



An Open Letter to our Family & Friends

Dear family and friends

I hope that you are all well. I need to explain a few things to you, things that are central to the way we now live our life, things you may never have realised, things we have perhaps unwittingly or even deliberately hidden as we've sought to understand.

Our family life is fraught, it's busy just like yours, we do sports, we go on holiday (sometimes short), have days out and celebrate events but we always ensure we plan, we have a plan A, a plan B and probably the most, a plan to respond to crises when the day just goes upside down. You see, we are not being rude when we are vague in our replies to invitations, to evenings out or to enquiries about our children's progress. Every day for us is progress, little steps, as many backwards as we do forwards.

I thought life was made of milestones. It is. Nursery, school, followed by uni and jobs and lots of adventures along the way. Isn't that how it is? I'm not sure anymore. I didn't bargain for having to hold my child's hand through some of the roughest terrain I've ever encountered. I had no idea he was heading for a fall. Sometimes there are clues along the way: struggles with uniform; shoes; homework; friendships and understanding, we brushed them off as part of 'normal' development, we'd get there in the end. You cannot tell the future, none of us can.

'My child does not attend school.' There, I've said it.

'What?' I hear you say, 'I'd make them go. How do you manage? What do they do all day? What do you mean, he can't? But, it's not allowed... What about uni? What about a job? Exams?'

What? All the stuff that 'normal' kids do?

My child just can't go to school, it's hard to explain. He cries, over time he's screamed, he's confused about it all. Sometimes he's poorly, sometimes so desperate he's violent or hurts himself. It's difficult to unpick. Reading's hard, spelling's worse. Friendships? Goodness, I don't know where to start. What is clear is that somewhere in there 'school' has made him ill and not being

there has helped him to be better; to be calmer; to be able to think; to be able to talk more; to feel he's safe.

'Surely someone can help?' I hear you say. Where would you like me to start? We tried the GP, they referred to CAMHS; the school nurse, I tried her too, along with the MP. School? Well, sometimes they care, sometimes they just don't have a clue, they are geared up for children who just keep on going. They've tried to threaten with fines and punishments, sometimes persuasion and encouragement but I'm not sure they really know what to do. My child just cannot cope with school.

Other people tell me to shout, to force, to drag out of bed: it so doesn't work. We just end up in a double meltdown, that's him and me. Counsellors claim to have the answers, therapies for this and for that, to support my child, to support me, to support the family but nothing stands out as succeeding. I've learned to follow my gut, maybe that's why you've never noticed. It hurts that I can't help my child, it's hurting that no one knows how to help. Maybe it's just part of growing up.

'Who else have you tried?' I hear you ask. Let's see, Counsellors, Paediatricians, school staff and oh yes, we started with the SENCo at the school, you see, none of this works very well unless they see it for themselves. I've become an expert at documenting every move; emails, letters they are all vital to our trail of evidence. I've amazing friends online who are drifting in the same stormy seas, the numbers are scary but no one seems to realise.

'Does he stay at home alone?' Well, sometimes, sometimes not. It's tricky, it depends on age. I used to work, we fought our way in to school, I juggled it all, until he could manage no more and we had to rely on texts and calls. He wouldn't answer the door and it worked for a while, but we had tears at night, we didn't sleep, we'd try for school every morning. I'd arrive at work frazzled and stressed, so, I don't do that anymore. I dropped the work, let's face it, I couldn't let my child fall.

So, what now? I could be fined, I could be prosecuted, I could even face a prison term (now you know the worst..) Will it happen? We're battling to gain support. I have no idea, I live day to day and hope that someone might just help but I've realised nobody can force this. What can I do? Well, I look after my child, I fight their battles, I speak to school, to counsellors, to CAMHS, to doctors, to try to find a way through the maze that we have found ourselves in. Above all else, I follow my child's needs and slowly we have improved how he feels.

You asked me what you could do to help? There are some things that could make such a difference:

Talk to me, come to the house, a cup of tea, a cup of coffee, it will help me to breathe (it's certainly not catching).

Think about the behaviour you have witnessed from my child, can you help me unpick it? I need to understand the triggers. I know it's not just a tantrum.

Listen to me, especially to my child; he just can't manage school. Attending other activities is still, perhaps more important, so yes, a playdate, sports, walks, a picnic, we'll try to get there.

Remember my child is just a kid, he's frightened and doesn't know what to do.

Please avoid making judgments (plenty already are), consider how you would feel if it were you. You might think of something which hasn't yet struck me.

Getting back to school might not be the answer, 'education' does not always mean 'school', help us find the right fit.

If I have to give up on my hopes and dreams or even my job, for a while at least, support me, I'm doing what my child needs. We're a ship that's gone off course and need to find our own route.

If I talk about alternative education; part-time school; flexi-school; Pupil Referral Units; online learning or even de-registration; 'unschooling' and elective home education, take an interest, smile and please don't shake your head.

In finding a way to understand the labyrinth we are caught in, consider if you could be a witness to the way I parent my children; how proud we are of our successes and find some time to attend the myriad of meetings where I act as my child's advocate, I'd be very grateful.

Being 'Not Fine at School' is hard. It's reassuring to know that someone might take the time to understand.

Thank you xx