



Challenging/Difficult Cases

Heidi Ball

Gary Stiefel

Children's allergy service

Leicester Royal Infirmary

Aims

- Introduce 3 challenging/difficult cases from Leicester Childrens Allergy Service
- How presented
- What was decided
- What happened

Audience discussion !

Case 1: Presentation

- Referral from safeguarding that siblings are reported to have presumed food allergy to milk, soya, egg & wheat, but need evidence of its presence. ? Fabricated illnesses
- Can you help?

Case 1: Background

- Under Gastroenterology for GORD (-ve impedance)
- Under Immunology team (low IgG, IgA)- on prophylactic septrin
- Long history of feeding problems
- Mother pursues many medical opinions
- GF products on prescription
- Children on multiple dietary exclusions

Case 1: What would you do?



Food Challenges

- Usually open challenge – visible symptoms prove diagnosis, *practical to our service*
- Not suitable when symptoms subjective, delayed, parent may bias results

BUT

- Blinded challenges may still be biased by a parent, will not give results 'on the day' if delayed, food allergen will be known if more than one challenge e.g. Blinded cake = egg, drink = milk

Case 1: Plan for food challenges

- A 'milk shake' type drink plus a home made biscuit (and 2 biscuits to take home) at each visit
- Parent to keep detailed food and symptom diary the **week before** (+ from school) and weeks following challenge
- Parent told drink/biscuit may or may not contain allergen

Case 1: Challenge Plan

- Week 1 , chocolate/strawberry rice milk mixed with flavouring in sealed cup plus dietitian made free from biscuit (no allergen)
- Week 2 – rice milk/cows milk flavoured drink plus free from biscuit with milk
- Week 3 – rice milk/soya milk flavoured drink plus free from biscuit using soya flour
- Week 4 – rice milk drink with 10ml raw egg plus free from biscuit containing egg
- Week 5 – rice milk drink plus wheat flour biscuit

All weeks 2 extra biscuits for home

Doctors/day care staff unaware of allergens

Case 1: Challenge & Diary Results

- Pre-study diary was not free from wheat or baked milk yet no symptoms recorded!
- No symptoms observed on ward
- Doctors looking at diaries (did not know 'code')

Noted that week 1 worst, Week 2 possible loose stool next day, week 4 rash and abdo pain at home.

Case 1: Conclusion

- Child symptomatic when no allergen! (week 1)
- Child had been having allergen unknown to parent prior to challenges (from diary)
- No problem with wheat or soya, no need for exclusion or coeliac products (week 3 and 5)
- No reason to avoid baked milk and cheese, gradual increase in other milk foods
- Allow baked egg, retry whole egg in 3 months

Children do NOT have severe symptoms attributed to multiple food intolerance and are being unnecessarily restricted.

Case 2: Presentation

- Referral from another hospital.
- 3yr old BF until 22 months
- Poor sleeper and vomiting frequently
- Yoghurt vomiting, rash on face
- Cheese – diarrhoea and profuse vomiting.
- Baked milk recently- diarrhoea and abdominal pain immediate.
- Never eaten egg

Case 2: Presentation

- Skin Prick tests
- Milk 0mm
- Egg white 4mm Egg Yolk 3mm
- Nuts all 0mm

Diagnosis IgE egg allergy?, Non IgE Milk Allergy

Case 2: Initial Plan

- Baked egg challenge (2 egg recipe) supervised
 - Lip swelling and hives after 1st dose. Mum insists on EpiPen
- Baked milk reintroduction advice (home)
 - Mild symptoms reported
- Nut introduction (home)
 - Several times and developed rash and itchy lip.
 - 6 months later supervised –ve peanut challenge

Case 2: Further Information

- Dietitian in community (not Leicestershire)
 - Liaison with pre-school and they have never witnessed any loose stool, eczema or abdominal pain
 - Previous Nursery no symptoms or problems reported
 - Would like Leicester to see again as finding management 'difficult'

Case 2: Dietetic Review

- Attended with both parents, who are now separated.
- His mother is extremely concerned over a range of symptoms which have been persisted or worsened - diarrhoea and abdominal pain, especially after weekend stay with dad
- Father reports he rarely finds him to have symptoms when with him (2 week holiday no symptoms even when had allergens)
- Mum wanting to find cure for symptoms (other exclusions) and dietitian to ensure dad follows diet
- Conflict ++++ in the room

Dietitian review - advice

- Both parents and nursery to check labels in case of label change
- Suggestion that may be non dietary cause/ relate to stress within the family.
- Keep diaries, no need for further exclusion at moment (thriving OK)
- Analysed diary & discuss with allergy team

Case 2: What would you do?



Case 2: Other information

- Second opinion from allergist suggesting that double blind challenges would be useful.

Case 2 – Dietetic involvement

Need for blinded milk challenges to establish if child

- Has symptoms as described
- Symptoms caused by ingestion of milk

Concerns of fabricating illness due (custody case)

Case 2: Dietetic Plan

- Keep diary of intake and symptoms prior to attending for daycase challenge
- Parent told that child would eat a biscuit on ward and take home 3 further days biscuits which may or may not contain milk to give us an idea of his tolerance to milk

Case 2: Outcome of Diary

- Diary showed no ingestion of milk with mother.
- Symptom free except for the 2 days after returning from weekend with father (presume milk ingestion but dad's diary no evidence of ingestion)
- **Very** detailed info including photos of stools in toilet (looked normal)

Case 2: Pre challenge letter



- RE: Forthcoming Challenges to assess tolerance to baked milk.
- One way of looking at this in more detail (which is what has been suggested/planned for XX) would be to keep a detailed food and symptom diary for a minimum of 1 week before the first challenge and on going throughout the trial period. There will then be 2 separate appointments (challenges) where XX is given a biscuit on the ward, with further biscuits to take home. **The 2 occasions will contain different doses of baked milk.**
- This will give us beneficial information in assessing whether food can give rise to the symptoms for which we are unsure of a cause
- Allow us to understand whether cow's milk is still a problem to him, and whether this sensitivity is at a very low dose (i.e. small dietary discrepancies can give rise to symptoms) or only at higher doses.
- We may then be able to identify the way forward. I hope this explains things a little more, and great news that he does not have a peanut allergy. I enclose diaries which I would be grateful if both of you could keep (and the nursery).

Case 2: Outcome of Daycare unit

- Ingested biscuit on ward
- Report from mother following day ..symptoms so severe she was not prepared to subject him to further biscuit. Mother encouraged to give further biscuit after 2 days, similar result
- Dietitian reports to Dr (early code break) that neither biscuit contained milk!

- XX will be admitted to ward 14 on Thursday March 17 after a biscuit challenge on daycare ward 19. He is to stay on ward 14 for the duration of his admission – until Wednesday 23 March.

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Medical and nursing plan

- He does NOT go in a cubicle.
- (Safeguarding) will provide a separate observation file for nursing and medical staff to record any confidential information.
- The nurses write down interactions of concern between XX and Mum, XX and Dad and Mum and Dad in observation file.
- Document everything he eats and drinks.
- Document any medical symptoms and signs in the clinical notes. Assess particularly for gastrointestinal symptoms (pain, nausea, vomiting, and stool changes), behavioural symptoms (discomfort, sleep) and git and skin signs.
- ALL stools **MUST** be seen and documented by nursing/medical staff according to the Bristol stool chart. Same for any vomiting.
- Document everything he eats and drinks **ACCURATELY**.
- On Monday please send bloods for FBC, coeliac screen, LFTS, U&Es, ferritin and vitamin D. essentially it is to rule out celiac as a possible other medical cause.

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Dietetic plan

- All meals and snacks must be milk and egg free. A meal choice will be ordered by the ward 14 dietitian for lunch and supper. This is **not** to be substituted unless it is from food brought by parents (BUT SEE NEXT POINT)
- Parents have been instructed that they may bring in familiar milk and egg free food items to include soya desserts, fruit, Oat milk, usual bread, a tub of dairy free margarine, sandwich filling e.g. ham and a selection of snacks such as crisps, bread sticks, rice, biscuits.
- All food from home **MUST** be clearly labelled with XX name, stored in an appropriate area (e.g. fridge), be kept in the original packaging where ingredient labels can be checked for the word MILK and EGG in bold type and only be given by nursing staff. XX is allowed ward Weetabix for breakfast (with own OAT milk).
- All food and drink intake to be recorded.
- All stools to be observed and recorded (comparison with Bristol stool chart).
- A challenge biscuit provided by the dietitian is to be given daily at a similar time (suggested 10.00am). The first biscuit will be given on daycare on day 1 (Thursday) with biscuit 2 on day 2 (Friday), biscuit 3 on day 3 (Saturday) and biscuit 4 on day 4 (Sunday). The biscuit should be given in 2 doses, ½ biscuit followed by 30 minute observation, followed by the remaining ½ biscuit. The daily biscuit should **ONLY BE STOPPED** if symptoms are felt to be too severe to continue e.g. frequent loose stools, severe vomiting, respiratory symptoms, angioedema and discussed with Dr XX.

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ADDENDUM

- The following instructions were sent to XX parents by Heidi Ball prior to the admission;

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Dear XXXXXXXX

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- With regards to XX planned admission on Thursday, providing allergen free food for inpatients can be quite limiting, so whilst we will be able to offer him a limited range of simple meals which will be milk and egg free. You may wish to bring a selection of the following items for use during his stay to ensure he has familiar allergen free food available.
- Cartons of Oat milk
- Soya desserts
- Dairy free margarine
- Fruit, fresh or canned (we can provide banana, apple and orange)
- Familiar Snacks e.g. bread sticks, crisps, biscuits, rice cakes (brought in original packaging unopened)
- Usual bread/bread rolls
- Sandwich filling e.g. ham (sealed in pack)

Case 2: Outcome of admission

- Child admitted for 5 days to observe symptoms of constant pain/crying/loose stool as mother questioning other food allergy
- 2 days observation (nothing of note)
- Baked milk ingestion (nothing of note)
- Fresh milk challenge (nothing of note)

Parents told to continue to allow milk at meeting on ward (difficult consultation)

Case 2: Further outcome

- Mother taken child to another consultant who diagnoses from verbal history Non IgE Milk Allergy and recommends strict milk free diet !
- Father reports weekend contact stopped due to solicitor reporting him to not be following strict milk free diet.
- Safeguarding involved.

Case 2: Further outcome 2

- Doctor and symptoms could also be due to the animosity that was evident between her and Dad. Mum did acknowledge this was a possibility.
- Referral to CAMHs & referral to a domestic violence support worker to do some work with child.
- Continues off milk and egg

Conclusions

- Dietetic blinding of food useful tool, **but always include no allergen placebo** and a **pre-challenge** 1 week food and symptom diary.
- Be prepared for conflict+++
- Document EVERYTHING, it maybe used by solicitors/courts
- Ensure everyone on team briefed.

Is this safeguarding??

Child with reported food allergy (EpiPen, dietary restrictions, special school meal) BUT negative SPT and refusing definitive food challenge???