

Learning from the tragic death by malnutrition of 7-year-old Alfie Nicholls

Zoe Connor speaks to the mother of Alfie Nicholls, an autistic boy with ARFID who died from malnutrition



In February this year, the national media reported on the death from malnutrition of Alfie Nicholls in north-west England. His mum Lucy wants professionals like us to learn from his death, in the hope it can prevent other children going through what he went through.

Lucy agreed to chat to me on Teams and for me to write up our chat for *Dietetics Today*. This is an edited version of our 90-minute chat. She has read and agreed the content of the interview.

I wanted first to offer my condolences, parent to parent. On top of that, I apologised as a professional for his preventable death. Despite putting a huge amount of energy into trying to raise awareness of the risks of eating issues in autistic children for over 20 years throughout my career, autistic children and their families are still widely let down by our profession and the systems we work in. This needs to change!

My heart feels heavy for Alfie, for Lucy and all the other family members and friends who loved him so much. Alfie's death was preventable. We can't bring him back, but we can honour his memory by doing our best to ensure it is not repeated.

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Let's let Alfie's story motivate us to have the hard conversations with colleagues and commissioners to push for better nutritional and feeding care for autistic children, young people and adults.

Alfie's early life

Zoe Thanks for talking to me, Lucy. Tell me a bit about you and Alfie.

Lucy Alfie's my first and only. I had Alfie at 22 so I was quite young. As a baby he took to milk like any other child. Very greedy, always every three hours. He was late at sitting up. He didn't walk until he was just turned 18 months. There were a lot of things he was behind on. But as he started to wean on food, food became a big worry. He loved porridge and Weetabix – beige, soft foods with no lumps. As soon as we tried the next steps and it came to lumpy foods, different textures, that's when it was very distressing. The only way I can explain it is, it was like he didn't understand how to eat – like he didn't understand the swallowing part, or he was just scared. But it was very, very distressing.

Autism diagnosis

Zoe When did Alfie get diagnosed as autistic?

Lucy It was a week after he turned three. His differences were picked up at his 18-month health visitor check. From a very early age he had speech and language therapists involved, an OT and a paediatrician. He was in a specialist nursery from three and then at five went to a specialist primary school. They told me he wouldn't talk, and he spoke! I couldn't have a conversation like, "Alfie, pass me your shoes" – he never understood that. But he understood words. And he could sing E-I-E-I-O. And he was very good with numbers.

He was very sensory. If a tiny bit of custard got on his face, he'd wipe his face frantically. He was very clean, Alfie. For a very long time, he wouldn't go on the grass with even just his socks on. He didn't like it. But then as time went on, he did.

I wouldn't have changed Alfie for the world. We had a special bond – it was Mum and Alfie forever. I love how Alfie was, like I wouldn't know him any other way, but it is hard when it looks like you're not doing enough as a parent or you're doing too much and it's like you or your kids are labelled as lazy.

Alfie's eating

Zoe Tell me more about his eating.

Lucy So, at first, he lived on a lot of milk. For a long time, he would have two boxes of baby milk a week, on top of porridge and rusks. It was like he didn't understand that other things were food. I was lucky if he would touch a biscuit. Eventually he would play

with it like an object in his own way. He would always scan things like across his eyes. And he'd always have to hold it in a certain way. If eventually it went in his mouth, it was never to eat it, it was licking it. Alfie took things in very, very small steps, so he might hold the same biscuit and lick it for a long time.

I fed Alfie most of his food. He stayed on baby porridge and loved custard and yoghurts. The yoghurts had to be a specific brand and type – the Milky Way yoghurt. For a long time, he would only take food off me (I'm a solo parent), but eventually he'd let my mum or auntie feed him. If we went to a different place, he would never eat. So it was always a constant worry. I was offered respite care but couldn't use it because I knew he wouldn't eat there.

He carried on taking milk from a bottle but only lying back. It was like he wasn't comfortable or didn't have the motor skills to sit up and use a cup. He was like a gannet. He would guzzle his milk as soon as he was out of nursery because he was that thirsty. He would only have this certain bottle and the teat – oh, it was shocking, honestly – but it was the only teat he would drink from. It had a big hole in the top. We tried every cup. We would try with straws. He didn't understand straws. But then when he was three or four, we lost his bottle when on holiday. And then he refused to have milk at all anymore. We then found it really hard to get him to drink anything.

"I was constantly putting water on his hand because he wouldn't let a drink near his mouth, and he'd lick it off"

Trying new foods was a very, very slow process. If there was something new, he'd get very distressed. One of the professionals told me to stop feeding him: "He'll do it when he's ready. If you keep feeding him, you'll be feeding him when he's an adult." And my answer was, "Well, if we need to feed him when he's an adult, that's what I'm going to do." I truly believe he really just didn't know how to eat.

The only things he'd feed himself were biscuits or certain crisps. He used to like those bacon Frazzles, but he'd only like lick them; once he'd licked all the flavour, they were done.

Zoe What would he eat on a typical day?

Lucy First, I'd warm some food up – baby rice pudding with custard and some vitamins added in. It was always a certain custard because he had to have a specific brand. And he always knew the difference. I'd wake him by opening his curtains. And then I'd say good morning Alfie, and some days, if he was that tired, he just used to just sit up, close his eyes and open his mouth for me to feed him.

He wouldn't always take anything to drink before school. For a long time, I was constantly putting water on his hand because he wouldn't let a drink near his mouth and he used to lick the water off his hand to keep him hydrated. That was the only way I could get it in.

For school, I'd pack stuff like a plain sandwich

with just bread, biscuits, custard and yoghurts in as well, and I'd always put different crisps in because sometimes he'd bring you the teddy bear crisps and lick them as well. But I'd always put something different in like a pancake. He did used to nibble on the pancakes sometimes.

He often only had five different foods he'd accept, which would sometimes change a bit. Towards the end of his life, he'd dropped a lot of foods and was mainly existing on custard. He'd have a lot of bowls of custard each day – I was constantly giving them to him.

My house was always stocked with food, even though he didn't always eat it. Nine times out of 10, the food got wasted. But I always made sure there were different things for him to try, even if it was just something like playing with Rice Krispies on the kitchen floor.

Help with eating

Zoe Did you get any professional help with his eating?

Lucy The OT did a little bit around food when he was younger, just a handful of times. They'd try and put food around him to see if he was interested in it, but he went nowhere near the food. At nursery he was doing a lot of food play and sometimes he would try a few new things. Once he moved up to primary school there was less support. The school nurse never even met him.

In the June or July before he died, he was really struggling with not drinking at school, so they referred him to someone to help and it took months to see them. Around that time, he started eating less too. He started going off his porridge so he was mostly having custard. In about August, someone came and tried to help him learn to drink from a straw, but they didn't cover food. We never saw a dietitian despite me repeatedly telling professionals how worried I was about his eating. His eating just seemed to be blamed on his autism.

The four weeks before he died

Zoe Can you tell me what happened in the weeks before he died?

Lucy About four weeks before he passed, he was knocked off a small bench at school and banged his knee. It wasn't major. We took him to the hospital for a knee scan because no one could understand why it wasn't getting





better. Alfie was still taking food from me, but it was becoming less and less, and he was losing weight. He was being weighed at appointments, but no one seemed worried about it.

At our third hospital visit for his knee, three days before he died, the paediatrician said his inability to walk was just his autism – that he was fixating on his hurt knee but there were no signs of damage. They'd lost some of his blood test results but said he needed to take some iron tablets.

"The school were on at me to get him back to school, if only for me to have some respite because I was going crazy"

The signs were there then that he was a really poorly boy. Alfie was always really happy. He didn't like anyone else making much noise, but he was usually so noisy. He was usually so funny – he'd sing you a song making up all his own words. But Alfie was becoming increasingly quiet, lifeless. He couldn't walk. He was sleeping all the time. He'd been weak for weeks and no one was listening to me. It was like hurting his knee took all his reserves.

The school were on at me to get him back to school if only for me to have some respite because I was going crazy. I said he was too poorly. Two social workers came the day before he died. The school wanted them to check Alfie was ok. I'd told them he now had bruises on his back. I honestly felt like they really weren't listening to me – that they thought I was going crazy and hurting my boy, but I really wasn't. No one would just listen to me.

When the social workers came round the day before he died, I was going crazy, saying they

THE JUDICIARY REPORT

The Alfie Nicholls: Prevention of Future Deaths report was published in February this year. It concluded that Alfie's death "was caused by a severely restricted diet and where the level of malnutrition and the consequential risk it posed was not recognised by professionals until after his death". It further stated that "the risk that his nutritionally poor diet could present to his physical health was not understood or recognised by professionals involved in his care".

The coroner raised concerns that "there is a risk that future deaths will occur unless action is taken". Particular concerns were that "normalisation of poor and restricted eating by children with autism meant that the impact on their overall health and wellbeing was not considered; and that the role of a dietician [sic] in supporting children with eating disorders could be fundamental in maximising the nutritional value of what they consumed. Demands on the service and a limited understanding of how they could work to support children with disorders such as ARFID (nationally) meant that there was rarely regular input from dietitians".

The chief executive of NICE issued a response in April 2024 that until there is more evidence to draw on, a guideline for ARFID is unlikely but that, in the meantime, "clinicians should follow the information provided by specialist groups such as the British Dietetic Association's ARFID position statement".

The response from the local NHS Integrated Care Board highlighted that, in response to Alfie's death, there has been a culture shift regarding eating problems in autistic children. A review of all children known to paediatricians resulted in three children having PEGs fitted. New pathways involving dietetics have been set up, including routine referrals to dietetics for all children with restricted diets.

The response from NHS England highlights that guidance on the management of ARFID in children and young people is due out for consultation soon. The response makes little mention of dietitians but highlights the need for more school nurses.

The Alfie Nicholls: Prevention of Future Deaths report can be found at judiciary.uk/prevention-of-future-death-reports/alfie-nicholls-prevention-of-future-deaths-report/

couldn't take him to school, he was too poorly. I eventually let them in, and they saw Alfie in his bedroom. They saw me feeding him in bed and how poorly he was. Then they just left.

The next morning, on Friday 17 December 2021, he didn't look right. I ran a bath because he seemed to be in pain. Alfie would sometimes have three baths a day, sometimes because it would help him poo, but he just loved being in the bath. I had to carry him because he couldn't walk. I was trying to stay calm but spoke to someone who said to ring an ambulance. They were there within minutes and I got him out of the bath and dry. I kept saying

“How many more children have had this and died and it’s been passed off as sudden death because they’re autistic?”

don't let him faint. Don't let him faint, because if he faints, he won't wake up.

But he did faint, and he never woke up again.

Life since Alfie's death

Zoe I'm so sorry Lucy, can you tell me what happened next?

Lucy Alfie got taken to hospital and I got interviewed by the police in the hospital like anybody else, and then they had to go and check my house. It was a very good thing, because even though he'd been poorly for a month they could see it was well stocked with food.

For a long time, especially after he passed, I thought it was my fault. When I saw someone for his sleep, they'd always say, don't feed him if he wakes at night. But I didn't listen, I still fed him, so was it my fault? I could never ever leave him if he was hungry. Maybe his sleep problems were because he was so hungry rather than the other way round.

There was an inquest into his death and I didn't attend any of it until the final verdict two years later. When I got to read all the folder of evidence, I was convinced it would be full of things I'd done wrong. In the year before his death, I was all over the place because my dad had died, and I wasn't getting the support I needed. I worried I hadn't been telling people about his eating. I couldn't really remember

as it was all such a blur. I was tired, totally run down. But it was there in black and white. I'd brought it up all the time. The bruising was from malnutrition. If his ribs hadn't broken while the paramedic did CPR – something unusual because seven-year-olds should have flexible ribs – his death might have been a sudden death verdict, and we wouldn't have ever known the reason for his death.

What's next?

Lucy Me and my friends want to set up a charity to raise awareness of eating problems and ARFID and autism. There seems to be lots of info about ARFID, and lots about autism, but no one seems to be talking about autism and ARFID. We don't want Alfie's death to be in vain.

We met a beautiful little boy at the weekend when we did a charity walk to raise awareness of ARFID. He's autistic and non-verbal and he's three, and because of Alfie they managed to get him PEG fed. He almost died as well.

I kept thinking after the inquest that everyone would think that I didn't feed my child, but now I'm realising there are many other children like Alfie and many other parents struggling. So we want to get the awareness out there. We want to get his name out there. I want to speak for Alfie. Children like Alfie need help to get better nutrition and help them to learn to eat.

How many more children have had this and died and it's been passed off as sudden death because they are autistic? I really hope we can try and make sure that everyone will be thinking about this when they see a child with a restricted diet.



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Dietetics

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