

Question: Is there any piece of advice you could give parent carers who are at the start of their journey?

Journey Battle Health Network Good
Luck Honest Push Expect Support Social
Services Fight Lots Child Learn to Help
Parents Diagnosis Ask Little Think

These are the individual responses of parents, many still feel the need to fight for services to achieve the desired outcomes for their child or young person.

Find out as much information about your child's needs as possible - including by law what they should be entitled to.

If you can afford it get private for OT and SALT as the twice yearly appointments Central Beds offer you is not enough to help your child.

Don't change authorities, I feel my child missed out moving from London.

You are not a monster for wanting what your child deserves, so don't be made to feel that way. Just keep chasing what you need and find comfort in those **fighting** the same battles as you.

Fight for everything or you will lose out.

Drive the EHCP.

Keep pushing, nothing will happen for your child if you do not push for it.

Just stick to it no matter how hard.

YOU are the expert about your child, the professionals are experts about conditions, not specific children. Stand your ground and **fight** for what you KNOW to be right for your child.

Don't be put off. If you think your child has problems, keep asking for help. Experience has taught me not to be brushed off with excuses of budget cuts and lack of facilities.

Make sure you find out as much as you can, don't sit back as it will be down to you to make everything happen. Do not rely on the school or the health service to be correct in their judgment.

Find a support group and read the Code of Practice.

Prepare to have to **fight** for everything for your child.

Move away from this area.

Yes, it is hard but there is always someone (if you know where to go and get the help) to help. You have to think positive and take one day at a time. Sign up for courses on your child's condition.

Don't give up and **fight** for your child. You might be only one person in child's environment who believe in him/her.

Fight! You are your child's best advocate, you know your child best. Be prepared to **fight** for what you believe in and need as nothing is offered without a **fight**.

Don't give up! Document and record everything. Be prepared to chase, and where necessary **fight** for what you feel is right for your child.

Keep **fighting** and pushing.

Keep **fighting** for what your child needs and don't give up.

Ask other parents for their advice as they're the best source of support.

Fight, fight, fight. You are the only one who fully knows your child, you are their advocate. Never give up until they get everything they need.

Good luck, you need it! Never give up!

Be strong and keep **fighting** for what you think is best for your child. Everything is little steps,

Believe in your child always.

Find other parents in the same situation as you otherwise you will never know what help is out there because the Local Authority do not tell you.

Unfortunately, you need to persevere and **fight** for everything.

Take every opportunity you can to find out as much as you can and talk to people in similar situations for advice and support.


Don't give up. You are the only one that can **fight** your sons/daughters corner. You may hit many brick walls but keep on going.

Get informed about your rights, knowledge is power. Have the courage to challenge any professional that is involved if you do not feel they are right.

Talk to other parents.

Good luck.

Don't give up.

Be strong and don't take no for an answer, you know your child best 

Communicate with Health Visitors and involve yourself. Don't let your pride prevent you getting help for your family.

Ask questions & never stop. It feels like you are told the bare minimum & have to claw information out of anyone.

Talk to other parent carers, it can be a lonely road and they know a lot! Also, if you need help ask!

Keep going - they are your children, they don't deserve to struggle - you will get there...we all will, as will our children

Keep on it. Don't assume anyone in the system knows enough or has your child's best interests at heart. Some do, but others are just box-ticking.

Log all information, dates and times. Be prepared for a battle. Don't give up!

You are going to get very little support from professionals so you need to do all you can yourself.

Find a support group. Be prepared to have to **fight** for services and for your views to be heard.

Be prepared to **fight** for all the help and support your child needs. Speak to other parents on the same journey they are often the most useful source of information and support.

Early intervention is key.

Meet with your child's tutors at enrolment (we did this) and follow up in the first few weeks of the first term, make sure you email concerns and be receptive to suggestions and work with your young person's tutors to develop the best outcomes.

Read up on all processes and find out as much info as you can.

You will know your child best and don't let any professional put doubt in your mind.

Talk to other parents. Until the professionals are forthcoming, other parents have the best advice and experience.

To ask for help when needed. To find out information about their disability. To join appropriate groups.

Never give up **fighting** for your child. Try to find support. Listen to your child you know them better than anyone, trust your instincts.

Keep proof of everything and keep notes.

Be pro-active, get as much support as you can.

You need lots of patience!

Read anything & everything, talk to others & gain a good network of positivity.

Good luck and shout very loud!

Keep on top of everything, don't be afraid to ask questions, make phone calls and send emails every day until you have the information you require.

Liaise with other parents.

Find parents in the same boat as you.

Listen to your gut feeling and keep pushing for help.

Learn to help yourself as you're on your own with no help from CBC.

Stay strong and never give up.

Fight hard you will need to.

Don't be afraid to ask for help and more information.

That it will be ok, your path will be a different one and you will have to learn to be brave and take on **fight**s, but you and your child will be ok.

You will have lots of Social Services involvement.

Don't be embarrassed or overwhelmed, reach out to anyone possible.

Fight hard and don't take no for an answer.

Find a local support group. Research your child's disability and consider what that will mean to your life as a carer. Expect a **fight**.

It's not as bad as you think it will be, your child sees the world differently.

Come to meetings you can find out so much and help others.

Strap in - link yourself into other parents. They know more than most practitioners and it can be a lonely intimidating place sometimes and other parents are the only ones who understand.

Come to the parent's events as a lot of the information I've received has come from other parents.

Gain friendships with other parents in the same boat.

Utilise all resources available.

I know of private support groups not related to the council who can help.

Get in touch with Outside In and Parent Partnership, go to as many talks/lectures as you can.

Move to somewhere that has better facilities and provisions for children/adults with special needs.

Be prepared to **fight** for all the help your child needs. Accept that the Education and Mental Health services are broken. Be prepared to go private to get the help your child needs.

Push for an early diagnosis if you feel your child need a help. Follow your instincts, you know your child best.

Don't expect anything to happen quickly and don't expect an easy fix.

Fight your child's corner

Find other parents who are in the same boat and share tips and stories so you know you're not alone.

Don't give up if you think something is not right, don't let anybody tell you otherwise as you are probably right.

Keep **fighting**, push your views, write everything down.

It takes time and nothing will change straight away overnight.

Be open and honest.

Go with your gut. If you are concerned, drop ins are brilliant. Your child thinks they're there for an explore of new toys and you get professional advice.

Fight, fight, fight. It's all up to the parents, you won't get any help from anyone else.

Join support groups - not just online. Meet up with like-minded parents in the same situation as you. My SEN mum friends are at the end of a text and it really helps.

Speak to other parents. CBC ARE useless and understaffed. Forget a placement as there is no space anywhere.

Find a good support network. It's a minefield where you are left on your own to find out what you can do next

Move out of Bedfordshire.

Find other parents on Facebook, they know their stuff.

Keep **fighting**, don't take no for an answer. You know your child better than anyone.

For hearing impairment, HAST have been amazing and their advice brilliant.

Be strong. Be confident about what you know about your child. Don't be afraid to speak firmly if necessary. Follow things up (including appointments and reports). Gather as much info as you can about the process and accept any help or support.

To communicate effectively with school & other professionals to ensure everything is being done to make sure your child is getting the best support available.

To keep **fighting** for their child & themselves to be supported. Do not give up.

Fight, fight and fight. Make your voice heard to everyone who will listen and don't take no for an answer.

Bring in social services early as they can influence the other agencies.

Fight for the services you need.

You will have to chase everything yourself.

If you don't **fight** for services, you get nothing.

Get a photocopier, loads of files and separate contacts/phone book just for your child. Gather good neighbours and value any family support you have because you are going to need it. Meet with other parents in SEND world at every opportunity.

Love needs no words.

Do and much autism-friendly research as you can i.e. only read books written by autistic teens/adults etc.

Ask and talk to Parents who are there already with a child in Special Ed.

Go to another county.

Meet other parents in the same situation as you find out lots of knowledge.

Learn the law so you can put yourself against the system with knowledge.

Don't give up, you know your child. Find a supportive GP - mine was fabulous and really helped make that initial step easier to take.

Get as much advice as you can from other parents and services.

Don't give up.

Speak to other parents. Attend support groups because that's how you find what you need.

Make contact with parents who are further along in the journey. Make sure you can understand the system. If you don't then get some advocacy.

Keep at it.

Go on courses like Outside In offer to help understand and come to terms with your child's needs.

Take each day as it comes and don't be afraid of changes, such as moving schools. Also join groups of parents in a similar situation to you, and access information through courses, breaking down barriers by Outside-In was excellent.

Fight, fight and keep fighting

COFFEE is the best. Talk to other parents and always be proactive, honest and flexible.

Keep asking questions.

Ask other mums because no one tells you anything.

A diagnosis is the beginning to understanding. Not the end.

Make contact with other parents in a similar position. Negotiating the system will take all of your time and energy, it will be financially difficult for you because you won't be able to hold down a job due to all the appointments and paperwork. Look after your own relationships as special needs can take over because the system is so disjointed.

Push all the way.

You have to push all the way.

Get used to **fighting!**

Things do get better, I never use to believe this but it really is true.

Be prepared to **fight**. This is a battle not a conversation. You are not alone and do your own research.

If you feel your child needs extra support don't stop asking, be persistent.

Speak to people that are on the journey.