

ALLERGY STORIES

THE EXPERIENCES OF PARENTS, CHILDREN
AND TEACHERS WHO ALL HAVE A ROLE IN
MANAGING ALLERGIES IN SCHOOLS

COMPILED BY BENEDICT BLYTHE FOUNDATION



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FOUNDATION



FOREWORDS

As a practising paediatric allergist, I hear stories from my patients every day about their experiences at school. Some of these can be truly inspiring – how staff and pupils have worked together to ensure there is true inclusivity, with genuine efforts made to ensure that fun activities include somebody despite it requiring extra effort to do so....and it is always hugely appreciated. Sadly, I also get to hear how a lack of thought and forward planning has led to truly traumatic events and near misses that leave lasting trauma, where parents are left feeling terrified about letting their child go to school.

Whilst we have made real strides towards more effective management of food allergy through science and research, we have done far too little to improve the safety and inclusivity of children with food allergies at school. To achieve this we need evidence-based policy change, but to get this evidence we need to move out of the traditional narrow quantitative research paradigms and do more qualitative work. We need to be listening to our patients' stories – about safety, about inclusivity and about how our patients' voice can help. One thing I have definitely learnt from listening to patients is that schools are safer for children with food allergies when they adopt a whole school approach – where pupils (and not just the ones with the allergies), parents and staff come together to learn about the challenges of food allergies, to work together to come up with policies and process that are both workable and effective. I very much hope this document is a true catalyst for change.

PROFESSOR ADAM FOX, TRUSTEE AND PAST PRESIDENT OF BSACI

As a teacher and parent of a child with allergies I understand both types of worry. As a parent you have to have trust in something you can't see – that behind the scenes there's knowledge, systems and processes to keep your much loved child safe.

As a teacher I know the weight of responsibility in protecting children in a chaotic, busy and ever-changing environment. I am so pleased this collection of stories helps us to understand the experiences of all sides involved in managing allergies in schools better.

I hope we learn from both the positive and negative, and it spurs us all on to find brave ways to do things better to serve pupils with allergies and make them feel safe and included. It's such important work.

LYNSEY, TEACHER AND MOTHER OF A CHILD WITH ALLERGIES

INSIDE

FOREWORDS	P2-3
BEING INCLUDED	P5
BEING HEARD	P23
BEING SAFE	P37
ABOUT ALLERGIES IN SCHOOLS	P53
METHODOLOGY AND APPROACH	P54

WE OFTEN LISTEN, BUT DO WE HEAR?

My son, Benedict, died from anaphylaxis after collapsing at school when he was just five years old. Following his death, parents of children with allergies reached out to me and my husband to share their stories.

Sometimes these were stories full of hope – they wanted to tell us how good their school was, they told us examples of collaboration, of where a teacher had gone out of their way to give their child a treat that matched the other children, and where they had made special provisions to calm the worries of the parent or child.

Often, they were stories of pain and fear, where parents were reaching out because they were compelled to after seeing their worst fear written down. They spoke of ambulance trips, near-misses, children not being able to safely return to school and of not feeling like they had a voice in making things better.

We also heard from teachers, who felt the weight of responsibility and either wanted to share how they go out of their way to think of ways to help children, or how they felt out of their depth and unsupported.

We founded Benedict Blythe Foundation in 2022 with an aim to protect pupils with allergies and remove the postcode lottery of receiving inclusive and safe allergy care. Our Action Paper outlines the research, guidance and legislation relating to allergies in schools. What we realised we were missing though, were real stories, from those who have to navigate the impact of allergies and what it means for their loved ones and those in their care every day.

The little research that has been done into allergy management includes some exploration of parents' lived experience. Mostly, these are dissected for data, and so the impact is lost. This book of stories presents a number of perspectives, all parents, school staff, teachers or caterers with a role in allergy safety in schools. Reading their stories helps us understand the experience of being involved in school allergy management and awareness, and gives us all the chance to find ways to make things better.

Our work is carried out alongside Sheffield Hallam University, where a longer-term study is being undertaken as part of post-doctoral research. Our methodology and approach can be found towards the back of this book, but we have carried out interviews, written submissions, workshops and drawing activities to arrive at this collection.

These are the voices of real people, and their language is kept as true to their authentic voice as possible.

Names, locations and examples may have been slightly altered to allow those submitting stories to remain anonymous, and while there may be examples that strike fear into the hearts of parents and teachers, there are also wonderful examples of care, hope and joy that give us a sense of what is possible.

This book is not meant to be a passive document; it is an invitation to engage, learn, and reflect. As readers, researchers, practitioners, and policymakers, we have the collective responsibility to honour these narratives and to create a society that values the voices of its diverse

members. By delving into these lived experiences, we hope to spark meaningful conversations, inspire change, and promote empathy and understanding among individuals from all walks of life so that they better understand what it's like to be, and to care for, a child with allergy in a UK school.

We are incredibly grateful to the families, teachers, caterers and children who have entrusted us in telling their stories for them and for their willingness to gift them to the world, so that we can all build a better understanding and empathy of what often goes unseen and unnoticed in the lives of those with allergies.

Helen Blythe

Founder & Director, Benedict Blythe Foundation
and mummy to Benedict and Etta

**THERE ARE
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At lunchtime, I always have to go into the hall first. I don't get to sit with my friends because I have to sit at the end of the bench.

I like that I always get to go in first, but I wish I could sit with my friends. Sometimes they'll be laughing about something and I can't hear them.



BEING INCLUDED

STORIES OF INCLUSION ARE THOSE WHERE BARRIERS ARE DISMANTLED, WHERE CHILDREN ARE GIVEN EQUAL OPPORTUNITIES, WHERE A CHILD FEELS RESPECTED, SUPPORTED AND A SENSE OF BELONGING – EVEN WHERE DIFFERENCES ARE CELEBRATED AND VALUED. THIS SECTION LOOKS AT WHERE CHILDREN WITH ALLERGIES ARE INCLUDED AT SCHOOL, AND SCENARIOS WHERE THEY ARE NOT.

THE COOKIE GIVEN TO HER, WRAPPED UP IN A BAG, AND OH-SO-TEMPTING, WAS FULL OF AN INGREDIENT THAT COULD KILL HER. BUT WORSE THAN THAT, IT WAS SOMETHING THAT MEANT SHE WAS MISSING OUT.

“IT STUNG, MISSING OUT ON A COLLECTIVE SHARED EXPERIENCE OF CHILDHOOD JOY”

The first week of school on the Friday afternoon, all the children were given a little bag. It said, 'well done on your first week of school' and they were so happy and proud. Inside each one was a cookie from the PTA.

It wasn't just a cookie though, it was one of those posh ones where they stamp a message into the blue icing and it had the same message on it as the bag, with a little rosette shape printed in. They were lovely, and so thoughtful. They'd even gone to the effort of writing the allergens in little handwritten labels on the back of each cookie.

My daughter's classmates all started munching these as they walked down the path from school holding their parents' hands, but my daughter couldn't. She couldn't because they contained egg, and she was allergic to egg. The cookie given to her, wrapped up in a bag, and oh-so-tempting, was full of an ingredient that could kill her. But worse than that, it was something that meant she was missing out.

I remember the feel of her little hand in my hand. The giggles, the gleeful shouts of her friends yelling 'look! It's made my tongue blue!', and the hot tear she dashed away from her small cheek, so no one noticed. It stung, for her as a child who didn't just miss out on something yummy - but on that collective shared experience of childhood joy. And for me as a parent, it was devastating. I wanted to swoop her right up out of that pain, and I was furious that she'd been put in this situation that just didn't have to be.

How do you raise these issues though without seeming ungrateful or emotional? To be honest, I was both.

What I didn't realise then, in that moment, was that this was only the first of thousands of moments like this. As they became more predictable, it didn't necessarily get any easier. One thing I can say though is it's not about the food, it really isn't. It's about safety and it's about fairness and it's about not being left out. I cry each time I tell the story about those cookies.

“MY DAUGHTER’S NEVER BEEN LEFT OUT”

Now and then, children are chosen at my daughter’s school to go to a ‘tea party’. If they’ve done good work that week, they’ll be chosen for that, or for doing something special or working hard. It happens a few times a year, to go have a tea party with the head teacher. It’s a big deal, and all the children want to be invited. The school obviously knew my daughter has allergies, so they’d always go out of their way to email before hand – telling me what they’d got. If it wasn’t suitable, they’d go get something else, or I’d be happy to go and buy something else. It was great, them making sure it was still special for her and that she didn’t miss out, I remember her being so happy when she got to go.

It’s not just the tea parties either, if the teachers are doing food lessons, they email me a picture of all the ingredients. I’ll tell them what she can and can’t have, even though they all know what she can and can’t have, it’s just the reassurance and extra set of eyes. It is useful sometimes because even when you do read the ingredients, you don’t always see the “may contain”, because sometimes they’re quite hidden and if you’re not used to reading for that you might miss it.

For example, one time they were doing a lesson on Judaism, and there was just no bread to be found that didn’t have “may contain sesame”. I don’t expect the teachers to hunt around for hours on end, I know what it’s like. So, I say don’t worry, I will bring something that’s similar to the product you’re having. So, my daughter’s never been left out. I don’t mind doing the work, and I’m happy they give me the chance to make sure she can join in.

The only thing that did happen once was when she was picked for the tea party, they didn’t email the snack through, and it was an ice cream with a “may contain nuts.” And luckily, she saw and just said, I can’t eat that. But if she wasn’t on the ball enough, it could have been worse. They were very apologetic when they realised. But most of the time her school is very good. I also don’t know whether they do that for all parents of kids with allergies or just because I’m so insistent that I need to see it, but that’s what they do for me, and I’m happy with that.

“WHEN TEACHERS BROUGHT IN REWARDS, SHE WAS SENT OUT OF THE CLASSROOM”

No one invited her home for tea, it was a really lonely experience for her at school. When the teachers brought in rewards, she was sent out of the classroom to minimise the risk. To other parents, I’d offer, “I’ll sit outside in the car if makes you feel happier” during playdates. I’ve had everyone over but there were never any play dates for her.

SO, I SAY DON’T WORRY, I WILL BRING SOMETHING THAT’S SIMILAR TO THE PRODUCT YOU’RE HAVING. SO, MY DAUGHTER’S NEVER BEEN LEFT OUT.

“THEY SAID ‘OH, BUT THEY’RE JUST ICE LOLLIES!’”

I’m a parent of a child with allergies, but I’m also a teacher. I do feel that some people at my school don’t realise how dangerous it can be.

Last year we had one boy who was allergic to nuts and after sports day the head teacher gave out ice lollies to all the children, no packaging. I asked if I could see the ingredients. They said ‘Oh, but they’re just ice lollies!’ as if there was no way these could contain anything problematic. I said ‘no – it may say ‘may contain’. The response was ‘well, if it’s just may contain, it’ll be fine!’

It’s hard because I know they picked the lollies so everyone could be included, but it’s still important to check. I said ‘no, no, you can’t just be blasé. My daughter is allergic to peas. You know peas turn up everywhere? Ice cream. Bread. Everything’.

Sometimes people just think, ‘it won’t be in that’ but you would be amazed how often allergens crop up in places you wouldn’t expect. It means teachers and school staff shouldn’t be making decisions about whether a ‘may contain’ is safe or not, but also, they should make the decision to always check.

You’ve got to be stricter. So, at my school we don’t really email parents the ingredients because that’s just not the setup we’ve got, we wouldn’t really be able to do it. But if I have a child with allergies in my class, I’ll either phone the parent, or if they’re there at pickup I’ll take a packet out to them and show them the ingredients, and say ‘we’re having this tomorrow, can your child have it?’ If they say they can’t, then I’ll go out and get something else. There’s not a system in place, that’s just what I do. I think for most of my colleagues we are all doing what we think is best.

THE RESPONSE WAS ‘WELL, IF IT’S JUST MAY CONTAIN, IT’LL BE FINE!’

“I SEE HER TALKING TO HER BARBIES ABOUT ALLERGIES SOMETIMES!”

My daughter is allergic to sesame, and I think some people just don’t think it’s as bad as having a nut allergy, even though it can be really, really serious. We sent my daughter to the same school my son goes to, but it turned out that for some reason, there was hummus on the menu every single week. I work in a school, so I really know how chaotic things can get, but I couldn’t get my head around it. I asked them why they had to put hummus on the menu consistently – it just seems as though it would be easy for something to go wrong. So, in the end, they wouldn’t budge on the menu, and we ended up deciding not to send her there at all.

Now she’s at my school instead. I do feel confident in the school, however, because of her experience, and because of the fact that I work in a school, I’m really aware of how mistakes can be made, and how something really quite minor can end up being a serious, life-threatening mistake.

Of course, it’s still difficult for her, and of course she feels restricted, but sometimes she seems weirdly proud of the fact that she has an allergy. Her friends will be eating something she can’t, and she’ll say: “Ooh, I’m actually not allowed this I have allergies,” with this real sense that maybe it actually makes her a little special. I’ve caught her playing with her barbies and dolls and talking to them about her allergies.

She’s ok as long as she’s not missing out – we try to mitigate that as much as we possibly can, even if it means making tough choices and sending her somewhere different from where we’d planned.



My school teacher is really cool. Sometimes there's like a party or someone's birthday and she doesn't let them bring in any food that makes me poorly, she tells them what they can bring so everyone gets the same. I really like that. And I love the sweets!



We did a special taste test at school in science and I was so happy because I was allowed to try everything!

“HE DOES WISH HE COULD DO THOSE ACTIVITIES AND HE HATES BEING TREATED DIFFERENTLY”

I JUST WISH THE SCHOOL COULD MAKE SURE THAT HE COULD BE INCLUDED AND FEEL SAFE AND FEEL LIKE HE COULD TRUST THE GROWNUPS MEANT TO PROTECT HIM.

My son's school did a science experiment last year where they got three types of chocolate and melted it to see which type melted quickest. Obviously, he was really stressed out and told them he didn't want to do this. The teacher said 'that's fine', and sent him out into the corridor with a reading book.

He was still really stressed afterwards because they'd been doing the experiment at the tables. He explained to me after that when he came back in, he had to sit down at the table again, where the chocolate had been. No one explained whether they'd been properly cleaned, he was expected to be unconcerned and to sit down as though there wasn't the potential risk of an allergen in front of him. His anxiety was through the roof that week and he was anxious from then on out. He didn't know what they'd do next week.

We've got a deal with the school now where he just doesn't do food-based activities now, because he just doesn't trust them. That's an agreement he wanted, but it's hard to know he's missing out.

The teacher phoned up one time and said they were doing this activity with milk, so he went out and did some reading with Year 1 just to get him out of the classroom. And after all that, then they did the activity right at the end of day so he didn't go back to the classroom, he just went home.

It breaks my heart to have him miss out on some of the fun, but that's the only way to keep him confident in school, because he'd lost complete and utter faith in that member of staff because they put him in so many situations where he did not feel safe. Avoiding the situation is the only way he can manage his anxiety, although I know it's not the best choice.

He does wish he could do those activities and he hates being treated differently, so for him to come up with that, it was very much a safety thing, and our priority was getting him to feel safe. He was having real anxiety, mental health struggles about being in school around allergens. He's chilled around food normally, he cooks at home, we eat out and it's fine. At the after-school club, they have food, he serves the snack. I just wish the school could make sure that he could be included and feel safe and feel like he could trust the grownups meant to protect him.

“THE LITTLE THOUGHTFUL TOUCHES ARE WHAT MAKES SCHOOL SUCH A LOVELY PLACE”

My son didn't actually know he had an egg allergy until it came out of nowhere at school. I don't know how he reached the age of 6 without trying egg on its own, but he did. Then they had lunch that was ham, egg and chips and boom - he reacted out of nowhere.

After that he was given an autoinjector pen, and we made a plan with the school. I remember it being really scary trying to work out what he could and couldn't eat in those early days, especially because I had to trust the school to get things right - but they were great.



There was Children in Need bake sale a week or two later. The school put an email out to all parents asking that they be mindful of my son's allergy and to send in egg-free cakes where possible, and to mark cakes that did have eggs in so they could be put separately.

I got an email from his teachers saying they'd bought a big egg-free cake they'd cut up and to check if I wanted to bring anything else in. It turned out that they set the whole thing up so that it was 'food Tom can have' and then 'the other stuff', so he came in with his friends and got to have a look around and spend his 20ps where he wanted. I never asked them to, they just did it, and they've carried on making sure he doesn't miss out with thoughtful touches like that - it's what makes the school such a lovely place.

My teacher gave everyone a biscuit. I was eating it when they suddenly said 'no! don't eat that! Spit it out!'. So I spat it out. It had soya in which I can't eat. It was a bit scary having everyone shout out at me. I wasn't poorly or anything, but the teachers were really careful checking all the ingredients after that. They'd make another grown up look at the packets before they gave me anything.

I DON'T KNOW HOW HE REACHED THE AGE OF 6 WITHOUT TRYING EGG ON ITS OWN, BUT HE DID. THEN THEY HAD LUNCH THAT WAS HAM, EGG AND CHIPS AND BOOM - HE REACTED OUT OF NOWHERE.

“HE’S LOOKING OUT OF THE CORNER OF HIS EYES AT THE PANCAKES FLYING IN MID-AIR WITH A SORT OF LONGING”

We love pancake day in our house, it’s one of those holidays where the children ask about it for weeks and weeks in advance.

My son’s got anaphylaxis to eggs and to dairy, so we’d spent years perfecting allergen-free pancakes. I don’t like to brag, but I like to think you wouldn’t be able to tell the difference.

On pancake day I was at work in the day, and I get a ‘ping’ on my phone from the app the school use to send us photos and messages. I swipe the message open, and I see my son’s happy little face in a line with his friends. It says at the top ‘children enjoy a pancake race’. I can see a couple of parents have already commented with hearts and thumbs ups, and a couple of the children have pancakes tossed in mid-air in the picture. It’s very sweet.

Then I notice my son’s frying pan. It’s empty. And then I look again at his smiling face, and he is smiling, but he’s looking out of the corner of his eyes at the pancakes flying in mid-air with a sort of longing. And I burst into tears right there at my desk. My poor little boy who is having to run a pancake day race, pretending to toss an imaginary pancake because no one asked me if I’d mind bringing one in – which I would have done, absolutely.

At pick up I ask him about it, and he says they had a fun pancake day race, and the other children got to eat pancakes afterwards. He said he couldn’t have one, so they gave him a digestive biscuit instead. That night I told my husband about it and cried again. I can only imagine what it feels like to be left out, forgotten, forced to be different.

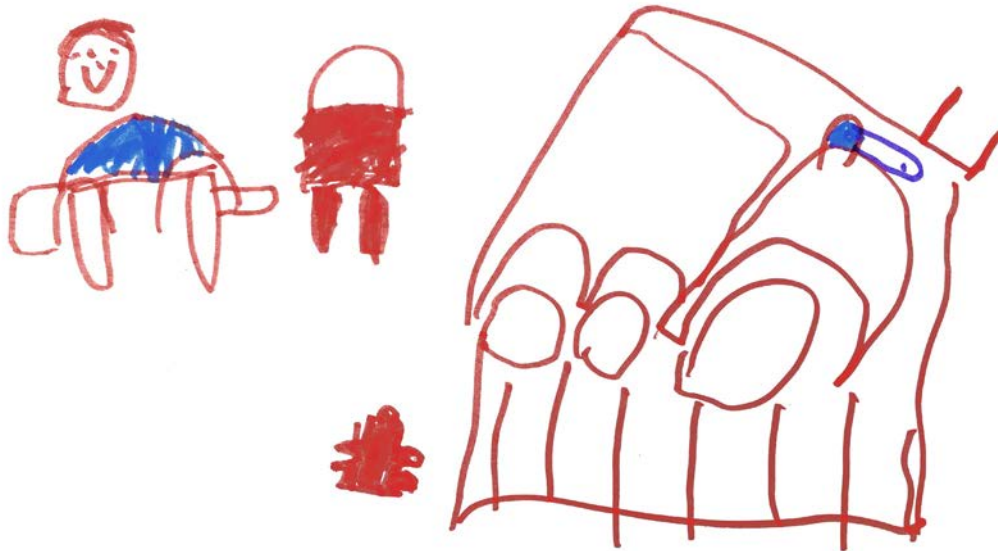
The next day I email the school to complain. I get an acknowledgement, and then time passes. A year later it’s pancake day again. I don’t want him to feel disappointed, but I also can’t change what might happen. So, on the way to school we play a fun game of ‘toss the imaginary pancake’, and giggle about what his invisible pancake might be made of. It still breaks my heart, but I feel ready for it and can help him be ready. Except when I pick him up, and after all the hugs and requests for snacks, I ask him what he’d done that day

...HIS THUMB IS RESTING ON THE BATTER OF THE PANCAKE, AND I FEEL SICK. THE SORT OF SICK WHERE YOU’RE LOOKING AT A PHOTO OF YOUR CHILD IN A MOMENT THAT COULD HAVE COST THEM THEIR LIFE.

he tells me ‘Mummy, I got to toss a real pancake this year’. I’m amazed, and so grateful my message landed. I couldn’t believe that someone had gone to the trouble of making him his own safe version (there weren’t any for sale pre-made in the supermarket at that point) and it made my heart glad that someone had put the thought into keeping him included.

When I get home there’s a message on the app from his teacher. It tells me that they had a pancake day race again and that they’d put a pancake in his pan that contained milk and eggs but asked him not to touch it, so that he could be included in the race like I’d wanted. They include a photo of him in the lineup. I can see from the picture that where his hand is gripping the handle, his thumb is resting on the batter of the pancake, and I feel sick. The sort of sick where you’re looking at a photo of your child in a moment that could have cost them their life. It wasn’t what I’d wanted or what I’d asked for, for him to be exposed to something that could cause him such harm just so he didn’t miss out on a childhood moment.

I remember the feeling so vividly, of not being understood, of feeling like I was being unreasonable and difficult. The message felt like they were saying, ‘well this is what you wanted, wasn’t it?’ Since then, I call him in sick every pancake day. I take a day off, and we stay at home and watch TV and eat a big pile of pancakes for lunch. I didn’t raise it with the school, and I know I should have, but I couldn’t face it. It felt easier to just avoid the situation and to make happy memories at home, safely, instead.



I sit in the library in between my classroom and the lunch hall at lunch time. I get to choose two friends to sit with and one of the grownups sits with us too. I have my packed lunch there, but my friends have their school meal. When all my friends are used to carrying their trays, then I might be able to eat with them. There are 90 children in my year, and they can be a bit messy so I have to stay out the way until they all know how it works better. I call lunchtimes my [tea party] because I get to sit somewhere different and my friends have our own special set up.



The children with allergies have to all sit together away from the other children. I'd like to be able to sit with my friends.

“FOR THEM TO PROVIDE FUNDING TOWARDS IT JUST PROVES WHAT A FANTASTIC SCHOOL THEY ARE”

The whole school washes their hands after lunchtime so that they can all play together. They weren't a nut-free school, but they are now, and I even emailed them about egg mayonnaise on the menu and they said yep, it's on our agenda. Beth carries the Autoinjector around with her everywhere she goes, all the teachers have been trained to use it and to recognise the symptoms. They really have gone above and beyond.

You know the free school meals? Obviously, we didn't have that because it's far too risky with all the allergens. So, I mentioned that there's nothing there for them, and the school has actually provided us with voucher so we can go buy packed lunches for her. Obviously, Beth's stuff is £3 for a loaf of bread, and it's not a big loaf, so for them to provide funding towards it just proves what a fantastic school they are.

“HE'S HAD SOME LOVELY EXPERIENCES AT SCHOOL, AND HIS FRIENDS ALSO LIKE TO SEE THAT HE'S INCLUDED AND THEY'RE ALL GETTING THE SAME THING”

My son's a really interesting kid, loves to read, but also very sporty. Extremely sarcastic. He goes to wraparound care, a before and after school club, and they are awesome. They made sure that anything they do serve doesn't have milk in it, but also make sure he can join in with anything they're doing. If they do any baking activities, it's always allergy friendly. He feels ridiculously safe there and I'm very grateful.

School very much depends on who his teacher has been. Obviously, we can't ask for it to be a milk free school – it's a primary school, that's just impossible. When he was in Reception, they do free milk for under-7s, so that was really stressful for his teacher. My son was really positive about it though, and a lot of that came down to how it was handled.

In my son's teacher's classroom, the children would all pour their own milk. Initially when we talked about my son and his allergies she said 'we'll just stop doing that', but we explained that it's important he learns how to survive around milk and be safe. He's never going to be able to avoid milk in the world, so learning how to be in the same place as others having milk and pouring it felt important. She managed it by setting up a safe area so that the milk was always in that one area and never left it. The children all had to wash their hands before and after they left the area.

The biggest thing for us was that she really educated the children on why milk was so dangerous for my son. So he was really, really safe in reception. His teacher understood and was vigilant, but also ensured his peers were too. You'd think it would have been his worst nightmare having milk poured daily around him, but because of the way his teacher handled it, he was fine with it.

He's had lovely teachers at school who have done things like making sure when advent calendars were given out that he had a milk free version. He's had some lovely experiences at school, and his friends also like to see that he's included and they're all getting the same thing.

“EVERY TIME THERE’S A BAKE SALE, I’M FILLED WITH DREAD”

When I had my first child and he went to school I never really thought about bake sales. They were just another thing I had to find 50p or £1 coins for, and where I’d end up making some 10pm cupcakes from a packet.

My daughter is 7 years younger than my son and when she went to school things felt very different because she has a severe milk allergy that saw her in hospital several times as a baby and meant I’d had to administer her autoinjector pen twice in the summer before she started school.

You don’t realise just how many bake sales there are. In her first term alone there were three! The first one I was assured they’d keep an eye on her and she wouldn’t be able to buy anything that wasn’t safe. When I picked her up at the gate the teacher caught me just as I was walking away. She told me there hadn’t actually been anything she could eat, so they’d taken her 50p and given her an apple instead. An apple! I knew there were safe cakes, I’d baked her a whole batch of dairy free cupcakes.

Apparently they’d let the children in in batches, and she’d gone in the final batch which meant the children had bought up all her cupcakes. The next time I made a couple of types, told the teacher, asked them to make sure she got them. I felt I’d done everything I could, and I knew they were looking at me like I was crazy obsessing so much over my child getting a cupcake. I pick her up and immediately ask ‘did you get a cake?’ and she says ‘yes mummy I did! A cool green one!’ Now, I didn’t bake any green cakes so I paused and opened her bag and there was a green cupcake covered in sprinkles that was NOT one of mine.

I marched up to the school and said ‘what’s this?’ They said it wasn’t one of mine, but they felt it would be ok. They said ‘it said it was gluten free, so we thought it would be ok’. I was livid, but you don’t want to look like you are. It’s this really odd thing where you want to shout right at them that she’s not allergic to gluten, she’s allergic to milk. That milk can kill her. That this isn’t a game. But I calmly explained, like I always do, and they looked sort of calmly surprised that cakes containing milk but not gluten would be an issue for her, and said ‘well we’ll know for next time’.

I could probably list ten or fifteen more bake sale experiences, and even when it’s gone OK it doesn’t mean I don’t have the fear. I now buy or bake a tonne of cakes each time, I have to remind the staff, prep my daughter, it feels like a whole thing each time. Each time I get the email saying ‘bake sale on Friday’ my heart sinks and I’m full of dread.

IT’S THIS REALLY ODD THING WHERE YOU WANT TO SHOUT RIGHT AT THEM THAT SHE’S NOT ALLERGIC TO GLUTEN, SHE’S ALLERGIC TO MILK. THAT MILK CAN KILL HER.

“IT SPOKE TO MY WORST FEAR AS A PARENT – THAT I WOULDN’T FIND A SCHOOL THAT WE FELT HE COULD BE SAFE IN”

When we were applying for a preschool, we applied to the local one opposite our house and they offered my son a place. When we went round to talk about his food allergies, they rang me up afterwards and revoked the place. Because we were applying for the place after his third birthday, they said they didn't have a statutory obligation to take him, so they said they didn't feel they could accommodate his food allergies. I was furious. Not only is this discriminatory, but it spoke to my worst fear as a parent. I was worried I wouldn't be able to find a school that we felt he could be safe in, and they said, 'yep, no we can't do that!'.

It made me really anxious about trying to find a school that would be able to take my son and he would feel confident, and then I would feel confident and then we'd all feel okay. This wasn't a good start.

He got offered a place at a different school, but their reaction could not be more different. I was a little hesitant to tell them about the food allergies but when I did, they said, 'that's no problem at all! Come in, we'll talk it all through with you.'

From the very first moment, they weren't dismissive at all, it was very collaborative. They got to know my son and they had clear protocols in place, and they were willing to change them to make sure he was accommodated. So those were two massively contrasting experiences, and that was before he'd even stepped into a classroom. I've been very happy with his school. There have been some incidents but overall, I'm really happy with how they've handled it – I don't have the same anxiety that a lot of other allergy parents do around every mealtime.

It goes to show though that whilst there are some schools which manage allergies and inclusion so well, there are others still waiting to exclude children with allergies, whether that's because it's hard or because they are scared which is just so wrong.

THERE ARE OTHERS STILL WAITING TO EXCLUDE CHILDREN WITH ALLERGIES, WHETHER THAT'S BECAUSE IT'S HARD OR BECAUSE THEY ARE SCARED WHICH IS JUST SO WRONG.

“I AM SO GRATEFUL THAT THE SCHOOL ARE TAKING THIS SERIOUSLY”

I asked my son if he'd like to draw a picture of what it's like having allergies at school, but he got upset when I mentioned it to him. He said it scares him to think about it because he thinks he'll be given milk whenever he thinks about it. He had a spate of reactions at nursery earlier this year requiring his AAI which left him quite anxious.

So far though his school have been excellent. We have tried to explain to him why sometimes he does things differently but he doesn't like it. He does now have school lunches but I always tell him what he is going to have on the morning (I actually plan to make little cards for him to show the dinner lady to

make sure he gets the right plate). He sits on the end of the table, 'protected' by non-anaphylactic allergy children, but the rest of the class are mixed up daily at lunchtime to socialise. The other allergy children are not (yet) his friends. This makes him sad.

He used to collect his lunch from the hatch with his peers, but this was changed when the teacher realised that quite often children would spill custard where his tray would pass through. He is now the only child to be served at the table. This makes him sad.

The free milk is given out at the end of the day as they leave school. He

is kept to the back of the line every day to make sure nobody drops their milk and it splashes him. This makes him sad because his friends always run to the front of the line.

The school are doing their utmost to keep him safe but it makes me feel sad too that he knows he is different, and at risk of harm if he doesn't do these things that isolate him. Of course I would choose this approach every day though. I honestly think the only way to make a safe allergy school is to ban at least the allergens that can cause anaphylaxis. He only has a milk allergy, but they cater for him daily and are also nut free. How hard would it be?

I HONESTLY THINK THE ONLY WAY TO MAKE A SAFE ALLERGY SCHOOL IS TO BAN AT LEAST THE ALLERGENS THAT CAN CAUSE ANAPHYLAXIS.

“THOMAS AND HIS FRIENDS AT SCHOOL ARE ALWAYS LOOKING OUT FOR HIM. THEY'VE SEEN HOW SERIOUS ALLERGIES ARE”

I think allergies can be really tough on Thomas because he's such an active kid. He loves to run around, he loves sports. Sometimes he'll find it a bit difficult to concentrate after he's been to play football and he's back in class, and sweaty. The eczema can get really bad sometimes. Sometimes he'll be red and raw from head to toe.

He couldn't wear shorts for two years because it was so bad. It just felt horrible because you just want to let him be a little boy. Sometimes he'd get a bit irritable because he felt so uncomfortable all the time, but he does feel a lot better now.

He can always be so thoughtful too, bless him. I don't want him to stop joining in in activities, and he knows how hard it can be for me to remember everything all the time! If we're going away, he'll ask me if I've got his medication, if I've got his asthma pump, he's taken it off my hands a bit.

His friends at school are also absolutely amazing. I'll see them all come out of school together, sometimes with a few sweets, and one of them will ask him if he can definitely eat it. And these are young boys! They take it really seriously because they know how bad things can get if it goes wrong. They've seen him become really unwell. It makes such a big difference.

Piggy Party



When it's your turn to go to piggy party it's because you have done something good in class. I had to make sure I could have the food before I eat it. I get to have the same food as everyone else but once they forgot to check with my mum and I couldn't have it.

At lunchtime the other children get the good puddings and I only get fruit. They had jelly and ice cream one day, but they weren't sure if it would be safe for me so they just gave me apple and orange bits on a stick. It wasn't very good.



THE WAY THE STAFF LOOKED AT ME WHEN I SAID HE WOULD HAVE SCHOOL DINNERS – IT WAS AS IF TO SAY, “YOU STUPID WOMAN.” THEY SAID IT WAS TOO DIFFICULT TO CONTROL BECAUSE OF CROSS CONTAMINATION.

“HE HAD TO MAKE GINGERBREAD MEN OUT OF PLAYDOUGH IN A SEPARATE ROOM”

The whole thing has been really frustrating. As soon as Tom got his place at school, I asked if I could have a chat with teachers and the cook to come up with a plan. He's got so many allergies. They said they'd check it out over the summer holidays. I literally heard nothing. I was hoping he'd be able to eat school dinners with the other kids – instead he's been made to feel so different from everyone else.

We've done a lot of work to make him feel more confident, to teach him about his medicine, to show him that it's not the end of the world. The way the staff looked at me when I said he would have school dinners – it was as if to say, “you stupid woman.” They said it was too difficult to control because of cross contamination. At that point I did stand my ground. I said that I know it will be tricky to work out what he needs but I want him to be included and to have that experience. I was so upset.

I do feel every time I see the teachers now that they don't want to speak to me. I'm the difficult one. At first, I thought they wanted to keep him safe, now I think they just don't want to provide him with anything at all. They told me when the children were being offered fruit that they would rather I brought it in myself as they were worried about what it might have touched at school.

One day, I was told all the children were going to make gingerbread men at school, which contain eggs. I asked them what Tom was going to do. I offered to bring in alternatives, different dough for him to make some and they said they still weren't sure.

So, he had to make gingerbread men in a separate room – out of playdough. I was in disbelief. I want my son to be safe. I know that that's the most important thing –

but is too much to ask for him to feel looked after and feel included too? What about how I feel, and how my son feels?

People don't think about all the anxiety allergies cause. It's something that needs a bit of consideration. I just want them to see how wonderful he is, how caring, and not just as the difficult allergy kid.



I went on a school trip in reception and I was allowed to bring a packed lunch. My mum was scared that I would share food, so I promised I would only eat my food.

“IT’S SO SCARY BECAUSE IT’S LIFE THREATENING AND IT CAN HAPPEN IN OUR CARE”

There’s just not enough funding to have individual minders, extra staff help per person, for a one-to-one person in class. We just don’t always have the resources. When we have severe allergies in a group, the children have to sit on different tables with a member of staff, and we have to provide that for their own safety because we’ve got no choice. We encourage handwashing anyway, but we really have to make sure everyone does it and make sure tables are washed down so that anything touched has been cleaned to avoid cross contamination. There was a lot more we had to do to ensure that child was safe.

We can’t exclude him from activities just because of his allergies, but obviously, things happen – staff sicknesses, there’s more SEN children, so unless children with allergies are given the funding, we can’t make sure the children with those needs are kept safe all the time. There were times a boy needed extra attention and we didn’t have the staff to provide it. And it’s so scary because it is life threatening and that can happen in our care. We haven’t got the funding nor support in early years to have a higher ratio of staff to watch these vulnerable children, because it’s life threatening. We’ve got 30 children, and then if there’s 5 or 6 with allergies, and 5 or 6 special needs children, and only 3 members of staff on lunch, it’s just not enough.

If we told the funding team that we’ve got a child with severe allergies, they say “yeah, and...?” If they’ve complex medical needs, which is like a child with epilepsy, or in a wheelchair, then yes, but not just for allergies. They wouldn’t even listen to us. We struggle to get funding for children with special needs, let alone allergies.

It seems to be more and more children with allergies every year. The children seem to be a lot more sensitive these days to a lot of things and they can come out of nowhere. We have loads of experiences with this at our school. One child must have touched something, and his eyes and his hands started to swell, but it was an unknown allergy to the family. They weren’t aware of him being allergic to anything. So sometimes it can be the first time an allergy appears.

We had a child last year who was allergic to several kinds of plants, eggs, she got severe eczema. They couldn’t pinpoint what was causing her skin flareups. The mum had to really advocate to get a test through the NHS and they did get it in the end, but it was a push. Parents are unequipped if they can’t get that testing through the NHS and it can take so long for them to get answers, so it sometimes feels like we’re working blindfolded.

WE’VE GOT 30 CHILDREN, AND THEN IF THERE’S 5 OR 6 WITH ALLERGIES, AND 5 OR 6 SPECIAL NEEDS CHILDREN, AND ONLY 3 MEMBERS OF STAFF ON LUNCH, IT’S JUST NOT ENOUGH.

THERE'S NOT ENOUGH TRAINING FOR PARENTS FOR ALLERGIES. WE TELL PARENTS, "YOU CAN'T BRING THIS IN" BUT THEN THEY DO ANYWAY, EVEN THOUGH IT COULD BE LIFE THREATENING TOWARDS ANOTHER CHILD.

“THERE WAS A BOY'S BIRTHDAY AND WE MADE SURE TO BRING IN CAKES HE CAN HAVE. HIS MUM WAS SO GRATEFUL”

We've never had to administer an epipen here, but we've had the training, and we have children who have AAls, but we keep it so we've never had to use them. We have a lot of asthma sufferers as well, and we administer inhalers throughout the day.

There's not enough training for parents for allergies. We tell parents, "you can't bring this in" but then they do anyway, even though it could be life threatening towards another child. We think, 'I know your child likes it, but we can't risk a child's life for just a piece of food'.

Some parents don't understand the repercussions of allergies because they haven't been exposed to it, their child doesn't have it, or they don't know anyone with allergies. There's not enough education as a whole in that older generation. For the people who aren't in school industries or don't work with kids, they just don't know what to do. We have to speak to parents all the time, at least one parent every single year, explaining it from our side because they don't understand.

We put up a sign as well, like they do on the airplane, "no nuts on the plane" because we've got someone with a severe nut allergy. We send an email round to all the parents explaining that as well. So, there can't be anything like that in lunchboxes. But then we've got parents who want to bring in cakes for a birthday, and we've got to give them information on what cakes they can buy, what cakes they can't. We can't accept cakes from home because obviously we don't know what they put in it. So, parents have to buy it from the shops so we can see the ingredients.

We've got one little boy at the moment and he's undergoing allergy tests, and mum is always really grateful for our work and what we provide for him. There was a birthday one time and we made sure to bring in cakes he can have. His mum was really grateful. She's always checking in with us, we're checking in with her. She's a parent that's very on-board, but we don't have lots of parents like that.



I told my teacher that I felt a bit poorly one time after lunch. A girl in my class had been sick with a tummy bug that week, so she told me if I was going to be sick to let her know but she let me go outside to play. I started to feel really poorly and my friend ran to get another grownup but couldn't find anyone, the teacher watching the playground was behind a wall. So she had to go into the school.

When the lady from the office came, I was all wobbly and then I had to be on my own while she ran to get my pens.

It was scary, but I'm OK now. It was funny seeing the grownup running, they don't normally run! It was just annoying though because I did tell them I didn't feel OK.

BEING HEARD

STORIES WHERE VOICES ARE HEARD ARE THOSE WHERE CONCERNS ARE ACKNOWLEDGED AND ACTED ON, WHERE OPPORTUNITIES FOR SHARING ARE CREATED, AND WHERE UNDERSTANDING GROWS THROUGH COLLABORATION. THIS SECTION LOOKS AT WHERE CHILDREN, PARENTS AND TEACHERS ARE HEARD, AND SCENARIOS WHERE THEY ARE NOT.

“IT’S AN ALL OR NOTHING APPROACH”

It makes me feel bad, like I’m really moaning when I have to contact school to query things, but I just want them to understand. I don’t want to stray too far from discussions about food, I want them to take me seriously for that. But it means I don’t tackle the school about any improvements I’d like to see – I want to see my son in a play, a nativity, more extra-curricular activities offered, but I don’t want to deviate from the message about his allergies in case they forget or I’m considered a trouble-making parent.

My son is six years old and in Year 2 now. He’s allergic to milk, eggs, beef and lamb as his confirmed IGE allergies. Fruit and veg causes him reflux and he goes really hoarse. He’s been on Cetirizine twice a day since he was four month’s old to control his allergies, since my partner kissed him one morning after he’d had milk on his cereal and he had a reaction.

He went to the nursery attached to the school, as I was keen for him to meet children he was going to be going to school with. The play group he’d been at was amazing. I’d met the nursery manager before he started who promised he’d be supervised at all times, especially mealtimes. He’d not been there long when he came home and told me he couldn’t eat packed lunch today because another child threw a cheese sandwich and the grated cheese landed in his lunchbox. More importantly, he’d had to FIND the teacher to tell them – at age 4. I was reassured that this wasn’t malicious, the child throwing the sandwich had behavioural difficulties. But then I was left even more

exasperated, thinking, why did you sit this child next to the one with life-threatening allergies?! He wasn’t being supervised as promised.

Starting school

Then there have been so many incidents since he started at school, especially in Reception. Covid meant that we couldn’t go in for settling in days with the teacher but she phoned me and said she understood and had first-hand experience of severe, life-threatening allergies with her own child. I felt she completely understood and promised to run anything to do with food past me.

I RARELY LEAVE THE HOUSE TO GO INTO TOWN WHICH HAS SUCH PATCHY PHONE SIGNAL – I’D BE TERRIFIED I’D MISS A CALL FROM THE SCHOOL.

But loads of little things happened. On pancake day, I had last minute phone call telling me they were making pancakes in an hour. What can he have? Luckily, I live three minutes away so I had to run to shops to find mix so he could join in. Then she sent me a picture of curry sauce, but the ingredients clearly said that it had milk in it.

The one thing he’d never come into contact with was raw egg – the hospital let him do a 16mL skin prick test but they wouldn’t let him

do the supervised feed, as they were so concerned about the life-threatening risk to him.

At the end of reception, he came home and told me all about how they’d been making gingerbread men – kneading dough that had raw egg in it. I couldn’t believe what I was hearing – they’d let him touch something he’d never been exposed to. It could have killed him.

I pointed all this out to the teacher – at first, she tried to blame me that it should be in his notes about touch and ingestion. We went to the reception to retrieve the notes and it was in the first line. She’s never forgiven me for pointing this out and I didn’t want to get her in trouble, she was leaving anyway. I’m ignored by her now out and about. She even made a joke, saying something along the lines of, “I wouldn’t want to knock your child off.” Nothing about what happened is funny. It was such a lucky escape and she made me feel bad for even bringing it up.

I arranged a meeting with assistant head and told her what had happened – she was shocked. She arranged a meeting with the new teacher for Year 1. With the teacher leaving anyway, the school asked if wanted to take further action. I said no but I’m now left with the guilt of thinking I should have reported her. It should have been recorded as a near-miss. But the responsibility shouldn’t be put onto the parent to report this and escalate it.

You know, if you have a child with learning difficulties, you automatically get a meeting with the new teacher as they move

up. For me, I've had to fight for it every year. I met with the Year 1 teacher to try to avoid mistakes happening again. When I worked at the Harvester, I didn't understand allergies that much. I tried my best but didn't realise how hard it was for people to keep their loved ones safe when they have allergies.

In Year 1 they had a blind crisp test where they blind fold the children in the class to show how hard it is to guess the flavour when you can't see the packet. They gave another child with allergies the cheese and onion crisps as they were so alert to my son's allergies, it's like they forgot there were others in the class. Because the other parent didn't make a fuss, they seemed to forget. That really put me on edge. There was another time I saw a picture of him drinking this smoothie at school. When I asked what was in this, it turned out to be orange. I complained to the teacher who was really apologetic and promised to be more vigilant in future. But it makes me panicky every year when there's a change and I'm worried they'll forget what he's allergic to.

The school took them to Hammerton zoo last summer. But because of their concerns over his allergies, they didn't get any of the children an ice cream. If they'd spoken to me, I could have told them all of the lollies he could have. It's an all or nothing approach.

One of the mums kindly messaged to check which sweets he could eat so he could be included when she sent in sweets for her child's birthday, which we really appreciated. But at Christmas, he was given cards by classmates that contained chocolate coins. That could have been disastrous and it was really upsetting for him on the way home – he really wanted that chocolate coin.

IN YEAR 1 THEY HAD A BLIND CRISP TEST WHERE THEY BLIND FOLD THE CHILDREN IN THE CLASS TO SHOW HOW HARD IT IS TO GUESS THE FLAVOUR WHEN YOU CAN'T SEE THE PACKET. THEY GAVE ANOTHER CHILD WITH ALLERGIES THE CHEESE AND ONION CRISPS AS THEY WERE SO ALERT TO MY SON'S ALLERGIES, IT'S LIKE THEY FORGOT THERE WERE OTHERS IN THE CLASS.

I'm worried they'll forget so he never has school dinner. A bracelet was issued by reception and year 1, but he's not had one in year 2. It's been really hard – I'm quite shy. I've got to do what I can to keep him safe. I should stop protecting other people like the staff. I feel like if I go all out guns blazing, he's going to get a hard time at school. I don't want him to be special and have special treatment – unfortunately he has to.

One time that really makes me upset is when I remember the heatwave they had in Reception. It was a really hot day, heat wave – 35 degrees. School sent a picture as someone had dropped off ice lollies – he was sitting there with a cereal bar and everyone was melting. That really upset me. I wasn't even offered the chance to speak to someone to see if he could have the lolly. I cried, seeing him sitting there, when he didn't have to be left out. They know I'm at home waiting for

them to ring. I'm three minutes away and would have brought a lolly up so he could join in. I saw his little sad face and it still makes me sad to this day.

He doesn't mind being different, but occasionally I feel like why does he have to feel like that? We can't avoid it, I've sent him in with his safe box of treats – but if the teachers have organised it, they could definitely pre-plan more to avoid him feeling left out.

I rarely leave the house to go into town which has such patchy phone signal – I'd be terrified I'd miss a call from the school.

Because I want them to focus on food and getting it right, I want them to take me seriously for that. But it means that I bury any other feedback I'd usually want to give the school; I don't want to deviate from focusing their attention on food.

AT THE END OF RECEPTION, HE CAME HOME AND TOLD ME ALL ABOUT HOW THEY'D BEEN MAKING GINGERBREAD MEN – KNEADING DOUGH THAT HAD RAW EGG IN IT. I COULDN'T BELIEVE WHAT I WAS HEARING.

“THE LACK OF EDUCATION IS QUITE FRIGHTENING TO ME”

This academic year, the receptionist rang up and said we need some more medicine, and as an aside I mentioned the Autoinjectors, saying they can go off as well and need to be checked. The receptionist answered “well I don’t know anything about that.” And she just said I don’t know, I don’t know, I don’t know. We’re just told to put them in a box. I explained what happens if you leave them in the sun. Again she said, well I don’t know. It was that sort of flippant answer that didn’t really fill me with relief. I feel pretty annoyed at the receptionist saying I don’t know over again, the delivery and tone of voice did not put me at ease.

I FEEL LIKE WITH MY DAUGHTER’S SCHOOL WE CAN’T SAY ANYTHING IN CASE WE UPSET THEM.

What someone should have said is ok, thanks for that info, let me check the Autoinjectors and get back to you. There’s no reassurance. The head teacher has a strawberry allergy and said she’d just had her Autoinjector training that morning. She completely understood, and she immediately went round and asked the staff whether they’d checked up on the Autoinjectors and got a lot of non-answers. Someone throughout the year should be responsible for that.

Because the head teacher also has an allergy it makes my daughter feel a bit better about it. She’s quite good at going and finding a teacher and reporting things if there’s a nut or anything. I feel like with my daughter’s school we can’t say anything in case we upset them.

We’ve got special Autoinjector holder for each our kids and we check them regularly, and my husband suggested we buy an Autoinjector pouch. And then head teacher say no, we have to have them in a box so we can see who they belong to. But the lack of education is quite frightening to me.

“IT’S NOT JUST THE MEALS, IT’S THE PAPERWORK, MAKING SURE THE PENS ARE ALL IN DATE”

The allergy admin is a lot. It felt like the old catering team weren’t really prepared to accommodate my son’s allergies, so we decided in conjunction with the school that he’d bring packed lunches for the first part of the year, and I’ve been meaning to call them since the caterer changed, but that’s on me – it slipped by with all the other allergy admin. It’s not just the meals, it’s the paperwork, making sure the pens are all in-date, and then making sure they’re stored correctly and that everyone knows how to use them, and then if you’ve got a playdate or an after-school club – it goes on and on.

YOU JUST LIVE ON A LEVEL OF ANXIETY THAT NOBODY UNDERSTANDS UNLESS YOU'VE GONE THROUGH IT. I HEARD THE AMBULANCE GOING THROUGH THE VILLAGE THE OTHER DAY AND MY BRAIN SAID "OH, THAT'S FOR MY DAUGHTER."

"SCHOOL WAS THE FIRST TIME I'D BEEN EXPOSED TO WHAT IT'S LIKE WHEN SHE'S NOT WITH ME"

Even now she pretends that she can read, and she looks at labels and says 'oh mummy, I can't have this', and she makes sure all her friends wash their hands. She's just that kind of character – she's only just turned four and she sticks up for herself. The allergies brought that out of her because she doesn't want to be ill or poorly, so she takes it upon herself.

School was the first time I'd been exposed to what it's like when she's not with me. When she was at preschool we had a massive number of meetings, and after a few months I saw how well they were taking care of her, and the anxiety went down a little bit. But every time the school number came up on my phone my heart rate went up, thud-thud-thud-thud, and every time I expected to get the call like, "you have to come in right now."

You just live on a level of anxiety that nobody understands unless you've gone through it. I heard the ambulance going through the village the other day and my brain said "oh, that's for my daughter." It's just what you live with and what you get used to when you have a kid with such severe allergies, especially since you know the worst has happened before to other families. And then you have to hold all that stress and try to not let on to your child that you're so anxious because you want them to live their lives. My daughter is quite good about it all – she just gets on with it.

When we were looking at primary schools, I told the headteacher about her allergies and she just took in the knowledge as if it were the most normal thing in the world and was able to explain in detail how they'd care for

her. But when I was looking for a preschool, some of them just said nope, we can't keep your daughter safe. And while I appreciate the honesty, I don't like that so many places are unwilling to accommodate, to know how to behave around other children with that kind of thing.

"EVERYONE'S DIFFERENT, YOU CAN'T COMPARE YOUR EXPERIENCE TO ANOTHER."

At junior school, we asked what their plan was. I got in touch with the school nurse who didn't know a lot. She wrote the care plan, but no one looked at it. In the school gardens, they had peanut and hazelnut bird feeders on the floor. She was just told to stay away from it. I've had to raise any concerns in a really friendly way. Kids are sometimes cruel and curious, so I was worried the nuts would be thrown at her.

The teacher had a nut allergy so I was reassured she got it. But one day my daughter came home with her lips red and swollen and said she'd made rice chocolate Krispy cakes. On the box, it clearly said 'may contain nuts'. When I put this to the teacher, explaining she was airborne and touch sensitive, the teacher said, 'oh but I can have them, it should be fine'. Everyone's different, you can't compare your experience to another.



There was a boy who used to be mean to me about my allergies. He'd say he would give me a peanut or something to see what it would do. I told the grownups and they said I shouldn't worry because it's a nut free school, but they never did anything to make him stop saying it.

“I CHECKED THE PENS AND THEY WERE SEVEN MONTHS OUT OF DATE!”

An incident related to the Autoinjector. I asked the school to check the expiry date – which they said was the responsibility of the first aider. When he brought his medication bag home for the summer, I checked the pens, and they were seven months out of date!

Now not only has the deputy made this her personal responsibility to check, but shortly after my son started at the school, the nurses

who we see regularly offered to go in and train all the staff in Autoinjector use which was fantastic.

For people who don't have a child with an allergy, it is something difficult to recognise the severity of the condition, but I am very happy with how my son's school continues to learn and listen.

SHE TAKES A PACKED LUNCH, MORE FOR MY OWN SANITY THAN ANYTHING ELSE, BUT THE SCHOOL HAVE ALWAYS SAID IF SHE WANTS TO HAVE SCHOOL LUNCH SHE COULD BE INCLUDED.

“THE WELLNESS OFFICER PHONED ME AND WENT THROUGH EVERYTHING”

My daughter was diagnosed with allergies at about six months because she had really severe eczema all over her body. She's 7 now, she's pretty good with it. She knows that she's got allergies and she'd never eat anything unless she checked it, or I had told her it was ok. It's sad sometimes like when you go out to ice cream shops and there's nothing she can have, it's all "may contain nuts", and so you can tell obviously she feels a little upset. But it's always been that way for her so she is used to it, and I'll just take other stuff we can swap it for, so she feels less left out.

We're quite lucky in that all our family and all our friends are quite onboard, and they'll cater to her needs. Before she started in Reception,

the wellness officer phoned me and went through everything with me, about her medical plan. I think that was quite good and reassuring because it let me know they were taking it quite seriously. She takes a packed lunch, more for my own sanity than anything else, but the school have always said if she wants to have school lunch she could be included. If any children have got allergies, they fill out a form saying whether they'll have the school dinners or not. Then they send a menu through with all the changes they'd make to accommodate your child. Normally everything's in black writing, but if they change a meal, they put it in red writing. They're very good like that.

“MY DAUGHTER DOESN'T WANT TO STICK OUT AT ALL IN THAT WAY... YOU NEED TO BE HYPERVIGILANT”

I was a teacher for 12 years, but never had anaphylaxis training as part of my first aid, and never really had to care for kids with allergies until I had my daughter. I don't teach anymore. After having completed the risk assessment, my daughter joined her current primary school, and I noticed that the school had some hazelnut trees on the school field.

And I flagged this up and said this could be a problem around autumn if the kids are playing in that area. I know she's not going to eat any, but children play, they pick stuff up. They said, “oh no, it's not going to be a problem.” I asked, could we look at maybe cutting them back? I know there's probably no budget for this, but I offered to pay for it myself and get a tree surgeon to come in and cut them back. They said no, it's not a problem. They always said, “as long as she doesn't eat it.” They threw back information that I'd given them in the risk assessment but misconstrued as a way of defending themselves. “As long as she doesn't ingest it, there's no risk of going into anaphylactic shock.” I told her that wasn't the point – the allergen has been thrown at her. Who's to say it won't accidentally get in her mouth or her skin, or another child touches it and then touches her. It's the fact that it's wrong, and don't do it, please, because beyond being a health risk it's extremely distressing for her. This was in 2021.

Last autumn, in 2022, there was an incident. Some children started playing a game throwing the hazelnuts in the direction of my child. It was a game, a bit like Stuck in the Mud, and they were saying to my daughter, “run, run, run for your life” and obviously my daughter was playing to start with, but then understandably so she got freaked out. I mentioned this to the school – they said it was fine. “Oh, she just has to deal with it,” they told me. “Just have her stay away from that area.” Can you imagine! I told them, it's a bit hard when the whole class is involved in a game over there – at the time she was only 7 – it's a big deal for a 7-year-old. The anxiety is real. The actual thing that if she ate it would make her really ill. But they said no, the children didn't mean any harm by it. That was last autumn.

A few weeks ago, there was a similar scenario. One girl told another boy to bring a hazelnut she'd found on the school field into the dining room when my daughter was eating her lunch, and put it on the table in front of her, and said “is this what can kill you?” My daughter went and told the head teacher straight away. I got a phone call from the head teacher describing the incident, and my husband and I said, “this is why we said in 2021 that we wanted these hazelnut trees taken care of!” They apologised and said we'll have them cut back now, and they have had them coppiced and they said they'd put up a fence. But to be honest it's really disappointing. You get to the point where you think, ok, the school have got it now, and then these scary anxiety-inducing things happen anyway.

My daughter doesn't want to stick out at all in that way. She's very bubbly and very outgoing, but her allergy has made her anxious and hypervigilant, and to a certain degree you need to be hypervigilant. But she does have to stick out in this way. She has trouble sleeping sometimes, worrying about whether the school will take care of her, and she gets scared at the sight of crumbs. She gets really scared in the lunch hall when people are having packed lunches. She doesn't trust that they won't throw something in her direction. It's made her really, really nervous.

...SHE GETS SCARED AT THE SIGHT OF CRUMBS. SHE GETS REALLY SCARED IN THE LUNCH HALL WHEN PEOPLE ARE HAVING PACKED LUNCHES.

“THERE ARE NO GUARANTEES IN LIFE, BUT YOU HAVE TO MINIMISE RISK AND GO FORTH”

The school right now is brilliant. They put in extra precautions and made sure it all happened. So, if something like an activity's not suitable for him, it's not suitable for anyone.

They keep the pens up to date and let you know when your pens are out of date, and you need to replace them. They're really on top of things. All their staff are trained. The pen

goes on all school trips, and he has a person assigned to him to make sure that medicine bag always goes with him on school trips. They send out communications to parents regularly.

They minimise risk to the best they possibly can. There are no guarantees in life, but you have to minimise risk and go forth.

THE SCHOOL RIGHT NOW IS BRILLIANT. THEY PUT IN EXTRA PRECAUTIONS AND MADE SURE IT ALL HAPPENED.



SOMETIMES PEOPLE ASK ABOUT MY ALLERGIES AT SCHOOL. IT'S NICE TO BE ABLE TO TALK ABOUT THEM, BUT SOMETIMES I DON'T WANT TO.

“IT DOES MAKE YOU FEEL SILLY FOR HAVING PUT YOUR TRUST IN SOMEONE WHO LETS YOU AND YOUR SON DOWN”

My son was first diagnosed as being allergic to eggs at around 18 months old, and at the age of three was found to be allergic to all nuts and sesame, so by the time he was ready to start school – he had a pretty good awareness of his allergies.

It was quite a daunting time, sending him to school for the first time and particularly to a school which hadn't been our first choice. But we went in with all the information about his allergies – and he started school with a comprehensive care plan and his medication bag, which contain Autoinjectors.

He had only been at school for a few days when I got a call from the school to say my son didn't seem too well – but they weren't quite sure what he had eaten. It turned out that he had eaten pancakes – which the school had assumed were ok because they were gluten free, but of course it was the eggs that caused the problem.

The school should have really called an ambulance and/or administered the Autoinjector; and there had been such a delay in contacting me that I raced to the school and drove him to the hospital myself.

It's difficult to say what the outcome would have been if they had used the Autoinjector, I personally think that staff think they may be over-reacting. We were lucky on that occasion; it could have gone the other way.

I felt very let down by the school and my initial instinct was to ask, 'How can I let him go back to that school?' I was very close to moving him, but they were mortified at what had happened and put extra precautions in place.

Just a few weeks later, I picked my son up from school and he came running out carrying a bag of shop bought bagels (that could have contained sesame) which the school had handed out to the children.

I was absolutely horrified. It does make you feel silly for having put your trust in someone who lets you and your son down.

I moved my son to a new school halfway through his Reception year, which was difficult at first. I remember one morning driving past my son's old school and him saying to me: "I wonder what my old friends are doing? I can't go to that school now can I as they didn't look after my allergies?"

I remember sitting with him in hospital, with his big swollen face and replied: "No, you can't go back there because of the dangerous situation they put you in."

When he started at his new school, they did say that they didn't have many other children with allergies – but they were very willing to listen and learn – and have continued to do so over the past couple of years.

They made some immediate adjustments to their procedures, and we have built up a good support network with other parents, whom I told about my son's allergies right from the outset. Whenever a child in his class has a birthday, they bring in sweets that he is able to eat safely.

There have been a couple of incidents, including my son being made to sit alone in the classroom at snack time while his friends were outside. The fear from the school was he may mix with a child eating something that may make him ill. I do

think that this was them being over cautious and explained that making him spend time alone could damage his mental health.

The school listened – and implemented a new rule that all children wash their hands after snack time.

As food allergies and intolerances run in the family, I have tried to normalise the situation for my son. If we go into a restaurant, he wants to show the manager his allergy bracelet and ask him to make sure he serves food that he is allowed to eat.

I thought long and hard about whether to move my son to another school, but with a lot of discussions, meetings and listening – he is still at the same school.

The school was scared – and I believe that it was because of what happened with my son that they were prepared to take on board and act on any suggestions as a result.

The outcome has been a positive one and the school is now amazing. When we first joined the school, it had never experienced an incident like ours before and as a result, every procedure has been changed, and I have no hesitation recommending it to friends.

They now go above and beyond and are very pro-active; no food that hasn't been prepared in school is allowed onto the premises, all children enjoy the same allergy-free snacks, on birthdays the kids have a fake birthday cake with fake candles to blow out, and on bonfire night; the children can enjoy gelatine free marshmallows – all these things ensure equality and inclusivity.

“MY CONCERNS WERE DISMISSED AS NOT AN ISSUE”

There was an incident where a child in the school who had autism only wanted to eat Nutella sandwiches. They didn't tell me that initially, but I found out because I was at school during lunch and I spoke to his teacher, and then I saw him doing it.

This is a nut free school. I completely understand that the other child has needs too that must be accommodated, but no one had told me their rules had changed – and not everyone was aware they had. When I queried it they did tell me he was going to be eating nuts in school now, but then they didn't put any precautions around it at all.

My concerns were dismissed as not an issue – the staff didn't understand cross contamination. This boy was in my son's class, and they sat near each other.

“I EVENTUALLY BECAME A WHISTLE BLOWER”

It really does depend on what school you've got. We've got a good school now. Had I not been there at the school, seeing it for myself, I believe my son wouldn't be here today. I would never have known what was going on.

The risk that was in his life on a daily basis, they spend most of their life at school. They should be safe. And I knew he was abundantly not safe. It was only when I started to work at the school – I started working there just at lunches to help out – I was looking around me and I was like, oh my god, everyone was eating together and there was no safety at all. The staff said they were trained, but nobody was trained. I asked them to get training. I offered to show them how to do things right.

My son couldn't be around anyone at lunch, and so they made the decision to put him on a mat on the floor away from everyone. He may as well have had a neon sign on his head. There was no inclusion.

They didn't understand and could not grasp anything they needed to do.

The pens, the inhalers in the medicine bag, it was all meant to go with him – but it was lost! It was lost so many times. One of the occasions they'd lost his Autoinjector, I saw them running up and down the school, they've lost his Autoinjector. I asked, where is he? He's miles away, he's on a school field. I said that I was going to take him home, because it wasn't safe, and the staff immediately closed ranks.

The mental impact on my son of not being able to trust adults who weren't in his family was absolutely devastating. It has had lasting effects. I eventually became a whistleblower to Ofsted and reported the school because it was so dangerous. The school found out it was me and sacked me immediately.

The whole situation was because they didn't want to embrace the help I was trying to give them, and instead they covered it up, lied about it, and just put children's lives at risk. He has not attended school regularly since then.

...THEY MADE THE DECISION TO PUT HIM ON A MAT ON THE FLOOR AWAY FROM EVERYONE. HE MAY AS WELL HAVE HAD A NEON SIGN ON HIS HEAD. THERE WAS NO INCLUSION.



My mummy gets really cross sometimes. It's because sometimes the school isn't very good. Like they forget to tell her we're doing something fun so she can't make anything for me and then I have to have an orange or a biscuit. Or she asks them questions about allergy stuff and they don't know it that makes her really, really cross.

“THEY DIDN'T TELL US SHE HAD AN ALLERGY UNTIL SHE HAD A REACTION”

I had a case in an after school situation where the parent didn't actually tell us that she was allergic to kiwi. They'd told the school, but they hadn't told us. We had kiwi on the table with some other things, some other fruits, to let the kids help themselves for snack time. But because of cross contamination she touched something on the same plate, and she had an instant allergic reaction. Luckily it was nearly home time for her, so her parents arrived and she said right away, oh, she's allergic to kiwi. I said, you've not informed us of this. On our registration forms it's a standard question - what allergies does your child have, do they need any medication, epipens, etc, we give all that out in our registration forms before the children start to let us know anything like that.

I got out the registration form to show the mom, to say look, you never put that on here. You might have informed the school some other way but you never told us. I reckon she just forgot. It was for the afterschool club and breakfast club and she was just so desperate for childcare I reckon she just filled it out as quickly as possible and didn't even look into it, because when I spoke to her classroom teacher, she said yes, we're fully aware of it. She had a few additional needs anyways. With children of a certain age you can of course teach them to say no, I can't have that. But at this age a lot of the children are unaware, so they'll just go to eat what they can't eat. So we have to have eyes everywhere.

“WE DOUBLE AND TRIPLE CHECKED WE HAD THE RIGHT INFORMATION, IT WAS IMPORTANT”

There was one student who had a peanut allergy. She was severely disabled and used a wheelchair among other things, and she used to have lunch in her classroom with three other students and a few members of staff.

The catering company would say, ‘you need a medical form’, and then they’d take that, and then it was just a case of how we display that information at the canteen. We got a big A4 with a picture, the allergies and all the intolerances and medication, and we did that every September when we got all the information. It was a really challenging job and a really important one. We definitely double and triple checked we had all the right information on those forms.

We would have a meeting with the canteen manager at the beginning of the year to go through all the allergies. She was really knowledgeable about exactly what students had and was very hands on. She’d be there alongside her colleagues giving out meals when the kids came up. I don’t know what training the catering company had, but she always made sure to ask whether it was an actual allergy or just an intolerance.

Some parents would say “no dairy for my child” and I’d ring the parent and ask whether they had an actual medical form, they’d say ‘oh no, it just makes them feel a bit sick’. I’d still put “no dairy” on the poster, even though it wasn’t proven medically, if that makes sense. I’d always just go off what the parents would say even if I didn’t have a medical letter. It’s important not to take any risks.

I managed all the mandatory training for the staff, and allergy training wasn’t something we had to do.

“THE PUPIL JUST DIDN’T LIKE THE FOOD WE COULD BUY TO ACCOMMODATE HER ALLERGIES – NOW SHE HAS A PACKED LUNCH”

So we do have a student that has a few allergies that we’re unable to accommodate. It wasn’t that our canteen couldn’t handle it, but it’s just she didn’t like the food we were allowed to buy. We use a catering company that we’re having some issues with – like the food doesn’t turn up, it’s a struggle to get turkeys and mince pies for Christmas, but they’re just told from the head office this is where we’ve got to get food from. There was one time we couldn’t get yoghurts, and our students love yoghurts, so our Head Chef had to just go to the supermarket and get them herself.

The allergy version of what we made was just versions of things like we were already on the menu, like spaghetti bolognese. But this student wasn’t really eating – she’d leave most of the meal at the table. She said it didn’t taste as nice as the stuff she could get at the supermarket. The parent brought that issue to us later, too, saying that her daughter said she didn’t like the food, so now they just have to bring packed lunch and that’s more expensive because she’s on free school meals, so they have to buy the packed lunch.

We’ve got one student with allergies who’s end-of-life, so his diet keeps changing. His food all has to be blended, double blended actually, and tube fed. We are trialing different things to meet his needs and getting updates on how it’s going. Parents, dieticians and canteen staff all work together to try and find an agreement on what would be best.



When we go on school trips, my teacher carries my AAI's in a bag. They make sure they go where I go, which means I can have fun with my friends without having to worry.

BEING SAFE

STORIES WHERE INDIVIDUAL SAFETY IS CALLED INTO QUESTION, WITH A COLLECTION OF STORIES OF TEACHERS GOING ABOVE AND BEYOND TO ENSURE THE ENVIRONMENT IS SAFE, TO CASES WHERE THIS HAS NOT BEEN FACILITATED AND THE IMPACT ON THE CHILD AND THEIR FAMILY AS A RESULT.

“HE SAID THIS PARTICULAR YORKSHIRE PUDDING WAS LOVELY”

I make him vegan Yorkshire puddings at home, so I think he assumed he was safe with them. He even actually asked the dinner lady beforehand if he could eat it and she said it was fine. He was only four or five. Luckily it wasn't a bad reaction. But it turned out he ate it the week before too and just didn't tell me about it. He came home with a bad tummy ache. He said he was allowed to eat it and clearly enjoyed it, he said it was lovely.

I emailed the school and told them that he had come home feeling poorly and asked if there was a chance the Yorkshire puddings contained eggs. There was no reply. I emailed again – I got no response. At that point I lost the plot. I said this was a life-or-death situation. It's on his allergy plan. So how did this happen? Eventually I spoke to the school, and they said there'd been a demand for more Yorkshire puddings, so they added it on to the menu. Now, he gets everything wrapped up with his name on it, to take away that doubt, and it means that he doesn't have to ask whether he can eat something or not. He feels a bit different when he's at the front of queue, but overall, he's ok. He gets to sit with the other kids. I tell him that he can still enjoy milky drinks with everyone else, he can still do anything he wants to do, it's just that his is a little different.



We try different foods for design and technology. I was able to have all the food, the teacher phoned my mum to check the ingredients.

“THE PE TEACHER HAD PUT ALL THE AUTOINJECTORS IN A CLEAR PLASTIC BOX IN THE SEARING HEAT”

School staff treat allergies a little carelessly. Last year at my daughter's sports day the PE teacher had put all the Autoinjectors in a clear plastic box in the searing heat. My husband was there and saw the PE teacher just leave them in the middle of the field. God knows how often

they store them improperly, even when they go on trips. They don't have knowledge of how to store the medicine, or it's not being communicated down effectively. I used to work for 12 years in education, and I remember having allergy training twice – you could elect to go, but in my first few years

of teaching we all used to sit in the hall and get the basic training, which was required if you wanted to go on trips. But even back then the health practitioner didn't say, for instance, you've got to make sure the storage temperature's ok.

“THERE’S NO WAY A CHILD OF 7 CAN INJECT THEMSELVES DURING ANAPHYLAXIS”

At Christmas time they brought in nut snacks for everyone to share. He’s sitting there saying to himself, “I can’t even be in this room right now.” He’s 7 years old. It’s not a thing you can take control of on your own at 7. They tried to tell me he could carry his own pens in that situation, and there’s no way a child of 7 can inject themselves during anaphylaxis. One of the symptoms of anaphylaxis is, they call it “impending doom,” it’s an extreme anxiety and you forget where you are. Someone has to take control at that age.



My teacher remembers to bring my pens to lunch. It makes me feel safe. The teaching assistant and my teacher know about my allergies and I like that.

The school makes sure other children know about my allergies too. A boy who is a year older at my after-school club said to me “You have allergies.” It’s nice that they know so they can help to keep me safe.

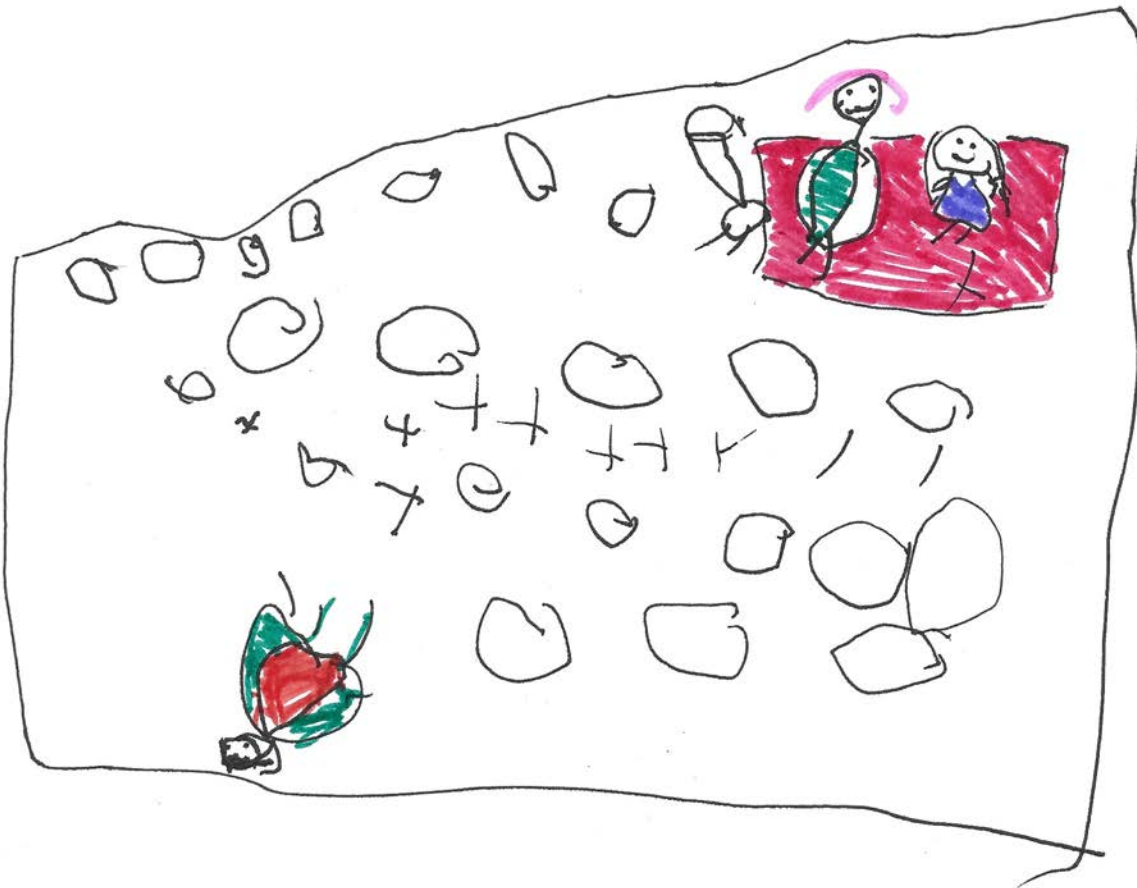
“LUCKILY IT WAS JUST SKIN CONTACT – A RASH, PUFFY EYES, BUT NOTHING THAT NEEDS AN AUTOINJECTOR”

He’s had situations where he’s had a skin reaction. One time they were eating ice cream for lunch. They didn’t send spoons down with the ice cream, so they all used apple slices to scoop up the ice cream. They improvised. There was a lot of contamination, they got it all over their hands, they got it all over their desks.

He ended up coming into contact with it, and luckily it was just skin contact – a rash, puffy eyes, but nothing that needs an Autoinjector.

But the teacher was like “you’ll be fine,” and sent him off to the after-school club. The club was amazing, and they dealt with it. They went straight to the bathroom, washed his face, and phoned us, the whole thing they were supposed to do.

We put in a complaint to the school about it. At no point should they be left unsupervised while he’s in the middle of a reaction.



The grownups get worried because I have to sit on the floor in the dining hall for assembly. There might be bits of milk or something on the floor so I have to sit with a teacher on a mat away from my friends.



When we go on school trips, my teacher carries my AAIs in a bag. They make sure they go where I go, which means I can have fun with my friends without having to worry.

“THE SCHOOL’S ALLERGY CARE PLAN HAS BEEN VERY MUCH LED BY ME”

We’re about three weeks in to her first year of Reception, so touch wood, it’s been mostly positive so far. She’s already been to one party as well, because as soon as they start, she gets invited. The mum of the boy whose party it was, was good about checking with everyone to get allergy information. I ended up taking our own pizza along because she couldn’t have it.

The school’s allergy care plan has been very much led by me. They’ve been accommodating, but only in response to what I’m making them aware of. Apparently, they’ve had other allergy kids there, but I don’t know to what severity.

There are a couple of things they’ve done that I’m really pleased about. The teacher comes for a home visit before your child starts school. At that home visit I made her aware that this is a life-threatening allergy – this isn’t just a little thing – and the teacher did inform all the other parents that my daughter has a sesame allergy, please bear in mind that when bringing

a packed lunch, don’t bring sesame. She even said this can be in hummus, breadsticks, seeded breads, etc.

I’m pleased that she made other parents aware. But the thing that still worries me is that there are two classes in Reception, and the two classes eat together, and allergy kids can feel fearful if they see the allergen around. I don’t know if the other class’s teacher has passed on that message to the families in her class as well. I was told that generally school lunch kids sit together, and packed lunch kids sit together, but I’ve recently learned from my daughter that they actually sit amongst each other. But I will have to ask the other class’s teacher to put out that message as well. The class teacher and the TA also came around to our house and did a demonstration with the injector pen about how to lie down, where to inject the adrenaline. And the teacher did that same demonstration with the lunchtime supervisor so that they were aware. Ultimately whatever the experience is, that fear factor is always there when your child is being cared for by other people.

ULTIMATELY WHATEVER THE EXPERIENCE IS, THAT FEAR FACTOR IS ALWAYS THERE WHEN YOUR CHILD IS BEING CARED FOR BY OTHER PEOPLE.

“IT’S REALLY HIT AND MISS”

We’ve had quite good experiences where for example they’ll ring us up and say, we’re having pizza, can we have vegan cheese for him, will that be ok? So, it’s really hit and miss. They’ve all been Autoinjector trained, but they haven’t been allergy trained. They’re a nut free school, but they don’t have any children

with nut allergies. They don’t have an allergy policy in place, so I’ll have to send them the guidance from Allergy UK sometimes. They have some other kids with intolerances, nothing life-threatening, but my son’s their only Autoinjector child. They’ve got the medical side sorted, but not got the environmental side sorted.

THEY HELD UP A CAN OF AMBROSIA CREAM RICE AND ASKED, “WOULD THIS BE OK FOR YOUR CHILD WITH A MILK ALLERGY?” AND IT’S JUST, OH MY GOD, SO FUNDAMENTALLY WRONG ON EVERY LEVEL.

“IS THIS SAFE? I DON’T KNOW CHECK THE INGREDIENTS”

The after-school club at the school was unfortunately run by an external provider. I just had a car crash of a meeting with them. I fight a lot for my sons who have food allergies – but sometimes you have to go, you know what? This is too big. They held up a can of ambrosia cream rice and asked, “would this be ok for your child with a milk allergy?” And it’s just, oh my god, so fundamentally wrong on every level. She’d already held up ten food things. Is this safe? I don’t know, check the ingredients. Is this safe? I don’t know, check the ingredients. This one actually says cream, of course it’s not safe! But also read the ingredients! You do have to fight quite a lot, but sometimes you just have to give in. In this case I just knew I’d never forgive myself if there were an incident, so I just pulled him from the program.

“IF I’D NOT EDUCATED THEM ON RISK, I DON’T KNOW WHO WOULD HAVE”

It felt like every interaction I had with my children’s school was like a training session. I’m no expert, but I just felt so strongly that they needed to know more than they do to keep a child safe.

I remember the reception teacher bringing out packet of cookie mix that said ‘dried egg’ in it and saying ‘I know this is probably ok, but I wanted to check’. I have twins who both have egg allergy and they’re allergic to it in even trace amounts, whether it’s fresh or dried. I couldn’t believe she thought it was ok.

And another time when they were away on a residential and the school bought pre-packed sandwiches to take. I happened to be stood next to them while I waited for the children to get into the coach and had a look, they all had butter in. I asked a teacher who said she would check what my two were having and brought them over. I couldn’t believe it when I saw ‘butter’ listed on the ingredients, but I was even more terrified when the teacher said ‘oh, but I thought they had a milk allergy? It wasn’t just training on allergy and AAls, sometimes it felt like I was having to just explain the basics of where food comes from – I don’t know how this can be written into any risk assessment.

The issue is, policies aside, you have to rely on a person’s knowledge and common sense to keep your child safe and that’s incredibly hard.

WHAT MAKES ME ANGRY, IN ADDITION TO THE CHEF GIVING MY SON THE FLAPJACK, IS THAT THE MEMBER OF STAFF SAT BESIDE HIM AND LET HIM TAKE A BITE – A BITE THAT COULD HAVE KILLED HIM.

“IT CAN BE EASY TO MISS THE SYMPTOMS OF A CHILD THAT’S DYING IN FRONT OF YOUR EYES”

It was around 18 months ago – in April 2022 – that my son was due to start school, having attended the nursery attached to the school. I had decided to send him in a term early to try and get him used to being left alone – he was 3 years old at the time.

I met with school catering team, the head of pre-prep and the head of the nursey to talk about my son, who is allergic to eggs, sesame, gluten and oats.

We had a good conversation, discussed him wearing a lanyard which gave details of the things he was allergic too and the use of different coloured plates at meals times. I was pretty confident that collectively we had covered everything ... until day two I picked up my son just after lunchtime and while driving home I noticed he was having trouble breathing – I recognised that he was going into full Anaphylactic shock, so I quickly grabbed my Autoinjector and administered it in the car.

It was a terrifying experience – I didn’t know what he had eaten, particularly given my discussions about his allergies with the school. I called 999 but managed to flag down a passing ambulance to take us into hospital. My son turned to me and said: “Mummy, I’m scared, I can’t breathe.”

The school had given him a flapjack – I was absolutely furious and could not believe that this had happened, in spite of the school

ensuring a member of staff would sit next to him during mealtimes. He was surrounded by the same children each time, none of whom had food allergies.

As you can imagine, I had meeting after meeting with the school – it turned out that even though my son’s allergy information was clear and visible, the chef thought his allergy was to the gluten in the oats – not the oats themselves, which is absolutely unbelievable.

The chef got fired from the school. The problem with many schools is that in a classroom full of children, the kid with the allergy going into shock – with the changes in breathing and the ‘floppy’ appearance – can be easily overlooked.

It can be easy to miss the symptoms of a child that’s dying in front of your eyes.

As a mum, you know what your child’s breathing is like, and if he hadn’t been in the car with me that day, the outcome could have been different – it doesn’t bear thinking about.

What makes me angry, in addition to the chef giving my son the flapjack, is that the member of staff sat beside him and let him take a bite – a bite that could have killed him.

I feel very strongly that schools should add Autoinjector training to their overall teacher first aid training. It only takes a few minutes to learn, and those few minutes could save a child’s life.

“THE TEACHER WAVED THE AAI IN THE AIR AND SAID ‘IF YOU NEED A BIT OF THIS LOVE, COME AND FIND ME’”

My daughter was in the canteen when she had her first severe reaction at school. Sat at the table, she could smell peanut butter. The smell was enough to trigger a severe enough reaction. The Consultant said, ‘you can’t be allergic to smell’, and I said yes you can as it’s airborne too.

After that, everything was wiped down and she was sat near the door so she could walk out if needed. Plans were put out in place to make it safer. I went on all the school trips to help out and because she didn’t trust anyone. People didn’t get it and we don’t know why but between October and February, she has more allergic reactions.

We looked back at junior school and could see how the teacher was always on the ball. On school trips, she always had the right documentation, she always provided wipes and made sure there was extra cleaning. She never made anything dramatic. There was a swap box if the children were being rewarded, making sure things were sealed and safe. She was committed to keeping her normal and being inclusive.

But at secondary school, no one ever wanted the responsibility. On the first day, the teacher waved the AAI in the air and said, “if you need a bit of this love, come and find me”. I had to explain that if she needed it, she wouldn’t be in a position to come and find her. Alarm bells started ringing.

“THE AUTOINJECTOR HAD BEEN GIVEN AND THE AMBULANCE WAS ON ITS WAY, BUT THERE WAS NO REPORT DONE OR RECORD OF THIS ANAPHYLAXIS”

In the June I got the call which is every parent’s nightmare. It makes me tear up thinking about it every time. I was told the Autoinjector had been given and the ambulance was on its way. I didn’t know whether she was alive or dead. I arrived and the ambulance was outside – I didn’t know what we were going into. Flora was crying amid absolute chaos. There was just the caretaker and the receptionists there. Flora was distraught.

I just remember hugging her. Because of my job, I knew the ambulance driver. I got in the ambulance and he told me that the first aider had held the AAI upside down and injected herself.

We’d always tried to keep her included in everything, including cooking classes. On this day, they’d checked about cooking chicken tikka masala. I said we can’t find a nut free paste. So 30 kids went ahead and made it. It was when Flora went back in the room that she became unwell in class. The teacher had really told her off for not doing it and because she was so arsey with Flora throughout the class, when Flora became unwell at the end of class, she felt she couldn’t ask for help. Luckily, she saw her best friend as she left class, who said, “you don’t look well”. Flora told her she didn’t feel well, and her friend managed to get her to the office.

They never told me that the first aider injected herself. We were keen to know if she was OK, we were worried about the person who injected herself. When we got home. Flora slept for most of day and she was off for good few days. No one rang to see if she was OK. There wasn’t one member of teaching staff around and no one followed up.

I rang the next morning saying, “just to let you know how she is...” I asked for a meeting because I wanted to know what happened. There was no report done or record of this anaphylaxis. Flora had anxiety. Nightmares. I was calling

the school and saying we need to know what happened and they basically wiped the floor with me and didn't want to listen to us.

When she went back in on Wednesday afternoon, we gave the receptionists chocolates and a card to say thank you for what she did. Flora had carefully chosen a happy flamingo card, to which the receptionist burst into tears and said, "you know don't you?" She was apologising and saying, "I wanted to save your daughter." I was horrified – I said I was so thankful but she told me, "we've been told not to speak to you. You want to hear what they say about you. We're not allowed to speak about that day, it never happened. We were told you were disgusted that we had to use the autoinjector pen." I couldn't believe it. I asked her if she'd had counselling for the shock of the incident?

I asked school for the care plan and the one they had on file was out of date. We had about 17 care plans in the end. I kept querying why the AAIs were in a locked cupboard, but this was met with the headteacher saying, "it's not locked, look, you just turn the key". My worry was always that someone would misplace the key to lifesaving medicine when a child needed it most. When we asked about who was AAI trained – they said we don't like AAI training. It's not a case of liking it – how

can you not tell me?

Flora still didn't feel safe at school. I put in a Subject Access Request as they still didn't admit that day happened. I was told not to talk about this, that we've got to move forward. So I went in and asked, can you get me the spare AAI? They couldn't find it. The School nurse told them they should have got it.

There are no records of around 13 allergic reactions at school. Flora had an allergic reaction in the computer room. The Teacher's response was, "oh Flora. Oh, will you take Flora to the office, she's having an allergic reaction". By time she got there, she was having an asthma attack. Help must go to the child.

The school ended up instructing solicitors against me, hiding behind safeguarding concerns so that they didn't have to release the reports I'd asked for. They never rang me to say, let's sort her attendance out together. Flora's had uncontrollable anxiety, meetings unearthed out of date Epipens and Flora was sometimes quizzed without me being there about home life. Allergy plans I created with the nurse had been copied and pasted incorrectly. Policies disappeared when I tried to point to how they should be caring for her at school.

It's made me fight. I would always say, it's not a complaint, it's a concern. How can I help you put the things in place that we need to make all children with severe allergies feel safe? I've always done it nicely. You'd always fight for your child.



The teacher always checks the sweets before she hands them out to everyone

“IT MAKES ME SO UPSET THAT PARENTS ARE ONLY LISTENED TO WHEN SOMETHING FATAL HAPPENS.”

My son's 9 and is allergic to all nuts, which cause anaphylaxis and so he carries an autoinjector pen. He also has an egg allergy, so he's on antihistamines. He's lived with that since he's been a baby and he has the asthma that comes with allergies. We discovered his allergies as soon as he was born, as he had eczema and was chesty as a child.

He took a bite out of a happy hippo and his head swelled to three times the size. That was his first bad reaction and we called an ambulance. Another time a little boy gave him a chocolate – he only took a bite out of it – he didn't swallow it but your body repels it if you're allergic. His tongue swelled, he was sick, we gave him his AAI and phoned 999. The four incidents with eggs at school have been over the past two years.

In the first two incidents, they gave him tuna mayonnaise. Then they brought vegan mayo in, and had it taken off the menu. The third incident involved them giving him an actual omelette. It's unbelievable. There was a big investigation with the council after the third time, where kitchen staff were removed from their jobs. But the Council never came back to me on it – they never formally responded to me and my complaint.

The fourth time was last week where he was given egg custard. What made it even worse was that it was given to him when he was just out of the high dependency ward after he'd been hospitalised following a severe asthma attack. He returned to school – where he wasn't supposed to do PE or anything that would put a strain on his body after he'd been so ill – and he was given custard on the second day out of hospital.

I got the phone call and the teacher was crying. I drove down straight away. He was sitting there, you know your own child and I could see from how he was, how quiet he was that it had made him so unwell. He had a couple of hives and was sick and that was it, thank

God. I got straight on the phone to the Doctor who told me to monitor him. This time, I went straight to the Councillor and Director of Law and Governance at the Council. They reported themselves to Trading Standards.

It's a great first step that they want me and my son to help identify what could be improved in the policies/approach but they haven't given any comments in the first stage response to cover themselves. The thing that no one is asking is 'what if?' – what if it had been a worse reaction? And no one is considering the stress and anxiety and the health impact on my son – instead, they're saying that they hope the first response is satisfactory to resolve the situation at this stage.

It's appalling that there's been four incidents. And in each case, just an apology. If I wasn't clued up on all this, I would be lost. What could have happened due to his immune system being so low in the circumstances is unthinkable.

My son was off for the rest of the week and when he returned to school on Monday, he was told he can't eat food that the school provides him with. He's being discriminated against through no fault of his own. I pick him up or provide him lunches now as I work from home. This is in spite of the legal duty that school has to make arrangements for those with allergies, including nut allergies.

The problem is that it's a nut free kitchen so it should be fine, but we feel we can't trust them as they've done this four times now, making mistakes with eggs. But if he sits with those who bring in packed lunches, there are students who bring in Nutella sandwiches. Luckily, he sits beside his best friend and I've spoken to their mum. But the environment is still a risk around him at lunch.

It makes me so upset that parents are only listened to when something fatal happens. My heart goes out to them, but why are you not

listened to before that? I want to be listened to now and I don't want a charity in his name just because people don't take this seriously. I've run campaigns before, making AAI training mandatory. It's not good enough that you have to make such a fuss to be heard and to keep your children safe.

After the incident with the egg custard, we thought about moving him. It sounds like although he uses a different colour tray, the cover staff were unaware of his allergy, which demands better protocols and training of the catering staff. But the trouble is that the council caters for all schools, so it would be the same

issues and he would be starting from scratch. All of his friends are at school and I think to myself, why should you be made to leave your friends and be the new boy? It's an impossible situation.

No one speaks enough about the emotional impact and distress of having a child with allergies – it's not talked about enough. It takes over your life. I'll be sat there constantly researching ways to make it better for him, we are investigating desensitisation treatment at hospital, which is so expensive. I just want a safer world for my son and for all children living with allergies.

“A PUPIL PINNED HER DOWN AND WAS BREATHING IN HER FACE AFTER EATING A SNICKERS”

My daughter went on to be bullied. She was getting death threats over voice notes, threatening to kill her with nuts. The teacher said they had no control so I had to go to the police. One day, she rang me in the toilets crying, saying “a pupil pinned me down and was breathing in my face after eating a snickers.” I had to ring the school to tell them she'd locked herself in the toilets. This led to her getting into so much trouble for using the phone to ring me for help. I then got a call back saying, “don't worry, it wasn't a big thing and it was only a mini snickers.” You can't believe what you're hearing. I kept thinking, “what are you not understanding or getting?”

She flourished during lockdown. She did brilliantly home schooling. She'd always been on constant high alert when she was at school. When they returned after lockdown, one of the teacher rewards was a chocolate bar with nuts. Everything,

all the time, was a constant battle. She just knew they didn't get it and was on antihistamines that made her tired. At home, she didn't have any of that.

Her anxiety over school was so bad she refused to go to school and was missing in action for 46 days. I asked the County council for help. I'd been to the MP and told school. In an attendance meeting, the SENCo was useless, and the two attendance officers were so hostile, they ended up throwing the pieces of paper across the table at me, including the copy of 'supporting students with medical conditions' guidance I'd brought with us. They said to her, “if you're not back in on Monday, your mum's going to court” and walked out. She was so tearful, insisting she'd come to school. But we felt nothing had changed, they couldn't even tell us who was autoinjector trained.

The attendance officer turned up while we'd gone for a walk and left note asking us to contact them ASAP. So I wrote saying nothing's changed. Wrote to board of governors. Wrote to the Head. Every time, saying I'm raising concerns, it's not a complaint. I was ignored. It's like peeling onions, trying to work out who best to speak to.

The school also sent home the thriller novel, 'One of us is lying', with the note, “hope you enjoy”. It's a mystery book about a pupil dying in detention from anaphylaxis. I come home from a late shift, she's distraught, sobbing. Page 13 is a graphic anaphylaxis description. When I asked why this was sent home, and that Allergy UK doesn't recommend it as reading for allergy sufferers, the response was, “but it's all about getting awareness out there, why aren't you happy?”

“IT’S SHOCKING. OTHER CHILDREN ARE ALLOWED IN. HE’S BEING PROPERLY EXCLUDED FROM SCHOOL BECAUSE OF HIS ALLERGY. IT’S JUST GOING TO GET WORSE.”

My little boy was born in 2020, but he was constantly covered in hives when he was six to nine months’ old. If he got wet, or he dribbled a lot, he was really poorly. I pushed a bit more after covid and that’s when we found out he has an allergy to water. It’s called aquagenic urticaria, meaning a water allergy. I was gobsmacked and then they said there was no treatment available until he was 11 or 12 years’ old – we were told to bear with it.

When it’s damp or raining, he must not leave home. So we can’t take him to hospital when it rains. GPs would laugh when they were told, saying things like, ‘you’re made of it’ and ‘how’s that possible?’ But he can drink water, just not touch it.

He’s currently at the pre-school attached to the school he’ll attend, but they won’t accept him now he’s been issued with an autoinjector pen. I was told the school won’t let him in until he has an EHCP, something there’s a 5yr wait for where we live. I said this to the school and they laughed, ‘well, he won’t be in school for a while then!’.

No work’s been sent home. No one’s checked in on us and checked the effect on him. I’m disabled. My daughter’s home educated. We’re a low-income family. There’s been no support or concern for his wellbeing. No thought of, oh, it’s Halloween, would you like any colouring materials sent home for him?

If a child has a nut allergy, they have to have an AAI. With Freddie, they’re not prepared to call it. The doctor had given them notes and everything – saying that if they did

have to give him the AAI, there’d be no harm done even if he hadn’t gone into anaphylactic shock. It’s shocking. Other children are allowed in. He’s being properly excluded from school because of his allergy. It’s just going to get worse. They’re pushing him out before they even have him properly because it’s too much to deal with.

I don’t know who to turn to. I called a specialist nurse who is really supportive. She said she’d never heard such rubbish – for the preschool it would be the same protocol for a nut allergy, but he’s being excluded purely because it’s water.

I got sent pictures from last week, showing him outside in a wetsuit they’d given him, paddling in the rain. I dealt with the aftermath of their actions. I feel his whole life people won’t believe him. I struggle to explain it to people who look at me in disbelief.

Even moments where we have got excited together – like when we put him outside in the snow for the first time, we were throwing snowballs when he was really little, but he got really unwell.

The preschool shares the area with Reception and Year 1. Even now, he knows not to go near the water play area. But the toilets are open – he’s washing his hands, but there’s no one to monitor it. With 30 children, one teacher and TAs, I worry about moments where there’s no monitoring. He’s mixing with teachers he’ll likely go on to have and I have parents’ evening tomorrow – how will that work when they’ve seen him four times

this year?

He’s on such high doses of antihistamine, he can tolerate exposure for a few minutes max, he just gets a few hives. Once a week/fortnight, he can have a bath in a big tub, where we cover him in emollient and submerge him but he is left sore – says it’s like being caught by stinging nettles. He prefers alcohol scrubs. When the weather’s so bad, it goes straight to his airways that close. In the last two weeks, we’ve had three incidents where they’ve closed and he’s had to use nebulisers as it’s airborne.

He doesn’t want to be there. He loved it on his first few days, but something’s changed – it’s like he knows they don’t want him. I worry if they can’t find a way to include him now and to allow him to attend and keep him safe, it’s going to get worse as he gets older. When it’s raining, he’ll be left to stay inside, away from his friends who can play outside. I worry he’ll spend his life isolated.

No one checks in enough or asks, is there anything we can do to help? Just – ‘give me an update whenever you can get one’. I feel like, now they’ve got the funding for him, they’ve left me to deal with the situation and I have no answers.

So I’m already having to consider whether to home school him. It’s hard, I didn’t want that for him. I want company for him and for him to make friends, but what do I do if they won’t let him in the classroom?

“I’VE TRIED MY HARDEST TO GET ON AUTOINJECTOR PEN TRAINING, BUT I WAS NEVER AT THE TOP OF THE LIST DESPITE LOOKING AFTER CHILDREN WITH ALLERGIES”

I have recently had my first allergy training as a teacher. I think it was about an hour and a half of videos, and then you had a quiz at the end, and then if you were successful, I think it was 80% in the quiz, then you’d get a certificate to say, “yes, I’d completed this training.” And actually, it was quite informative.

But this was the first time I’d gotten such training. EpiPen or AAI training has been available throughout my career. I’ve tried my hardest to get on it, but at the school I was at for 10 years, I was never really designated as somebody that needed to have that training because I was first-aid trained. We had a proportion of staff that were EpiPen trained, so I was never at the top of the list for that training. I’d still quite like to access that training, but it’s not been made available to me recently in my new school despite me looking after children with allergies.

All our students at my current school have an EHCP. They wouldn’t be able to come to our school if they didn’t. One student for example has a dairy allergy, but she’s very anxious about it. So if anyone in school is poorly or exhibits signs of coughing or complaining about sore bellies or anything, she can then get very worked up because she’s worried that she’ll get sick. That’s her anxiety there. We have to be adaptable with these young people, but I don’t know if the school offers the right expectations for these kids or visibly does enough to make her feel safe and secure.

The school I used to teach at, I remember they were very assertive about the uniform and how it should be presented. And every morning we had to do a check on uniform, which is fine, but if we had the same kind of concern about allergies or safeguarding students, we could be checking, have you got your medication? What activities have you got today we need to be mindful of? We’d be able to manage that risk a little bit better.

WE HAVE TO BE ADAPTABLE WITH THESE YOUNG PEOPLE, BUT I DON’T KNOW IF THE SCHOOL OFFERS THE RIGHT EXPECTATIONS FOR THESE KIDS...

YOU HAVE THIS LINGERING FEAR OF, IF THE WORST WERE TO HAPPEN, WILL I REMEMBER THAT PARTICULAR KID AND WHAT THEY'RE ALLERGIC TO AT THE RIGHT TIME?

Our school has over 1000 pupils. During the 7 years I've worked there, we have a robust system in place to protect the pupils. This includes annual training on allergies and EpiPen use to remind us of the symptoms and give us the confidence to act when we need to. Every year a list of pupils with allergies is published and put on the wall of every office in the school showing their name, picture and what they are allergic to. But you have this lingering fear of, if the worst were to happen, will I remember that particular kid and what they're allergic to at the right time?

The pupils are expected to carry their autoinjector pens in their blazers, so they are to hand if they ever need to be administered but we have spare EpiPens in the medical room in case they are ever misplaced or if they've forgotten them.

Despite all of this, it is still a worry for many members of staff that they might do the wrong thing or fail to act in the right way when necessary. There are a large number of pupils in the class these days and spotting the symptoms early is obviously key. You also have no real control over what the other pupils bring into school and they are not all going to be aware of the vast range of allergies within the school and how serious this can be.

The good news is that during the 7 years I've been there I don't remember there being one incident of anaphylaxis or an AAI having to be administered. This is probably, at least in part, due to the awareness within the school and the training and systems we have, but there is almost certainly an element of luck too.

WHEN SUGGESTED IT WAS SAFER TO KEEP AAS IN CLASSROOMS, IT WAS DEEMED TOO MUCH HASSLE TO REMEMBER

I teach at a small one-form-entry private school where we have posters displayed in every classroom of all the children who have intolerances or any severe allergies so that all members of staff are made aware – particularly for those who have severe allergies. Staff are really good at checking beforehand if there is any potential risk in terms of allergies. We have a strict no nut policy in place and all snacks and food is catered for, so the only real place we have to be extra vigilant is on school trips where the children may bring in a snack.

In the lunchroom, the children are given specially coloured plates – red for anaphylaxis and severe allergies, blue for dietary requirements that are religious and white plates for children with no such concerns. Again this is monitored closely, and in my experience working with older children, they are usually amazing themselves at making sure their food is safe and okay for them to eat.

What has worried me in the past is that EpiPens are stored in a central location – in the staffroom. This would seem challenging at a normal school but ours is set over 5 flights of stairs and so I do really worry that in the event of an emergency, would we get there and back to the child in need in time? I much preferred my previous school's policy, where bags were stored in the classroom with autoinjector pens and the child's information placed inside, easily accessible and portable when moving around the school to lunch and different lessons. When suggested at my current school, it was deemed too much hassle to remember and too cluttered for the classroom... A worry when considering the logistics of emergency situations and just how quickly things can deteriorate.

I LIVE IN FEAR THAT I'LL GET A PHONE CALL TELLING ME A CHILD HAS HAD AN ALLERGIC REACTION ON MY WATCH

I'm a headteacher across three large primary schools. It's a stressful role, but I love it. What you hear in the news about teachers having to do more with less is so true though. It feels like there are more and more children, fewer and fewer adults, and more things we have to do during our time.

We've always had children with allergies in our schools, but this year we had a little boy start in reception who had several very severe allergies. Some of them were contact allergies and some were airborne, including to citrus.

To be honest, I felt totally out of my depth. I knew we had to do something to keep him safe, but where do you start? Do we ban everything? Do we separate the child? You don't know whether you're doing the right thing. Some of the ideas we had to keep the child safe and eliminate risk just sounded so sad for him – like sitting and having lunch on his own or with me in my office.

I read so much guidance, but the best thing I did was sit down with his parents. His mums were great and they gave me so much information about what level of risk was appropriate and where we needed to put precautions in place. In the end we did ban citrus from our schools because it was the right thing to do, there was no other way of guaranteeing he could be safe. We did it across all three so that teachers who moved between the schools didn't forget.

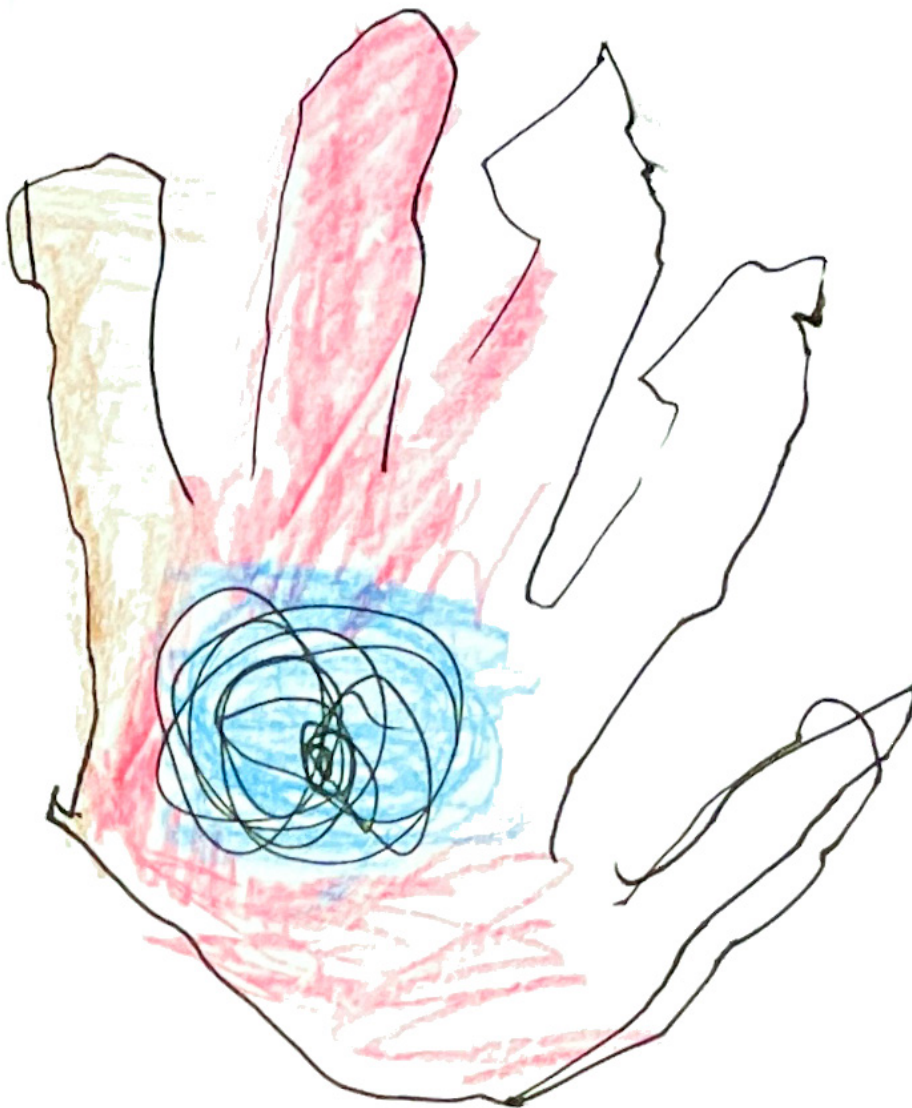
We agreed lunchtimes would be a mix of school food and home food. On days where they had roast dinners we identified none of his allergens were present, and it meant there also wouldn't be any in the dining room, so he'd eat lunch on that day in the dining room. On other

days he did have to eat in another room, but we'd let a couple of children join him so he wasn't on his own. I'll be honest, it's been a lot of extra work. It's not just the planning, it's the staffing, remembering we have to factor in a teacher being with just a handful of children is harder than you think. Banning citrus also got a lot of complaints. There were children who would only eat the orange out of the bowl of fruit at snack time, and taking that away from them was a difficult thing to sell, but it was the right thing to do.

I don't have allergies, no one in my family does, so I don't really know what it's like. But I do believe children shouldn't be left out, shouldn't be made to feel different or like there's something wrong with them for something that is not their fault and already limits them in different parts of their life. I also think we should do everything we can to keep them safe, even if it means we have to do things differently. We're grownups in a position where we have the power to be brave, and we have the responsibility to do that. It's really important to me.

I live in fear that I'll get a phone call telling me a child has had an allergic reaction on my watch. It worries me so much we'll do something wrong. I know though that mistakes can happen, we just need to try our hardest to

Some children eat the food I am allergic too and then they go straight out to play. When they've eaten food I can't have but haven't washed their hands I just don't play with them. It doesn't bother me, but it's annoying they don't think and just wash their hands.



I have to wash my hands more at school, but the soap makes my hands hurt. One time blood even came out, but I have to keep washing them because the grownups say there's lots of allergens all over the place and they don't want to make me poorly. I like being at home so my hands don't hurt.

ABOUT ALLERGIES IN SCHOOL

Allergic disease is the most common chronic condition among children, affecting around 7.0–8.0% of children worldwide or about two children in an average-sized classroom of 25 children. It is also unique in its ability to cause serious illness or be fatal within minutes.

Children spend at least 20% of their waking hours in school. Thus, not surprisingly, data shows that 18% of food allergy reactions and 25% of first-time anaphylactic reactions occur at school. Moreover, anaphylaxis due to food allergy occurs in schools more than in any other setting. It's not all about lunchtimes either, 79% of reactions take place outside the dining hall. Food-related anaphylaxis has increased considerably over the past 20 years, particularly in younger children. This has prompted a need for schools to consider their preparedness for managing increasing numbers of children with allergies.

In 2016 and 2017, three food-allergy related deaths occurred in schools: a 9-year-old boy died from anaphylaxis due to an undetermined allergen, a 14-year-old and 13-year-old boy, both with dairy allergies, died after suffering allergic reactions to school dinner and physical contact with a piece of cheese, respectively. Inquests identified key contributions included a lack of adequate staff training, policy implementation issues, AAIs being out of date and not available. In 2021, five-year old Benedict Blythe collapsed at school and died from anaphylaxis.

What can be done in schools to make them safer and more inclusive?

It's important to understand that every allergy and every child's response to an allergen is different. It means schools can't adopt a 'one size fits all' approach to allergies. It needs to be as individual as each child. It's also important to take all allergies seriously, whether it means a child gets a bit of an itchy tummy when exposed to an allergy or they have a history of anaphylaxis. Allergic reactions are unpredictable, and allergy is allergy.

In our research, schools that were brave and willing to do things differently so that pupils with allergies were included and protected were the ones that parents felt the safest and happiest sending their children to.

If you are a parent, you can ask your school to consider implementing the following recommendations. If you're a school, we recommend these are implemented.

- An allergy policy should be in place, which should be easily available to parents and staff. You can find a model allergy policy from BSACI as a template. This should include clearly defined roles including an Allergy Lead.
- A co-created Individual Healthcare Plan (IHP) for all children with allergy, that includes children who get an itchy tummy and those with hayfever as well as children with autoinjector pens. Allergy is allergy.
- Training and education – focussed on prevention of allergic reactions and inclusion, not just first aid. This can include pupil education too, whether as part of lessons on nutrition and health or as stand-alone sessions.
- Spare pens should be purchased and held by the school in an accessible place as well as having two, in-date prescribed AAIs for pupils who need them. There should be clear procedures for storing, holding and administering allergy medication.
- A review of allergy should be part of every risk assessment as standard.
- An anaphylaxis and emergency plan should be in place which is rehearsed like a fire drill for school staff to be able to respond confidently in an allergy emergency. This may include creating tools such as emergency cards.

You can find out more about Benedict Blythe Foundation's campaign to Protect Pupils With Allergies at www.benedictblythe.com/protect-pupils-with-allergies or you can browse our collection of school allergy resources including guides, model policies and videos at www.benedictblythe.com/safe-schools

We recognise that some of the stories in this collection may be upsetting, however it's important to note that research tends to elicit the very good or the very bad. Families and teachers don't come forward to tell us that 'my child went to school and nothing noteworthy happened', so it's worth bearing that in mind if your child is starting their education journey. Whether you're a teacher, member of school staff, or a parent, we hope this collection of stories helps you to better understand and hear, gives you opportunities to identify scenarios you want to avoid as well as ideas to adopt, and that it gives you the momentum to push for things to be better for children with allergies in school.

METHODOLOGY AND APPROACH

LIVED EXPERIENCE RESEARCH IS A QUALITATIVE APPROACH THAT SEEKS TO UNDERSTAND THE UNIQUE PERSPECTIVES AND NARRATIVES OF INDIVIDUALS WHO HAVE DIRECTLY EXPERIENCED A PARTICULAR PHENOMENON OR CONDITION. THE APPROACH ACKNOWLEDGES THE IMPORTANCE OF FIRST-HAND ACCOUNTS AS A SOURCE OF KNOWLEDGE, INSIGHT, AND INSPIRATION. IT SERVES AS A BRIDGE CONNECTING ACADEMIC SCHOLARSHIP AND PERSONAL NARRATIVES, GROUNDING ACADEMIC DISCOURSE IN THE LIVED REALITIES OF PEOPLE WHO HAVE FACED ADVERSITY, TRIUMPH, AND TRANSFORMATION.

The significance of this research

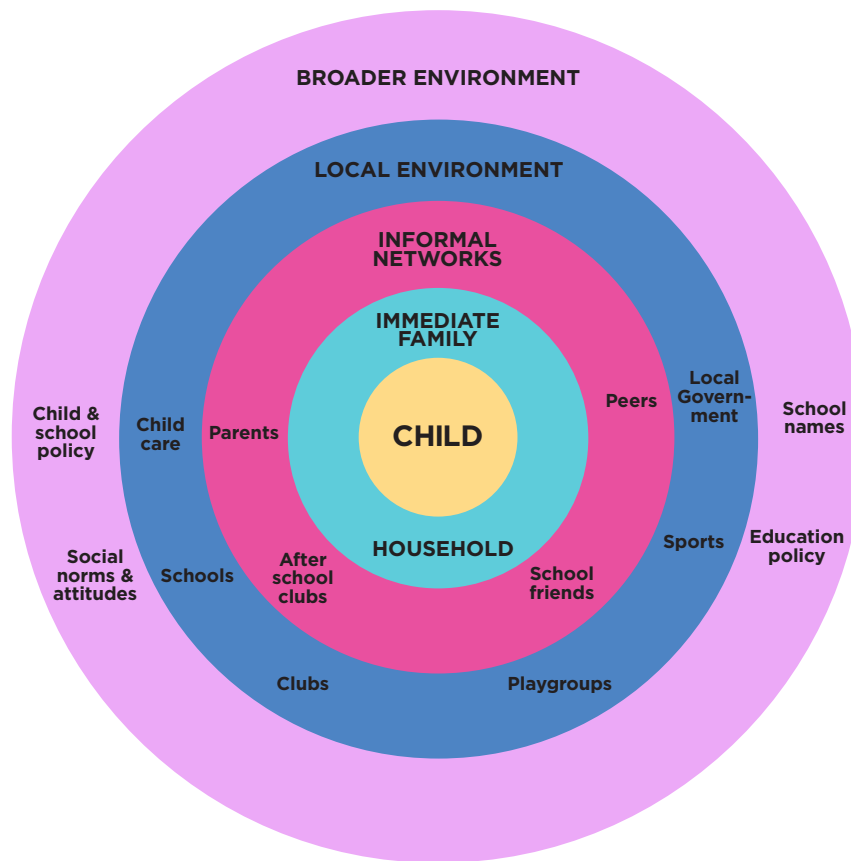
The significance of lived experience research into allergy management and awareness in schools lies in its capacity to challenge and reshape our understanding of complex social issues, identity, roles, mental and emotional impact and more. By centring the voices of those who have lived through these experiences, this research approach not only contributes to a deeper comprehension of the issues at hand but also empowers individuals to reclaim their narratives and provide valuable insights for researchers, practitioners, and policymakers. Moreover, it fosters empathy and compassion among society at large, enhancing the connections between people and encouraging positive change.

Ethical considerations

A core tenet of lived experience research is ethical practice. This research approach demands careful consideration of the ethical implications of sharing and interpreting the stories of individuals who have faced challenges and adversity, particularly where they are second hand accounts of the experiences of children. In our report, we place a strong emphasis on preserving the privacy, dignity, and autonomy of the participants who generously shared their experiences. All data collected adheres to ethical standards via the Sheffield Hallam University ethics process, and every effort has been made to protect the identities of our participants.

IN THIS BOOK OF SHORT STORIES, WE PRESENT A COLLECTION OF NARRATIVES THAT SPAN A WIDE RANGE OF THEMES. EACH STORY IS UNIQUE AND PROFOUND, CONTRIBUTING TO A RICH TAPESTRY OF LIVED EXPERIENCES THAT INVITE READERS TO EXPLORE AND ENGAGE WITH THE NARRATIVES ON A PERSONAL LEVEL.

The illustration gives an indication of what this structure looks like in the context of a child or pupil with allergies. Participants were defined based on the Bronfenbrenner model's tiers, with groupings including parents/carers, teachers/school staff, caterers and a child's peers.



Data gathering

To understand the experiences of a child with allergy, exploring the complex interplay between factors in human behaviour and development that are impacted by relationships and environment is necessary. The Bronfenbrenner model is a widely used theoretical framework in social sciences research that helps explore the complex interplay between factors in human behaviour and development. The theory posits that individuals are shaped by a series of nested environments, ranging from the microsystem (a child's peers and immediate family) to the macrosystem (cultural and societal influences).

Methodology of research

- Initial social-media research to gather key school scenarios parents would like to talk about during interviews to structure questioning. These included: Having Lunch, School Trips, Bake Sales, Crafts & Activities, and Celebrations
- Initial workshop with clinicians to test overall research design
- Interviews with parents with lived experience, teachers and school staff and school caterers – each around 45 mins in length

- Workshops with children with allergies using a create and art-based approach to gathering their experiences through drawing
- Development of 'Activity Packs' shipped to 25 children and distributed by email to a further 30 for them to contribute drawings created in their own time
- Key themes identified from thematic analysis of stories collated
- Stories are drafted and approved by participants and structured according to the three themes

Structure

In this book of short stories, we present a collection of narratives that span a wide range of themes. Each story is unique and profound, contributing to a rich tapestry of lived experiences that invite readers to explore and engage with the narratives on a personal level. The report is organised into distinct sections, with each section addressing a specific theme or aspect of lived experience research. These sections were defined based on light thematic analysis of the collated content, with safety, being heard and inclusion being the most common themes. Therefore, the findings are structured against those three areas: Being Included, Being Heard, and Being Safe.

THE BENEDICT BLYTHE FOUNDATION WAS ESTABLISHED IN 2022 IN MEMORY OF 5 YEAR OLD BENEDICT. AN ENTHUSIASTIC LEARNER, HE LOVED TO 'PLAY NUMBERS' AND LEARN ABOUT THE NATURAL WORLD.

INSPIRED BY HIS PASSION FOR KNOWLEDGE, EXPLORATION AND PLAY, BENEDICT BLYTHE FOUNDATION SEEKS TO SUPPORT OTHER CHILDREN TO HAVE THE SAME POSITIVE RELATIONSHIP WITH LEARNING AND EDUCATION REGARDLESS OF THEIR ABILITY, AND REMOVE BARRIERS TO EDUCATION BY CREATING SAFE AND INCLUSIVE SPACES FOR CHILDREN WITH ASTHMA AND ALLERGY.



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