Developmental pathways in food allergy: Case studies

what can we learn from psychology that will help us to support children, teens, and parents with food allergy ?

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What I will talk about.....

- Why should we pay attention to the developmental process ?
- What can we learn from the developmental pathways in food allergy that will help us to approach and support children, teens, and parents ?
- Exemplar Case studies : Emma, age 7; Peter, age 12, and James, age 16.
- A brief overview of the Train the Trainers '*Food Allergy Matters*' programme for Support Group Leaders.

Why is the developmental process important ?

- The developmental process plays an important role in shaping and determining physical and psychological health and health related quality of life over the life course.

  - *'the boundaries between what is innate and what is acquired become so blurred as to be at the very least uninteresting compared to the powerful questions of developmental process'.*
  - **Thelen and Smith**

one example....

Paradoxically…as children develop the competencies to reason effectively and make decisions as they grow up, they also develop shortcut and biased judgement strategies that are used inappropriately in some situations.

- For example, heuristics (cognitive shortcuts, which become automatic) are more likely to be used in situations in which ...
  - self-interest (appearing 'cool'),
  - prior beliefs ('it won't happen'), or
  - uncertainty ('you can never be sure')

... are involved.

DunnGalvin et al., 2009;10;11.

- Understanding developmental processes in food allergy gives us, as clinicians and health professionals, important information and insights with which to support children, teens, and parents.

Another example

- Transition points … can change the meaning of having food allergy

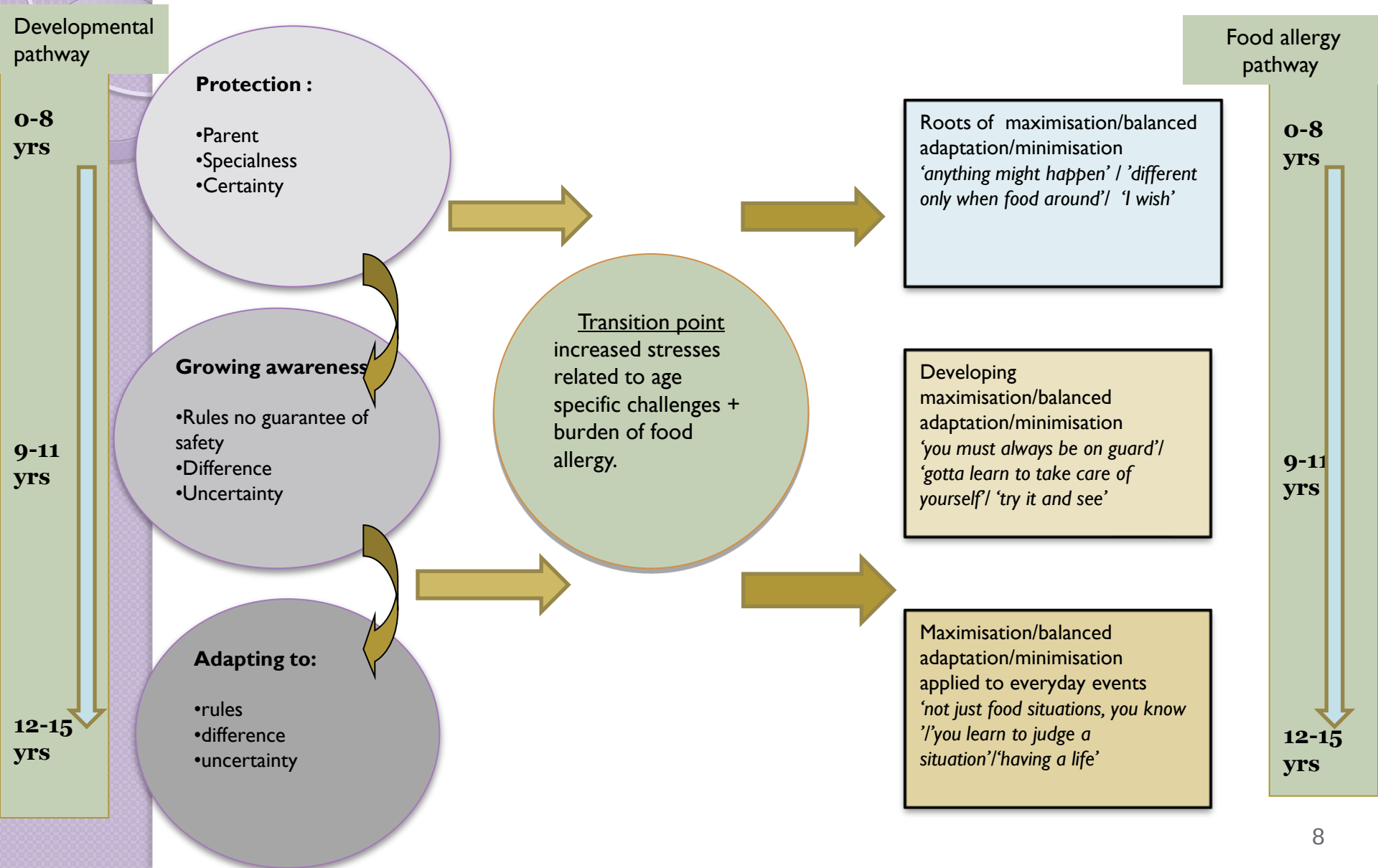
Middle childhood:

- when children learn or feel that they cannot prevent a reaction from occurring
- evidence of an over-interpretation of ambiguous information in terms of processing of potential threat not directly related to food.

Adolescence :

- when teens encounter unstructured ‘‘novel situations’’ and peers and their automatic response patterns are challenged resulting risk - social (self-concept) and/or personal (safety).

The Developmental Model :
Maximisation/Balanced Adaptation/Minimisation



Case studies *

* Therapeutic activities based on ‘Food Allergy Matters’: a psycho- educational intervention for children, teens and parents. DunnGalvin et al.

Example 1 : Emma, Age 7, peanut allergy

younger children

For young children particular issues include:

- how to feel part of social occasions such as birthday parties while being and feeling safe;
- how to communicate with friends, restaurant staff, and other children and adults in novel situations;
- how to deal with difficult people and situations (e.g., teasing and bullying);
- how to cope with transition points, such as going to ‘big school’.

Background

- Emma presented as an anxious child, who was very dependent on Mum. She was emotionally mature for her age, in her manner and thought processes. Mum scored Emma very highly on the 'Food anxiety' subscale on the FAQLQ-PF (6 out of 7). She was highly fearful of anaphylaxis and would interpret many social non-food situations (e.g. going to the cinema) as 'threatening'. She would also ask Mum again and again to check if packaging contained peanuts.
- Both Emma and Mum were very eager to discuss her fears. It appeared that Emma was 'anxious/avoidant ' and that the emotions and behaviours associated with this were generalising to non-food situations. Both cried as they described what it was like to live everyday with food allergy. It was clear that they felt overwhelmed.
- Emma is categorised under 'maximisation'

Goal of Therapy

- The most important goal of therapy, therefore, was to foster a perception of personal control over, and confidence in managing, food allergy in Emma and Mum.

What happened next?

- I asked Emma to discuss those occasions when she became anxious (from the first moment onwards).
  - 'What was going on ?';
  - 'What did her body feel ?';
  - 'What thoughts did she have ?'.
- She found it very difficult to remember events that led up to her experiencing physical and psychological symptoms such as throat tightening and panic

A few example activities ...

- 'Body and mind works together' activity-
- 'Worst case scenario' activity– what was the worst that could happen ?
  - What would Emma do if the worst happened and she accidentally ate a nut ?
  - This scenario was described several times with gradually changing outcomes.
  - She began to be aware of how similar symptoms of panic and symptoms of anaphylaxis are.
- We created 'a personal plan for Emma' together and set up a diary plan for her.

Outcomes

- I had a meeting with her after she had just returned from a holiday in France which she had really enjoyed. She took part in many activities, although she still avoided restaurants. She appeared much less anxious.
- She was using the 'personal plan' to very good effect and it was now becoming automatic.
- She now checked a packaged food item herself and only needed to look once to feel confident.

Older children and teens

Example 2 : Peter age 12, with multiple allergies

For older children and young teens particular issues include:

- How to balance peer pressure and positive self-perception while staying safe;
- How to communicate in novel situations such eating out and making new friends;
- How to manage feelings such as embarrassment, self-consciousness, difference,
- Managing the removal of the parental safety net, and development of effective self-care.

Background

- Peter presented as a confident and articulate child. He has had experienced anaphylaxis twice in the relatively recent past, and Mum is very worried.
- Peter scored highly (5.2) on the third subscale of the FAQLQ-PF impact of 'social and dietary restrictions'.
- Peter, thinks wishfully of food he would like to eat and/or being no longer allergic. He is very frustrated by the 'rules' of safety and feel that 'are pointless' because of the uncertainty of allergic reactions, labelling of ingredients, and low awareness. He compares his life very unfavourably with other children who do not have food allergy, and does not tell them about his food allergy because he expects a negative reaction.
- Peter has begun to take risks (such as not reading labels, not telling others of his allergies), as his way to try and exert control over uncertain conditions. Peter resents parental protection which he regards as 'nagging' and sometimes 'forgets' his pen.
- Peter is categorised under 'minimisation'.

Goals of therapy

- The most important goal of therapy was to foster a sense of positive identity, to feel ‘the same’ as his peers, and develop constructive ways of coping with risk.

Some sample activities …

- '*Who am I ?'* encourages children to talk about self and identity and *'everyone is different'* counteracts a perception of difference.
- '*what I can do*' Look at what you can do and can eat, not what you can't.. '*Like riding a skateboard …there are things you can do. Some things you can't change and you have to learn to skate around them'*.
- *'It's good to talk'* deals with how and when to tell others about food allergy.

Example : 'Telling others'

- For older children, stages in problem-solving are identified as:
  - identifying and defining the problem and any associated feelings;
  - alternative thinking to generate several possible solutions (e.g. asking "*What would the little green man from Mars suggest?*" as a way of introducing objectivity);
  - looking at the pros and cons of each solution
  - decision-making, carrying out the plan and monitoring the outcome.

What happened with Peter ?

- We developed an agreed goal : tell others in situations when there is a risk, while maintaining positive self-identity.
- When to tell ?

- EG Compromise – you don't have to tell 'everyone' and you don't have to tell others 'right away'.
  - Find a way/language that suits.. Peter himself came up with this statement : *'I can eat most stuff, but not that..got an allergy...not sure if I mentioned that..it isn't a big deal 'cos I got it under control'*
  - Carry out the plan with one friend that he hasn't told up to now
  - What happened ? ...
  - Modify/reinforce plan based on evaluation

Changed expectations ⟺ Changed behaviour

- Peter gradually began telling more friends – a big breakthrough came when he told some ‘new’ friends he made during an activity camp holiday.
- He was using the ‘personal plan’ to very good effect and it was now becoming automatic.
- It was time to move on to other issues surrounding risk such as feelings of difference, sense of frustration and paying attention to labelling.

Teens and young adults

Case study 3 : James, 16 years.

For older teens particular issues include:

- Going out independently with friends,
- Starting to drink alcohol,
- Cooking and sharing food with housemates
- Going away to university
- The first independent holiday, and attending clubs or discos.
- Romantic relationships,

Example :
Not carrying the pen in all contexts

- Increasing cognitive sophistication as children grow, but also increasing heuristics, thus … …

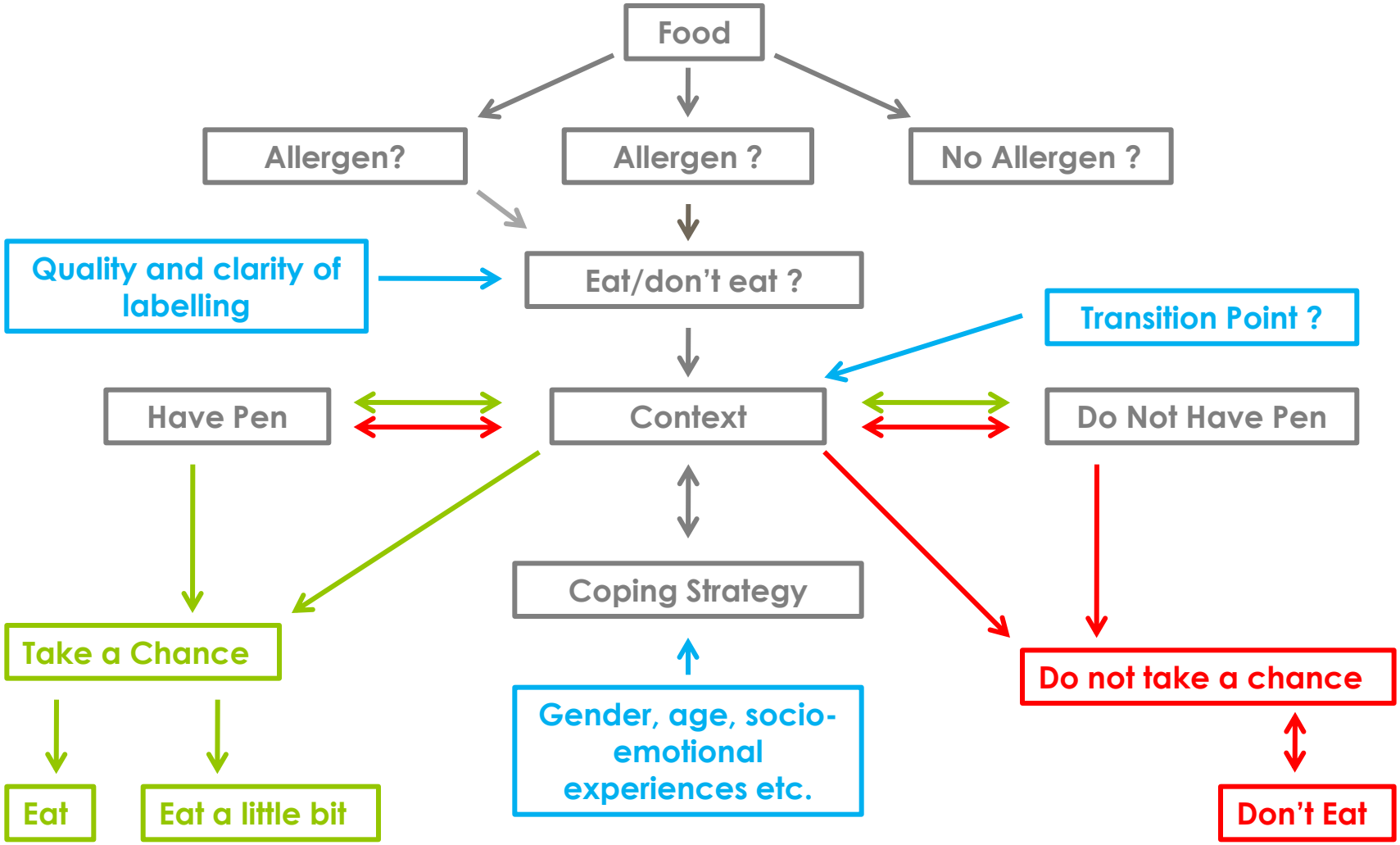
  … … teens and young adults are aware that they should bring the auto-injector with them at all times, they are many barriers to full compliance.

- In many cases, "*at all times*" does not generalise to non-'usual' occasions, or activities.

- Knowledge does not necessarily translate into behaviour

Decision Making Model

Green = eat/eat a little bit
Red = don't eat
Blue = influencing factors



The problem ?

- James; '*I have been having reactions since I was six, and, it's a bit weird to say it, but you do get used to it .I do ask in restaurants about what's in [the food] but sometimes I let it go so not to make a fuss.*

- With regards to carrying the auto injector, James says that he would '*remember it in the usual situations...it's just that if it's something out of the ordinary, you know or like if you are going somewhere with friends that isn't like a restaurant, that's ok then, isn't it ? It's just the sheer hassle of having to take it, although I know I should, but...I have been fine so far.....If I bring it along and I don't need it (again !), I feel it's been a complete waste of time and a bit stupid*'

Goal of therapy for James

- self-management skills that generalise to both everyday and non-typical situations

Example Activity

- Create a word cloud of every situation you can think of in your life.
- Next, assign a risk quotient to each situation specifically with regard to potential for allergic reactions
- Next, think of anything that happened in your life in any situation that was unexpected..what happened ? What do you wish you had done? What would have helped ?
- Now, assign a risk quotient to each situation specifically with regard to potential for allergic reactions

Update

- James began to create a new cognitive schema about the pen/ and a more flexible coping strategy that can be applied to real world contexts, and will eventually become automatic.

- James also created his own ‘mantra’ : *‘sure i’ll bring the pen, what’s the harm, if nothing happens that’s a result, not a waste of time’*

A word about parents

Particular issues include :

- How to manage their own and children's anxiety
- What to expect as children grow,
- How to manage sensitive transition points
- Negotiating the line between supporting children's independence and keeping them safe
- Managing feelings around the burden of responsibility
- Enhancing self-management skills that both children and their families can draw on, and that generalise to both everyday and non-typical situations

- *'Family life can be difficult enough..but when you add food allergy to the mix those difficulties are multiplied'*
  - (Claire, mother of Becky, age 10, and Jane, age 13).

Therefore ...

- when treating children, it is important to address any parental anxiety, to improve their understanding of their child's food allergy, thereby improving a sense of control.
- For example, allaying parental anxiety reduces the child's anxiety and creates a positive feedback loop, which ultimately helps both the child and parent .

Train the Trainers

A brief overview of the Train the Trainers '*Food Allergy Matters*' programme for Support Group Leaders.

The ‘Food Allergy Matters’ psycho-educational programme.

AIM

- to assist children, teens, young adults and their families with the day-to-day management of food allergy, and its consequences, by providing an understanding of, and establishing and/or enhancing, social, emotional and behavioural skills.

Development and methods

- Based on empirical research (focus groups and interviews in UK, Ireland, US, Australia, Italy), in addition to many years of clinical practice
- Methods actively involve individuals in the learning process
- Addresses cognitive, behavioural, and affective components relating to living and coping constructively with food allergy.

Train the Trainers 'Food Allergy Matters' Programme

- Participants : Patient Support Group co-ordinators who are interested in delivering the 'Food Allergy Matters' programme for children, teens, young people and/or parents.
- Duration : 2 day workshop
- Purpose of workshop : to provide participants with all the skills needed to deliver and/or train others to deliver the food allergy matters psycho-educational programme.

Content

- The principles of learning and training;
- Language and Communication – appreciative enquiry, active listening, communicating issues related to food allergy;
- The principles of Cognitive Behavioural Therapy (CBT);
- The 'Thinking, Feeling, Doing' Model;
- Steps to effective problem solving;.
- How self-management skills generalise to both everyday and non-typical situations;.
- A wide range of age appropriate activities and games to promote learning

Training process and methodologies

- Participant workshops with underpinning knowledge and exercises
- Workshop approach and group discussion
- Group and individual exercises
- Role plays and practical presentation
- Opportunities for practice
- Real world cases
- Real products including menu's, supermarket items and epipens are used in role play.

conclusions

What can we learn from the developmental process that will help us to approach and support children, teens, and parents ?

Living and coping with food allergy …

… … is a cumulative history of interactive processes (both age and disease specific) that are embedded in a child's developmental pathway, therefore …

… … one of the goals of a consultation or intervention should be to promote a stable growth dynamic by including issues that are food allergy specific, as well as age and context specific.

Important questions to ask in the clinical encounter ?

- What is really threatening for a particular child or teen ?
- Are they experiencing a transition point ?
- What is ‘normality’ for an individual child/teen/young adult ?
- How do they cope in different contexts ?

Final message

- Understanding developmental processes gives us, as clinicians, parents, and health professionals, important information with which to help children, teens, and parents.
- The early incorporation of a developmental framework into a treatment plan is essential.
- Greater support is important at time of diagnosis and at the different transition points along the development pathway.
- Health professionals need to work closely with parents/children/teens own understandings about food allergy about 'compliance' and about risks
- Include issues that are food allergy specific, as well as age and context specific.

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