Psychosocial Dynamics of Living with Food Allergies

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Disclosure

- We have no potential conflicts to report regarding food allergies
Learning Objectives

- Explore the psychosocial dynamics of living with food allergies: challenges, emotions and accomplishments

- Discuss approaches that build and enhance stability, security, and sensibility

- Identify successful resources for assisting the food allergic patient and family
Living With Food Allergies Feels Like You Are Navigating Through An Obstacle Course
- Hurdles
- Challenges
- Surprises.....Uncertainties

How Do You Promote Strength Vs. Fear?
- Establishing an atmosphere of confidence & trust
- Vigilance

How Do You Tackle Uncertainty & Insecurity
Do You Know What Your Food Allergic Patient & Their Family Are Struggling with as They Live & Cope with Their Food Allergies?
<table>
<thead>
<tr>
<th>Feelings</th>
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<tbody>
<tr>
<td>Frustration</td>
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<tr>
<td>Angry</td>
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<td>Sadness</td>
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<td>Fear</td>
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<td>Overwhelmed</td>
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<td>Worried</td>
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<td>Depression</td>
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<td>Astonished</td>
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<td>Uncertainty</td>
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<td>Unhappy</td>
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<td>Denial</td>
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<td>Anxious</td>
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<tr>
<td>Confused</td>
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<td>Stress</td>
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Dear Haslem,

Plaqs help me get my allergies away.

Louis
Life Threatening Food Allergies

- Promotes anxiety & fear
  - Not eating or missing special events
  - Management of the food allergy
- Depression
- Social isolation
- Psychological distress
  - Maladaptive coping responses that interfere with the psychological and social development and optimal functioning of family members
  - Impact on Relationships
Poor outcomes

Food Allergy Impact Scale

- Assess Impact of Food Allergy on Daily Activities
- 87 Families
  - 70% had significant impact - Aspects of daily life were affected family meal preparation
  - 79% - significant impact of going to restaurants
  - 10% - No engaging in activities with relatives
  - 11% - No play dates at friends’ houses
  - 10% - Missed birthday parties
  - 10% - Home schooled

Food Allergy Quality of Life-Parental Burden Questionnaire (FAQoL-PB)

FAQoL-PB – Disease specific QoL by Cohen et al

- 17 item instrument
- Focused on emotional responses
  - Sadness
  - Worry about future
  - Helplessness
  - General anxiety
- Family functioning impacted
  - Family/Social activities
  - School/camp
  - Meal preparation time
  - Health concerns
  - Emotional issues
  
Families whose child had 3 or more food allergies & if there was an anaphylactic reaction

Time To Worry

- **Age 7: Increased Anxiety** – Cognitive ability to comprehend serious nature

- **Adolescence**
  - Most Common among teenagers and young adults
    - Risk taking, faulty perceptions of risk
    - Internet Based Questionnaire 13-21 yr olds
      - 54% of 174 responses
        - Purposefully ate tiny amount of food containing allergen
        - Previous exposure w/out reaction
        - Judgment
        - Wanting to eat the food
        - 61% - carried epi (depending on situation varied)


Chronic illness is a risk factor for developing anxiety. Anxiety symptoms are prevalent in children with chronic illness.
Concurrent disorders (medical and anxiety) seem to result in greater impairment than either an anxiety disorder or medical condition alone.

Ramsawh, H et al
The burden of responsibility that food allergy exerts upon individuals and their families can have a significant influence on QoL. Primeau et al. found that peanut allergy is a condition, which forces parents to exert extreme dietary vigilance and face continuous uncertainty over the possibility of accidental exposures. Avoidance of food allergens requires constant alertness and is complicated as the presence of allergens is not always obvious. In a study of community allergic reactions to foods, 60% of participants were aware that they had a food allergy, yet over 50% were unaware that the food they were consuming contained the allergen. This reflects the difficulties associated with total allergen avoidance, and the burden taken on by those who see themselves as responsible for that avoidance.


<table>
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<tr>
<th>Coping Patterns</th>
<th>Effect Parental Response</th>
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- Study by Deena Mandell et al. 2002 discusses how families describe their adaptation to living with anaphylaxis in their child.

- Initial high anxiety proved motivating towards seeking education and resources.
Anxiety Among Parents of Children With Food Allergies

Mary Klinnert PhD unpublished talk 2008
Anxiety Patterns Among Parents of Children With Food Allergies

- Acute Stressor
- Settling Down
- Chronic Anxiety
- PTSD

Mary Klinnert PhD unpublished talk 2008
Validated Instruments

- “The Food Allergy QoL Parental Burden questionnaire (FAQL-PB) measures the parental burden associated with having a food allergic child.”

- Validated instruments allowing parents to report on QoL in the child from the child’s perspective and for children and teenagers to report on their own QoL.


The Kübler-Ross Grief Cycle

- Shock
- Denial
- Anger
- Bargaining
- Depression
- Testing
- Acceptance
Obstacles to Coping

- Lack of public understanding/cooperation
- Inconsistent medical information
- Mislabeled and/or inconsistently labeled foods
- Multiple food allergies

Mandell, 2002
Strategies

Wiser / Better Choices
- Address Fears
- Promote Reassurance

Building Vigilance
- Empowers
- Confidence

Resources
- Support
- Security
Fear Factors

- Anaphylaxis
- Death
- Restaurants
- Vacations
- Grocery Store
  - Food Labels
- Holidays
- Camp
- Field Trips
Educational Targets
Food Allergy Management Strategies

- Parents
- Grandparents
- Peers
- School
  - Child Care Providers
  - School Personnel
- Parties
- Sleepovers
- Holidays
- Restaurants
- Grocery Stores
- Camp
- Babysitters
- Celebrations
- Travel
**Eating Out**

**RESTAURANTS**
- Calling Ahead
- Speaking with manager & waiter - communicate clearly
  - Viewing ingredient list
- Oil
  - What is fried together
- Cross Contamination
- Preparation
- Products made outside the kitchen
- Carrying Epi Pen
- Avoiding risky environments (Chinese restaurants if peanut allergy exists)
- Restaurant Suggestions
- Chef card (FAAN)

**OTHER LOCATIONS**
- Speak with Hostess
- Contribute items
- Have safe food alternatives....bring safe food with you
- Provide education
  - List of food allergies
  - Preparation
  - Cross Contamination
Recommended Menu Items for Guests with PEANUT Allergies

Listed below are item options if you have a peanut allergy/intolerance.

**THIS INFORMATION NOT VALID AFTER 12/1/08**

THIS INFORMATION IS VALID ONLY FOR SELECT U.S. RED ROBIN RESTAURANTS. Red Robin relied on our suppliers’ statements of ingredients in deciding which products did not contain certain allergens. Suppliers may change the ingredients in their products or the way they prepare their products, so please check this list to make sure that the menu item you like still meets your dietary requirements.

From time to time we may substitute products due to inventory shortages. We can’t be sure that the substitute products will be free of the allergen you wish to avoid.

As we cook, prepare, and serve your meal, the listed menu option may come in contact with the allergen you want to avoid. For example, we might cook the listed menu option on the same broiler as a menu item that contains the allergen you want to avoid. That’s just the way our kitchen is set up. Red Robin cannot guarantee that any menu item will be prepared completely free of the allergen in question.

NOTE: Peanuts and ingredients containing peanuts are present in the restaurant.

**APPETIZERS:**
- Creamy Artichoke & Spinach Dip
  - No tortilla chips
- Fresh-Fried Cheese Sticks
  - No pasta sauce
- Onion Rings
  - No Red Robin Seasoning
- Just-In-Quesadilla
  - No chipotle beans
  - No tortilla cups

**SOUPS:**
- Chicken Tortilla Soup
  - No tortilla strips

**SANDWICHES & WRAPS:**
- **Not available with side options**
- Whiskey River BBQ Chicken Wrap
  - No tortilla strips
- Caesar’s Chicken Wrap (available without changes)
  - No tortilla strips
- BLTA Croissant
  - No Red Robin Seasoning

**SALADS:**
- **Dressings not included – see list of acceptable salad dressings**
- Apple Harvest Chicken Salad
  - No candied walnuts
- Side Caesar Salad (available without changes)
- Asian Chicken Salad
  - No dry coleslaw mix
- Fajita Fiesta Pollo Salad
  - No tortilla strips
- Dinner Salad
  - No tortilla strips
- Crispy Chicken Tender Salad (available without changes)
- Cobb Salad (available without changes)
- Mighty Caesar Salad
  - No blackened chicken (grilled chicken or salmon are available options)

**SALAD DRESSINGS:**
- Bleu Cheese
- Creamy Caesar
- Honey Mustard Poppyseed
- Oriental
- Ranch
- Baja Ranch
- Dijon Vinaigrette
- Balsamic Vinaigrette

effective 10/28/08
School

- **Food Allergy Action Plan**
  - Picture
- **Epi Pen (2 dual boxes)**
  - What
  - Where
  - When
  - Proper training annually
- **Meet with School Personnel and Team**
  - Recognizing symptoms of allergic reaction and what to do
  - Letter to Families.....communication with parents
  - Education/Awareness
  - Special Programming/Celebrations/Projects
  - Substitute Teachers / aides
  - Not using food as incentive or reward
  - Lunch / Snacks – hand washing, not trading or sharing
- **Holiday Planning/Parties**
- **Field Trips**
• **Reading Labels**
  ○ Carefully and continually / Ingredients change
  ○ Varying product size → different ingredients

• **Being smart when unsure**

• **Purchasing only with label**

• **FAAN alerts**

• **Cosmetics, lotions, bath products**
Travel

• List of food allergies in language of country

• Letter for flying with medication

• Notifying airline of food allergy prior and day of

• Travel with allergy-friendly food and medication with you
Strengthening Coping Mechanisms
Building Skills

- Having a food allergy management plan
  - Psychosocial parameters
- Know emergency plan
- Having and carrying at all times epinephrine
- Having and knowing emergency numbers
- Recognizing symptoms early & responding quickly
- Communicating effectively
- Not trading food
- Learn how to read labels
- Having a responsible adult in every environment
- Maintain best achievable asthma control
- VIGILANCE
Case Vignettes
Resources

- Newsletters
- Magazines
- Support Groups
- Internet
  - Blogs
  - Chats
  - Education
  - Forum
  - E-newsletters
- Counseling
- Education
- Psychoeducational (Klinnert M. & Robinson J.)
- Dietician
Resources

- **FARE: The Food Allergy and Anaphylaxis Network** *(Foodallergy.org)* and **The Food Allergy Initiative** merged & will be dedicated to Food Allergy Research and Education with the mission of ensuring the safety and inclusion of individuals with food allergies while relentlessly seeking a cure. FARE combines FAAN’s expertise as the most trusted source of information, programs and resources related to food allergies with FAI’s leadership as the world’s largest private source of funding for food allergy research.

- **National Institute of Allergy and Infectious Diseases**: Guidelines for the Diagnosis and Management of Food Allergy in the United States
  [http://www.niaid.nih.gov/topics/foodAllergy/clinical/Pages/default.aspx](http://www.niaid.nih.gov/topics/foodAllergy/clinical/Pages/default.aspx)

- **Kids With Food Allergies** is a national nonprofit food allergy organization dedicated to fostering optimal health, nutrition, and well-being of children with food allergies by providing education and a caring support community for their families and caregivers. *(kidswithfoodallergies.org)*

- **Asthma and Allergy Foundation of America** *(aafa.org)*

- **Allergy & Asthma Network, Mothers of Asthmatics** *(www.aanma.org)*

- **Why Risk it? A Canadian food allergy website for teens**. *(www.whyriskit.ca)*
Asthma Explorers Club is the place to go for kids who like to play, have fun, and learn more about their Asthma. We also have great information for parents too.

Discover what type of asthma and allergy triggers to be on the lookout for during the holiday season.

Let’s figure out the Word Power words together before our friends get done making their snowman. Pick your skill level, then pick letters to fill in the blanks!

Dust - Any fine, dry powder can be called “dust.” Dust can be made up of things like soil, mineral particles (chalk, plaster, etc.) or even tiny particles of dead skin cells or clothing fibers. Dust mites are tiny animals related to ticks and spiders that live on dust! Most people who are bothered by dust are actually allergic to these tiny dust mites.

Holiday Food Allergy Tips
Have a food allergy management & emergency plan
Carry with you 2 self-injectable epinephrine
Recognize symptoms early and respond quickly
Communicate food allergies when dining out
Epinephrine Auto-Injector

Twin inventors Evan (left) and Eric Edwards near their offices in Richmond, VA.

the Auto-Injector that Talks

It took allergic twins Evan and Eric Edwards 15 years to develop and test the Auvi-Q with the input of patients. But their compact device is finally a reality.

by MARY ESSELMAN

Allergic Living I Winter 2013

Auvi-Q™
epinephrine injection, USP
0.15 mg/0.3 mg auto-injectors
Stability, Security, Sensibility

Vigilance
- Epi Pen
- Beliefs
- Attitude
- Knowledge

Prepared
- Education
- Building Navigational Skills
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