



Presentation to Allergen Bureau Conference

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The Food Allergy Journey

- Often begins with exclusively breastfed infant (few weeks of age) being unsettled (wide-spread dry skin or eczema, colicky, reflux etc)
- Condition doesn't improve, mother suspects food she eats is the cause; begins to adapt own diet by eliminating suspect foods
- More serious reaction may occur when first introduced to cows milk
- GP may or may not agree and may or may not investigate possible food allergy

What foods?

- Diagnosis in infants is complex but clinical history combined with tests can be assessed by an experienced health professional
- Most common in infants is allergy to cows' milk. However tests may also show high IgE to other foods such as eggs and peanuts. Is this allergy or sensitivity?
- Most common immune system response is IgE (immediate reaction). But there are also non-IgE immune system delayed responses which cause similar symptoms but harder to link to a specific food and more difficult to test for.

Impact on the Family

No diagnosis:

- Baby irritable, not gaining weight, not happy feeding, not sleeping; may be in pain because of eczema and/or gastric upset
- Parents worried, not getting sleep, stressed...
- Mother may try eliminating food from her diet, with risk of both mother & baby not getting adequate nutrition at a crucial time of baby's development
- Risk the mother may decide to give up breastfeeding or supplement with formula – and baby has a severe reaction on first exposure to cows milk & ends up in hospital.

Impact...

With diagnosis

- Baby should be referred to paediatric clinic or specialist for assessment and monitoring
- Mother should be given advice on diet; it may be possible initially to keep breastfeeding if able to maintain an exclusion diet while getting alternative nutrition; certainly need specialist advice on infant formula
- However this is where the family is introduced to the complexities of managing food allergy day to day.

Steps to managing FA

i) Understanding what it is

- Hard for many people to grasp the concept of allergy to food
- Trying to explain to others e.g. extended family...when you don't really understand it yourself
- Where to go for information and advice? Paediatric clinics often have limited time to allocate to anxious parents
- Some may hear 'risk of anaphylaxis which has potential to be **life-threatening**'..and hear nothing else
- Emotional response – relief, guilt, grief..

Ongoing management

ii) Understanding what food is suitable

- That eliminating 'dairy' is not just milk, yoghurt, cheese, but anything with dairy in it.....so learning about:
 - the importance of, and how to, read labels
 - the risks of cross-contamination and how to avoid this in preparing food and/or checking food prepared and/or served by others
- That replacing nutritional elements lost through eliminating food allergens is important to prevent developmental delays in the child (consultation with a registered dietitian should be part of the health management but very few get access)
- As the infant grows – use of formula, what foods to introduce & when, how to manage risk of possible allergies to other foods (refer back to slide 'What foods?')

Ongoing management

iii) Maintaining normal family life

- Diet has to be adapted for whole family
- Shopping becomes a lot harder and more expensive
- Preparing meals takes a lot more time e.g. pre-packaged meals, takeaways now a 'no-no'
- How to make up to FA children for missing out on treats e.g. chocolate easter eggs

Ongoing management

iv) As the child grows, teaching them to:

- only eat food prepared by Mum
- always say no to food offered by others
- read labels (as they learn to read)
- ask questions about food on offer
- not succumb to peer pressure....
- **AND ALWAYS BE PREPARED FOR AN ACCIDENT**

Ongoing management

v) Pre-school/School

- Understanding what pre-schools can/should do (and what they can't)
- Giving plenty of time to sort problems out before start of pre/school e.g. start enrolment 6 months ahead
- May require lots of tact, diplomacy, gritting teeth – hard if you are anxious about your child's safety
- And what do you do if you feel your child is not safe in that school environment? Parents need to be strong advocates.

What is vital about VITAL?

- Standard 1.2.3 clause 4 in Food Code very 'black & white'; industry & consumers left to interpret the grey areas e.g. cross-contamination, with no guidance
- Consumers' experience is of the industry using a wide range of 'may contain' type statements to 'cover themselves'; consumers left to interpret risk for themselves
- Has lead to even more restrictions on foods available for food-allergic consumers

VITAL

- VITAL provides guidance to the FI on decisions on labelling allergens, based on a risk assessment approach
- Allergy NZ involved in discussions from early on; satisfied the approach is appropriate given the resources available at this time
- Challenge is to educate consumers so they understand how risk has been assessed – most still see it as another version of ‘may contain’
- Also need to get information out to consumers of products labelled according to VITAL.

Why should the Food Industry consider VITAL?

- Primary objective of food labelling is public health & safety; and the prevention of immediate-type food allergic reactions is probably the most significant safety consideration for labelling
- Secondary objective is to enable consumers to make informed choices. Plethora of 'may contain' statements significantly reduces the opportunity for food –allergic consumers to make informed choices
- VITAL does not guarantee 'free-from' allergen foods; it does provide consumers with labelling which is based on extensive knowledge of the safety issues associated with food allergens; and aims to give consumers the information they need to determine the safety of food (i.e. informed choice).

Other Food Labelling Issues

- 'Free From' claims: while food-allergic consumers want more 'free from' allergen food, technically anyone making such a claim could be in breach of the Fair Trade Act; also a concern at number of small manufacturers using such claims without necessarily understanding the issues. Recommend NZFSA & Commerce Commission develop guidelines for the use of 'free from' allergen claims.
- Imported food: labelling should comply with NZ regulations but not being monitored; allergen labelling may be over-stickered in English but not clear how much research was undertaken on food allergen-management (as distinct from simply interpreting the label in English)

Other Issues

- **Very little research** on food allergy in NZ – we have a quite different population mix and diet to Australia; and far fewer allergy specialists per head of population
- We do know that FA affects all ethnic groups; and that many children experiencing adverse food reactions are not being investigated for FA
- Where children & adults have been diagnosed, many report this took a long time, a lot of money, and difficulties in maintaining health professional monitoring
- This means potentially many thousands in NZ suffering from poor health and risk of life-threatening reactions, with potential for developmental delays in many children.

Pharmac & Auto-injectors

- The only treatment for anaphylaxis is an intra-muscular injection of adrenaline
- Pharmac subsidises ampoule, needle & syringe, however specialists will not prescribe to patients as impossible to use if you/your child is having a severe reaction
- Most doctors prescribe EpiPen (autoinjector) but this costs average \$150 each - & Pharmac wont fund it
- Major safety issue in consequence – many prescribed but cant afford to buy/replace; also has implications for schools, workplaces etc
- However note ACC claims for anaphylaxis can cover cost of patient's EpiPen if used.

Health professionals

- Lack of guidelines for diagnosis/referral/treatment etc e.g. child hospitalised for severe reaction which started soon after eating food – but FA never investigated or child referred to a specialist
- Lack of access to dietitians, which should be integral to successful management of FA
- Lack of access to nurse-lead eczema clinics to help manage this growing problem

About Allergy New Zealand

- National patient/consumer organisation, purpose is:

To enhance the health and well being of people living with allergies by sharing current knowledge & expertise and leading positive change through being a strong and credible national voice



Organisation

- Head office in Auckland
- National volunteer support network
- Membership based with elected Board of Directors
- Medical Panel
- Associate members of ASCIA
- Founding members of the international Food Allergy & Anaphylaxis Alliance



Services

- Information on all aspects of allergy – check www.allergy.org.nz and our magazine *Allergy Today*
- Resources: e.g. brochures, books, posters, DVDs, dustmite covers, action plans, FA ID cards
- Education: guidelines and resources for pre/schools; education resources for health professionals and food industry
- Support: Groups & networks in local communities around NZ

Advocacy (where to start?)

- Pharmac: Auto-injector; infant formula; eczema treatments
- NZQA: inclusion of anaphylaxis in First Aid Unit Standards
- Ministry of Education: guidelines & resources for schools, parents & students
- NZFSA/Government: FA consumers' risk in hospitality sector to be addressed in FCPs – so what has happened to the Food Bill???
- Australian Ministerial Council review of food labelling law & policy
- Health sector (Ministry of Health, DHBs etc): access to allergy/immunology services for patients and
- Access to clinical guidelines, education & resources for health professionals...
- Airlines: becoming difficult for FA people to use airlines in some parts of the world
- Insurance: no clear policy around cover for allergy as pre-existing condition; cant claim for EpiPen as not subsidised by Pharmac (Catch 22); travel insurance etc..



Anaphylaxis e - training

- Launched this month by ASCIA
- Developed for school and childcare staff where face to face training is not possible (or feasible), or as a refresher, or for interim training whilst waiting for face to face training.
- ASCIA anaphylaxis e-training courses are free and can also be taken by parents, friends, carers or patients themselves.

Access from New Zealand

- Go to www.allergy.org.nz (Allergy NZ) and follow links
- Before starting the module, please note the following:
 - The anaphylaxis e-training module for New Zealand includes administration of two auto-injectors, EpiPen and Anapen. The Anapen is not available in New Zealand at this time but participants will still need to review the related information and answer questions to complete the module.
 - The emergency response for NZ indicates 'dial 111 for ambulance'. We recommend people also tell the emergency services when dialling 111 'anaphylaxis, need adrenaline' (this is because not all ambulances have paramedics able to administer adrenaline).
 - The module does not include the Guidelines for schools and pre-schools in New Zealand. These can be ordered from Allergy New Zealand

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