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Today’s Presenter

Gwen Smith
Allergic Living Magazine
Presentation Outline

- Adult Onset Facts
- Gwen’s Own Experiences
- Findings from Allergic Living’s Reporting
- Adapting to Diagnosis
- Challenges – Social, Workplace, Restaurants
- Importance of Self-Care & Attitude
Personal Experience — Shellfish

- Mid-1990s: severe reaction to supper of fried shrimp.

- Didn’t know, but classic symptoms: itchy, red skin, hives, stomach cramps, vomiting, oral inflammation.
  - Worst of all: breathing distress; wheezing.
  - Less obvious as a patient: blood pressure plummeted.

- History of pollen and other allergies. But no known food allergy.
  - Didn’t own epinephrine auto-injector.
Off to Hospital

- Relief! Few doses of epinephrine ended worst symptoms and eased my breathing. Lesson: epinephrine is well worth the needle.

- ER docs felt this was a clear case of anaphylaxis to shrimp.
  - Followed up with allergist. But 1990s, low awareness: no labeling, no talk of cross-contact or prevention. It was a risky time.

- Shellfish allergy (crustaceans and/or mollusks) in adults — who knew it was so common? Not many.
2004, FARE-Mount Sinai School of Medicine study first revealed the true size of seafood allergy: 2 percent of 5,500 households had an individual allergic to shellfish and 0.4 to fish.

- Seemed oddly high, so data were reviewed, but verified. It turned out to be an adult phenomenon: when you pulled out the small number of children with these allergies, a combined 2.8% of adults were allergic to a form of seafood.

In newer studies\(^1\), again, shellfish emerges as the leading adult allergen, 2-3% of adults internationally.

\(^1\) Sicherer, SH. Seafood Allergies, Fish and Shellfish, *UptoDate*, November, 2006.
- Peanut was an obvious culprit; tested mildly positive; later failed an oral challenge.

BUT, the reactions continued to occur. Many small and bigger reactions; started to worry what I ate at all.
- Elimination diet - GP took me basic chicken and rice. Ate that fine; good, now add a vegetable, OK now another. Tough-going and life-changing.
Allergist decided to look at soy; it was also in the satay sauce; skin-tested positive.

Soy allergy in an adult? Allergist wasn’t convinced. Had me return to skin-test with actual samples of soy foods.

Cut soy out, and all my mystery hives and other symptoms ceased – that is, once I learned about labels.
New Shopping and Dining Reality

- My case not unusual; when you don’t read labels all the time, you don’t really ‘get’ what’s in packaged food.

- Food labeling law had just passed; allergen labeling was just starting to be reliable.

- Soy, like dairy and wheat, was in the vast majority of packaged foods. An emulsifier. Big learning curve in terms of what to avoid.
Patients stories to the magazine:

- Extremely confusing to have eaten a food like shellfish or nuts without issue one day, but the next, a big reaction.

- They usually struggle to ‘re-learn” how to shop and to eat:
  - What adults eat is complex. Example: Beef stew or quesadilla.
Little research about adult-onset food allergies and why they arise.

In kids, food allergies are an issue with the immune system not properly “switching over” from the Th2 mode we’re born in to the Th1 fighting mode that fights bacterial infection.

- So the big question is: What’s going on in adults that they can “gain” food allergies?
We know that 5% of adults in U.S. have food allergies vs. 8% of children.

In August 2014, Northwestern U. researchers shed some light with: “Prevalence and Characteristics of Adult-Onset Food Allergy” study\(^1\).

- Assessed records of 1,111 adult food allergy patients. At least 15% first diagnosed over age 18.
- Age at onset from 18 to 86; but most patients have their first adult-onset reactions in their 30s.
- Opposite of children, more women than men have adult food allergies.
- Other allergic disease: hay fever and/or eczema were associated with increased food allergy risk.

\(^1\)Bryce, PJ et al. JACI In Practice, August, 2014.
Author Dr. Paul Bryce to Allergic Living:

“With children, it may be that they have failed to develop a tolerance to the foods that they’re encountering early in life.”

“With adults, we think that this is something very different; that they’re losing tolerance to foods they’ve already been able to be exposed to and to eat. That may be an important difference in understanding how food allergy develops – rather than how tolerance is not occurring in children.”
The Northwestern study found common triggers were: shellfish and tree nuts.

However, *all* Top 8 allergens were observed in adults.

The 5 most common food allergies among 171 adult onset patients:
- shellfish (54%); tree nut (43%); fish (15%) soy (13%) and peanut (9%)
- Even adult-onset milk allergy.
Dr. Ruchi Gupta, part of Northwestern study team, told Allergic Living that her big question is: *What* triggers someone to lose tolerance to a food in adulthood?

- She wonders about something in the person’s environment; maybe a change in environment; a relationship to infection or virus.

Stay tuned: Dr. Gupta involved in big study with Stanford University.
Northwestern study found significant first reactions occurred more frequently in seniors, perhaps due to other conditions, such as heart conditions.

Beta Blockers and possible contraindication with epinephrine\(^1\).

Prediction: Safe food in hospitals will grow as an issue, with more adults with food allergies.

\(^1\) Lieberman, P, Simmons, FER. Anaphylaxis and Cardiovascular Disease: Therapeutic Dilemma, Clinical & Experimental Allergy, July 2015.
Adult Allergy Challenges

- Diagnosis & Missed Symptoms
  - Sometimes there are no hives, but rather just vomiting or other GI. Easy to mistake for the flu or food poisoning. Happened to many adult-onset patients we’ve interviewed.

- Adults are busy, working, organizing families
  - Don’t always pay close enough attention to symptoms.
  - May miss mild ones’ relationship to food.
  - Question for those with adult-onset allergies: Was a first “big reaction” really your first? Or did you mistake or ignore earlier symptoms (e.g. mild ones)?
Fear Factor – common for a time, if a big reaction lead to diagnosis.

- Often followed by weight loss, fear of dining out, even general fear of eating.

- In minority of adult cases, fears may be well beyond simple need for precaution. May be taking psychological toll in which professional counseling would help.
Allergic Living Interviews: Adults Struggle to Adapt

- Flip side – the “food allergy deniers”

  - Lack of education about complete allergen avoidance, cross-contact and ‘may contains’ on labels.
  - Too cavalier. For e.g. 2009 survey of food-allergic college students at U. Michigan, Ann Arbor found that only 21 percent of study participants owned an auto-injector.
  - Food Allergy community role in educating; risks are often under-estimated.

“I try not to take my nut allergy too seriously. Otherwise, it would drive me and everyone else crazy!” –40-year-old real estate broker.
Finding Self-Care

- Essential to adjust to fact food allergy is chronic and legitimate disease.
  - 24/7, need to respect it and prepare for it.
  - Try to find the place of balance between precaution and fear/denial.
  - At first, likely will feel a burden to others (e.g. as a dinner guest). Need to get past that. “Legitimate health issue.”
  - Same at work: Tell your boss you now have medically required diet needs, but frame in a positive way. e.g. You can book the next business lunch at a “safe” restaurant. Events with food? Get on planning committee.
Challenges: Family and Friends

- Explaining food allergies to other adults is tough.
  - Family and friends may recall you eating that without a problem. Now they may question or be confused.
  - What I got: Can’t you pick the shrimp out? Or who would put soy in a dessert?
  - Important to be firm and not take chances with food.
  - But also patient. There is a learning curve, and those who care for you tend to come around.
  - Difficult to impress upon them seriousness – unless they saw reaction.
As an adult, what we eat is “complicated”: meals with sauces, spices, condiments, many vegetables.

- Fine for your own kitchen, with safe foods. Sauces, salad dressings and desserts best avoided when eating out. Minefields of ingredients.

- Always have a safe snack in a handbag or office drawer.

- Build a cooking repertoire of shortcuts and frozen snacks. The adult answer to the frozen cupcake.
- SafeFARE.org – FARE program to train restaurants in partnership with National Restaurant Association and MenuTrinfo.

- AllergyEats app – community restaurant reviews.

- Allergic Living Safe Dining Guide – and reviews at Allergicliving.com, along with our Step-by-Step Dining Out Guide.

- Allergy chef cards and translation cards.

- Eating at a friend’s dinner party:
  - Keep an easy email about your food allergies, with examples of ingredients you need to avoid.
Adult Allergies — Other Factors

- Oral Allergy Syndrome – also can be common in adulthood. May or may not require carrying epinephrine.

- For some at-risk individuals, co-factors can pre-activate mast cells and make an allergic reaction more intense.

  - Exercise
  - NSAIDs – e.g. aspirin
  - Alcohol
  - Hormonal state
Tips for those With Adult Onset Allergies

1. Remember the Girl Scout motto: Be Prepared.

2. Spontaneity isn’t your friend if it involves food.

3. Always have a safe snack.

4. Never assume it’s OK – assumption is the mother of all screw-ups.

5. Tempting food: Just ask yourself “How badly do I want to go to the ER?”

6. Carry your epinephrine, and be ready to use it.Forgot it? Then you’re not eating.

7. Get past embarrassment. This is a legitimate health condition, and avoidance is managing it.

8. Take charge of your condition and speak up: workplace, restaurant, with friends.

9. If you’re not comfortable with what’s being served, just don’t eat.

10. Be kind to yourself: again, legitimate disease.
Thank You!

Resources:

- **Free E-Book**: 18 Things to Know About Food Allergy Reactions
- **How to Read a Label** with Food Allergies
- **Steps to Dining Out** with Food Allergies
- **Managing Food Allergies at Work**: FARE
- **Insider’s Guide to Eating Out**: FARE
- **Food Allergy & Anaphylaxis Emergency Care Plan**: FARE
Our Next Webinar

Presented by:

Jim Long
former Senior Attorney
Office for Civil Rights, U.S. Department of Education
Denver Enforcement Office

Wednesday, February 17
1:00 – 2:00 PM ET

Member registration: Wednesday, January 27
General registration: Monday, February 1