

# Management of children with potential anaphylactic reactions in the community: a training package and proposal for good practice

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## Summary

**Background** The increase in potentially dangerous food allergic reactions (e.g. to peanuts and nuts) in children had lead to an increase in the prescription of adrenaline, including adrenaline for self- or parent-injection. This raises problems in the management of these children in schools. Our experience in response to this is described.

**Objective** To develop a training package to ensure that each child can continue at school but receive optimum emergency treatment in a safe environment. To provide education, training and support to school staff, and to support parents.

**Methods and Results** This paper describes a model of good practice in the support of children with potentially fatal anaphylactic reactions. The following points are emphasized. Children with a history of anaphylactic reactions should be expertly assessed prior to the prescription of adrenaline injection. A written treatment plan is essential. Parents need expert support in managing the child. Schools need training and support. Children should lead a normal life, and not be stigmatized or labelled by their problem. Close liaison between primary care, acute services, community services and education services are essential for the successful management of this problem. Data from a questionnaire showed the training package was of benefit, with considerable reduction in anxiety in school staff and parents.

**Conclusion** A broad training package is essential: training in administration of adrenaline is only one aspect, and emphasis is placed on education, recognition of allergic reactions and prevention. The presence of children in school needing access to adrenaline is no longer perceived as a problem in our area. We recommend other health authorities provide a similar service.

**Keywords:** anaphylaxis, children, school, nut allergy, protocol

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## Introduction

Children who are highly allergic to food substances are at risk of developing a severe and rapid immunological reactions mediated by IgE antibodies. Although such severe allergic responses are uncommon, symptoms can appear immediately and most commonly include facial angioedema

and urticaria progressing to marked respiratory difficulty (laryngeal oedema or bronchospasm) and/or hypotension causing collapse or unconsciousness (anaphylactic shock). This type of reaction is life-threatening in nature and may rarely be fatal if prompt emergency action is not taken. In 1992 a report from the United States on fatal and near fatal anaphylactic episodes in children found that four of six deaths occurred at school, and none of these children had adrenaline available at the time of their reaction [1]. This paper concluded that at-risk children should have access to

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adrenaline at all times, a practice followed in Cambridge. The problem of food-induced anaphylaxis has been receiving increasing media attention recently, and was commented on in a recent Chief Medical Officer's Update [2]. In some areas there has been much media coverage concerning children who have been excluded from school [3]. It is likely that the wide media coverage and the formation of The Anaphylaxis Campaign (a group established to support those with potentially fatal food allergies) following the deaths in 1993 of two young adults who ate peanuts, has encouraged parents to seek help from their GPs who in turn have referred the family for specialist help. The large number of children living in one area with this problem suggested to us that the problem was more common than we had previously been realized. This was confirmed by a survey of community paediatricians in the rest of the Anglian part of the Anglia Oxford Region (Cambridgeshire, Bedfordshire, Norfolk, Suffolk) in June 1995 which identified an additional 82 children with this problem (in addition to the 28 known in our area at that time). The recent report on the Health Needs of School Age Children from the British Paediatric Association [4] commented on the difficulties faced by children and schools around medication in schools.

This paper aims to show how good liaison and communication between acute and community health services, the local education authority and schools enables children with serious food allergy problems to receive optimum therapy with minimum or no disruption to their education in main stream schooling.

We have developed a training package for schools and nurseries and this paper will describe the package and its benefits. We recommend that other health authorities provide a similar service to ensure that children are adequately supported in school.

The overall aim of the training package is to ensure that each child can continue at school but receive optimum emergency treatment in a safe environment if a reaction should occur. It is hoped that by providing information on all aspects of prevention, identification and treatment of attacks, that the anxiety felt by parents and school staff is minimized.

In 1993 the experiences of two families living in the Cambridge area caused concern. The children, as part of the medical management for their food allergy problems, required access to an adrenaline injection at all times for the treatment of potential episodes of anaphylaxis. These parents wanted minimal disruption to family and school life, but accepted that modifications to their lives were inevitable. Clearly the food eaten by their children had to be checked carefully. For their children to continue their education in main stream schooling the co-operation of school staff was needed. Parents found the situation stressful and school staff were apprehensive about administering

medicines in an emergency situation, especially when they realized that they might need to give an injection. The advice of teaching unions was that staff should not administer any medication, and there was no Local Education Authority policy on medication in schools. At this point it became clear that a comprehensive training package was required to bridge the gaps between the acute and community services, the education authority, schools, the family and the child.

A Research Paediatric Nurse (LM), running an action research project funded by the Department of Health to assess and respond to the needs of children with a variety of life-threatening illnesses and their families living in the Cambridge area and a Consultant Community Paediatrician (DV) agreed to assist these two children and their families. Since then many other children have been referred. A training package has been developed. The aim is to take the advice of the allergist on emergency management and translate this into a practical reality in the community. By providing training for school and nursery staff this allows the child access to emergency at all times and provides education and support for those involved. We describe this package and its delivery by the community paediatric team and suggest this as a model of good practice. An assessment of its efficacy is also reported.

## Materials and methods

### Patients

Fifty-six children living within Cambridge Health Authority boundaries with a diagnosis of potential anaphylactic reactions to foods (who have been assessed as requiring access to immediate treatment with adrenaline) have been supported. All have been allergic to nuts with the exception of one child with a milk allergy. All children are assessed at the designated Allergy Clinic at Addenbrooke's Hospital in Cambridge. Advice has been supplied to community paediatricians on other children, assessed at Addenbrooke's Allergy Clinic, but living outside the Cambridge Health Authority boundaries.

### Assessment by allergist

In all cases a detailed clinical history was obtained. The severity of the allergy was assessed by the severity of the reaction(s) in relation to the amount of allergen ingested. The majority had experienced significant symptoms, i.e. laryngeal oedema with or without bronchospasm and/or hypotension; the foods involved were identified from the clinical history and were confirmed by skin-prick testing. However, minor symptoms on inhalation of peanut vapour without contact or exposure to a trace amount, e.g. contact

on the lip, may also indicate a patient at risk. Patients are categorized as mild, moderate or severely allergic and appropriate medication for emergency management advised. Not all patients are given adrenaline. Of those who are, some are given injected adrenaline (usually with inhaled adrenaline) and some inhaled adrenaline only. Patients are given an individualised written treatment plan, setting out in lay terms the symptoms that may occur (grouped as mild, moderate or severe) and the appropriate management for each group.

It is important to recognize that the need to have adrenaline available at all times, whilst solving some problems, creates others. Locally therefore we recommend that all children are assessed at the Allergy Clinic to try and ensure that they do need access to adrenaline, and the associated training package. In this paper, all the children referred to had been assessed as needing access to adrenaline (48 have access to injectable adrenaline, and eight only have access to inhaled adrenaline). All children requiring injectable adrenaline are issued with an auto-injection device (Epipen) with the dosage dependant on the child's age. The use of inhaled adrenaline is controversial with no clear agreement about its value or role. It is highly effective for mucosal oedema, one of the major risks [5] and is user-friendly and carries none of the disadvantages of injectable adrenaline. We recommend it widely, but for defined symptoms (anything suggestive of mild to moderate laryngeal/pharyngeal oedema) and encourage its use early and in large doses. Ten puffs are given, repeated within minutes if necessary. Children who only have access to this have been assessed in the Allergy Clinic as less severely allergic and hence at lesser risk. The purpose of this paper is not to discuss which children should carry adrenaline or the role of inhaled adrenaline – this will be addressed elsewhere. (Ewan PW, in preparation).

#### *Parents' concerns*

Discussion with parents highlighted several areas of concern. Their main concern was that their child maintained as normal a lifestyle as possible while remaining in a safe environment at all times. They found it stressful dealing with school staff directly and often felt that the situation was not being taken seriously. Many felt as if they had been labelled as over-anxious parents. A concern voiced by a few parents was that their child was being seen in an adult immunology clinic. Although it has been recommended that children with allergic disease have their care and treatment managed by a paediatrician since the progression of allergies differs in children from that in adults [6], there are few Paediatricians with an interest in allergy so it is more practical to aim for combined management. Because of the large numbers of children being referred to the Allergy

Clinic, we have created a children's area with full facilities for children (for which we received a King's Fund award). In addition we have established a joint follow-up clinic for these children involving a Consultant Allergist, Consultant Paediatrician and a Paediatric Nurse Specialist.

#### *Nursery and school staff: concerns*

The main concerns of nursery and school staff revolved around practical and legal issues; how could they accurately identify an allergy attack and safely administer treatment. While teachers have a general legal duty to act *in loco parentis* they are under no obligation to administer or to supervise children taking medicines [7]. Concerns were voiced about their legal status if anything untoward happened to a child after they had administered the first aid treatment. Teachers felt that they could be blamed and that they might not be indemnified by the Local Education Authority. This problem was resolved in the Cambridge area by discussion with the Local Education Authority resulting in information about the training package being circulated to all schools in the area whether or not they had an affected child in their charge and the agreement of a Medication Policy [8]. Teachers were assured of the Local Education Authority's support if they chose to volunteer to support the child as long as they felt that they had received appropriate and comprehensive training to deal with the situation. Discussion also took place with the local representative of the Head Teachers Union, resulting in support from that quarter also. In Independent schools the same issues arise, but the support of the Proprietor is required, rather than the Local Education Authority.

#### *The training package*

The aims of the training package are.

- To relieve parental anxiety by providing training to nursery and school staff, to other family members and to pre-school child care providers.

- To reduce anxiety in nursery and school staff.

- To offer practical advice on preventing a reaction from occurring. This includes advice on school dinners, sharing of food, celebration cakes, art work materials, and pet and bird food. In the case of nut allergy emphasis is also placed on how to identify where and how nuts can be hidden in foods.

- To provide written information on how to identify an allergic reaction.

- To provide written information on the procedure to follow if a reaction occurs. This includes how to summon immediate help from the emergency services and local GP surgery as well as a practical demonstration of how to safely

administer oral antihistamines, and inhaled and injectable adrenaline.

To provide practical advice on the safe storage of medicines as well as safe disposal of any equipment (including needles) should it be used.

To offer information regarding needle stick injury.

To offer advice on the precautions to take when these children are involved on school daytrips and overnight holidays.

In training sessions emphasis is placed on prevention, as detailed below.

Never offer the child any food if you are uncertain of the ingredients.

During times of celebration (e.g. Easter, Christmas and Birthdays) when children often bring food from home, ask the parent of the affected child to supply a packet of 'special' biscuits or cake that the child can have without feeling left out of the celebration.

Consider banning peanuts and peanut butter from the school, i.e. by explaining the situation to other parents by letter and asking for their co-operation.

Examine art work materials carefully; in nursery schools in particular nuts and nut shells are often used in collage work.

Involve the school cook in discussions so that her staff are also aware, especially if the child has school lunches.

Try and observe the child closely at break times and dissuade children from sharing food if they have packed lunches. Several schools in the Cambridge area have been granted funding from the LEA to employ extra learning support staff for up to an hour each day for supervision and observation purposes.

Discourage staff from stigmatizing the child; therefore supervision and observation should be discrete.

If pets are kept in the classroom ensure that the food is of a nut (or other allergen) free variety.

If wild bird feeders are used outside ensure that these are away from where the children have direct contact, i.e. the playground.

Ensure that all staff who have received the training know where the emergency kit containing drugs and instructions are kept. Office staff may also be involved, either being asked to bring the kit or call for assistance. Therefore it is essential that they are familiar with the emergency telephone procedure.

If the child leaves the school premises for any reason, e.g. sports or day trips, the emergency kit should accompany the child. Several parents have provided a small backpack for such purposes.

We do not recommend the use of labels such as 'No Nuts' as we believe this potentially stigmatizes the child, and may result in schools feeling they can continue to have the allergen in the school.

While the majority are allergic to peanuts (these belong to the legume family) it is recommended that the child avoids contact with all nuts, nut oils and nut essences. It is extremely important to realize that nuts can be hidden in foods and that even the smallest quantities of a nut can cause a reaction to occur. For example, one child has only to smell peanuts in a bowl on entering a room to feel a tightness in his throat.

The Anaphylaxis Campaign has done much to lobby the government to change legislation for the accurate labelling of food by the manufacturer. Supermarkets have begun to label foods with bright warning stickers identifying that nuts are present. Most supermarkets supply on request lists of their brand name products that are either nut free or contain a certain nut.

Parents become very adept at reading labels and even the child from an early age learns to ask whether a food substance is safe to eat before putting it in their mouth. In our experience these children are sensible and they appreciate the need to avoid their allergens. One of the tell-tale signs that an allergen has been eaten is a tingling feeling in the mouth and throat accompanied by a sudden desire to spit the food out. Vomiting is also common in young children and this usually prevents a severe reaction from occurring as less of the foodstuff is actually ingested.

Practical issues are also discussed. Although we recognize that allergic reactions are unpredictable in their progression, and may not always occur the same in a patient, it is helpful for staff to have a guide to the type of reactions they might see. We define three types of reaction – mild, moderate and severe. These are individualized for each child. It is emphasized that the groups and symptoms are a guide and that if in doubt about the type of reaction staff should respond to the severest type.

Mild reactions are treated with oral antihistamine. Typical symptoms include itching and urticaria. The child is observed and parents contacted.

Moderate or severe reactions will need either inhaled or injected adrenaline depending on the child's protocol. Emphasis is placed on calling for help via the '999' system. If adrenaline is given, staff are asked to complete an administration sheet, and are told to give this, together with the child's treatment kit, to the ambulance staff. Typical symptoms include respiratory problems and collapse.

Staff are told children must go to hospital if an ambulance is called, even if recovered, as they need observation in case of relapse.

A clear telephone procedure, including details of what to say to ambulance control, parents and GP numbers is provided. Many parents have cellular phones to be available at all times. The decision to purchase these was usually taken around the time of first diagnosis. We do not suggest parents need to be constantly available, as they have a right to a normal life as much as their children.

Delivery of medication is discussed and demonstrated. We recommend that children with injectable adrenaline have two devices in school, both because of the potential need for a second dose and in case there is a problem such as faulty technique or damage to equipment.

#### *Organization of training sessions*

These training sessions last for  $\approx 60$  min, and generally take place at the end of the school day. All staff and parents are invited and parents are encouraged to take part and are asked to describe the child's previous symptoms and idiosyncrasies. At first the sessions were run by two of us (DV & LM) but since early 1996 a community paediatric nurse has taken over the training sessions. We believe that schools are best reassured by training provided through specialists who regularly provide the training package rather than by the school nurse and doctor who may be unfamiliar with the protocol and less able to deal with issues. However, we encourage the School Health Team to attend. This meeting is a good opportunity for close liaison and is beneficial in that all parties know what concerns have been raised and the solutions suggested to solve particular problems. Following each session we write to confirm that the training programme has taken place naming those members of staff who have received the training and demonstrated competence in the practical parts of the session. This letter is copied to the parents and the child's General Practitioner. We frequently offer follow-up sessions for staff who were unable to be present for the initial training session, allowing a further opportunity for questions to be answered. Each school will receive an annual updating session and we have recently trained all our school nurses to deliver the follow-up/updating sessions. This involved a training session and developing a resource pack for their use. Feedback from these nurses suggests that, despite this support, they would not feel competent to provide initial training.

#### *Assessment of value of training sessions*

Our subjective experiences, described below, suggest that these sessions are of benefit. To try and explore this further in July 1996 we sent a postal questionnaire to the parents of 56 children attending 45 different schools (including 15 private schools or nurseries). Replies were received from 41 parents (73%) and 33 schools (73%). From the questionnaire sent to schools replies were received from seven nursery schools, 20 primary schools and six secondary schools.

### **Results**

#### *Assessment of value of training sessions*

Having undertaken almost 60 of these training sessions it is

clear that they are beneficial. By removing from parents some of the responsibility for providing training, their anxiety levels are reduced. Likewise, anxiety in school staff is diminished once they receive information about how to prevent a reaction from occurring. We emphasize that with thoughtful prevention the chances of a child having a reaction which requires the administration of an injection are very small. Schools also realize the importance of prevention and the common initial reluctance to ban food stuffs such as peanut butter at the parents request, is replaced by these requests being taken seriously and acted upon. Anxiety has been reduced even further with the introduction of the Epipen, which is a fully automatic device, pre-loaded with the correct dose of adrenaline for administration by intramuscular injection. The previous device, requiring preparation and with an exposed needle was very user unfriendly and schools were reluctant to accept it. A trainer device (without drug or needle) allows staff and parents to practice the administration of an injection. Staff are amazed at how simple this device is to use, one comment from a staff member typified this, 'Oh, I thought we were going to have to find a vein or something'. Our subjective experiences suggest that these sessions are of benefit.

The background work for the training sessions is time-consuming as the written information concerning symptoms and drug dosages must be individualized for each child (based on a template — a copy of which can be obtained from the first author), discussed with parents to gain their agreement, and then checked with the consultant allergist (PWE) to ensure that all information is correct. Occasionally as a result of the training sessions these written instructions are amended further to take into account particular aspects of the school environment. We recognize that training sessions are both time-consuming and expensive.

#### *Questionnaire: schools*

The major concerns of schools prior to training were lack of knowledge of the condition, anxiety about giving injections (mentioned specifically by most schools) and general issues around medication in schools. All schools except one felt the training was delivered at a convenient time, and all but one felt sufficient time was allowed. All felt the written information (protocol) was clear and that the practical demonstrations of Epipen and inhaler/spacer use were helpful. When asked to indicate the most useful component of training 11% chose the written information, 40% the practical demonstration and 49% the question/discussion part of the session. Following training only three schools still had concerns about injections, as opposed to 24 prior to training. The overall level of concern was lower after training, with every school reporting that their anxieties had been

addressed. Most schools still had some concerns, particularly mentioning preventing reactions, school trips and personal indemnity. There was a clear recognition by schools that the problem could not be totally solved, but that the existence of a clear protocol, supported by training, was helpful. Most schools felt annual updating was adequate, although five (16%) would prefer a termly update and 10 (32%) mentioned the need to train new members of staff. Three schools had been successful in obtaining extra learning support assistant time to help with observation of the child at breaktimes.

#### *Questionnaire: parents*

Forty-one parents replied to the questionnaire. This included the parents of three of the eight children who only use adrenaline via an inhaler. Like schools, most parents felt annual updating was adequate, although seven (17%) would prefer a termly session and 10 (24%) mentioned the need to train new members of staff. Thirty-two parents (78%) were able to attend the training session, and all felt that it met their needs, except for one parent who felt more time was needed. Parents who did not attend usually had difficulties with work commitments although two thought there were not invited (this is probably incorrect as all sessions were arranged after contact with parents). However, it was striking that almost all parents still had anxieties about their child at school, ranging from the problems created by staff turnover, school meals, children swapping food, the need to maintain a vigilant approach, anxiety about recognition of symptoms to concerns about change of school. Parents generally felt training for schools was helpful, but it did not completely resolve all their anxieties. However, this needs to be put in the context of their level of concern prior to the training sessions. Quotes in reply to the question: after your visit to the Allergy Clinic what were your main concerns include 'how a child of 8 became of such interest when no medical person had believed me before', 'what to do about school', 'how will school cope', 'I do not want her to feel different', 'that she was going to find it increasingly difficult to lead a normal life', 'would school accept responsibility', 'I had heard stories of schools not wanting to accept children with serious allergies'.

#### **Discussion**

The survey shows that training is successful in dealing with the anxieties of schools. Parents continue to be anxious, but find the provision of training in schools is helpful. It is difficult to assess if this programme reduces the number of reactions that occur. We know that one child, with milk allergy, has had an anaphylactic reaction in a nursery. Successful Epipen treatment by staff resulted in prompt recovery. One other child has used an adrenaline inhaler following inhalation of peanut vapour from a bowl of nuts. All other children have remained successfully in their local school, with occasional use of antihistamine or inhaled adrenaline for minor allergic symptoms. The presence of children in school needing access to adrenaline is no longer perceived as a problem in our area, rather as another type of child with a special medical need.

To adequately support these children is complex and time-consuming and requires close liaison between clinicians, schools, families and those responsible for policy-making. Failure to do so may result in severe disruption to family life and schooling. It is essential that children are expertly assessed prior to the prescription of adrenaline injection and that schools and parents are well supported. This results in children leading a normal life unstigmatized or labelled by their problem, yet safe.

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