety trap?

Be gentle with yourself. Realize that each day is a balancing act between trying to live a normal life and keeping your child safe. Take one day at a time. Be proud of your victories and celebrate them with people who get it. "I was so proud when I finally learned to make hot dogs buns that were sort of recognizable. My son's school cafeteria staff jumped up and down with me," recalled Hogge.

Educate yourself. Find out as much as you can about food allergies through reliable sources: seek guidance from an allergist to help with food allergy management questions and to ask what is worth being concerned about and what is not. Also, check out food allergy books and cookbooks, local support groups and others who are successfully raising children with food allergies.

Share responsibility for allergy management with your child in an age-appropriate manner. Increase the amount of responsibility you share with your child as he gets older. For example, have him help you plan and problem solve how to deal with different situations.

Every now and again, remember to pat yourself on the back for a job well done. Chances are your child is relatively happy and healthy because you've already been doing many things as a dedicated parent with good judgment.

"We notice the good things others do, but minimize our own successes—don't. Surround yourself with supportive people, and if you are just starting this journey, realize it can take some time to find those people—try to be patient," said Hogge. "When people

are not supportive, do what you can to rectify the situation, and move on if things don't change—realize that they have done you a favor by letting you know that they are not someone who can give you and your child what you need."

Children with food allergies live in a world where most people don't have them. That might understandably enrage some parents. Know that there is hope on the horizon. Keep moving on with the lives you want your children to have and model a balanced and healthy approach to life yourself. You will have more energy to meet the needs of your children and you will feel more confident—making it easier to face the daily challenges the world brings.

RESOURCES FOR PARENTS IN NEED

Hogge suggested the following for parents to help themselves cope with depression, anxiety and/or stress. Friends and family who allow you to be who you are and share your joys as well as your fears and frustrations are invaluable. Support from other parents of food-allergic children is very helpful. Find the type of support that works for you (online, local support group, friend in the same shoes, reading about someone else's experience, etc.)

A mental health professional (psychologist, licensed social worker, psychiatrist, licensed professional counselor, clergy with mental health training, etc.) can be of help if the avenues listed above do not provide adequate support or if you or your child develop specific coping difficulties as a result of dealing with your child's food allergies (panic attacks, marital conflict, child becomes phobic of all food.) Your allergist, pediatrician, family doctor, clergy person or school counselor may be able to recommend someone. If not, mental health centers can usually help or provide referrals. Keep in mind sometimes it takes more than one try to find the right fit with a mental health professional.

Beth Puliti is a professional writer for a national healthcare magazine.

KFA'S COMMUNITY IN ACTION

Community in Action Team Makes a Difference on a Local Level

"I am so excited to get involved!" That's what one member said about joining Kids With Food Allergies' Community Action Team (CAT), a nationwide volunteer team of supporters enthusiastic about furthering KFA's mission.



Kristin Johnston, CAT leader, with children Molly and Tommy.

GROWN FROM THE HEART

Launched in the fall of 2009, the CAT developed out of a growing need to bring together individuals whose lives have been touched by KFA and who want to share KFA's mission with others. Comprised of more than 60 supporters, CAT members range from professionals interested in volunteering their talents for KFA projects, to those interested in introducing KFA to the medical professionals in their community, to those who want to host KFA events.

Kristin Johnston, CAT leader and KFA board member explains, "that's what makes this team such an incredible one—every member has a unique perspective and interest in bringing KFA into their community, making the CAT greater than the sum of its parts."



Cristi Schwamb uses a Pampered Chef pot purchased during a KFA fundraiser to make allergen-free recipes.

COMMUNITY IN ACTION

Although the CAT is only a few months old, its members are already making an impact. December's Pampered Chef Fundraising Event was initiated by the family of one CAT member who knows firsthand that KFA families rely heavily on quality cooking and baking equipment. A CAT Member in Texas was instrumental in helping KFA receive a Community Giving Grant, which in turn inspired an upcoming KFA Family Fun Expo in the Houston area in October 2010. Hundreds of free KFA informational brochures have been ordered by team members and distributed in communities nationwide, and CAT members were instrumental in beta testing KFA Friends Connection, a new KFA Family Membership benefit. CAT members share ideas and support on a dedicated online forum hosted at kidswithfoodallergies.org, and receive periodic e-mailed newsletters that offer ideas and opportunities to get involved. Team members volunteer between one to five hours per month and work closely with KFA leadership and staff on projects and events that interest them.



Kristin Johnston, KFA Board Member, accepts a \$1,000 check for a grant from Wal-Mart in Katy, TX.

GET INVOLVED!

KFA's CAT welcomes new members and encourages you to become part of a growing network of parents and supporters who enthusiastic about improving the quality of life for kids with food allergies and their families. For more information, contact Kristin at kjohnston@kidswithfoodallergies.org.



WHAT OUR MEMBERS SAY:

"I recommend KFA to anyone who knows someone struggling with food allergies or has kids with food allergies. It truly is a 'world of support.'"

"KFA has been invaluable to me as I have walked the road of raising a child with food allergies. I would be so lost without it! I recommend it to anyone I come across who has a child with food allergies. Thank you!"

INSIDE THIS ISSUE:

- Healthy coping skills for kids and parents
- Free e-book for those with a new diagnosis
- Three-year-old uses active imagination to creatively cope with food allergies

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