



**You are
not alone**



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Intro



Finding out your child has an additional need can be overwhelming, filling you with many thoughts, feelings and questions.



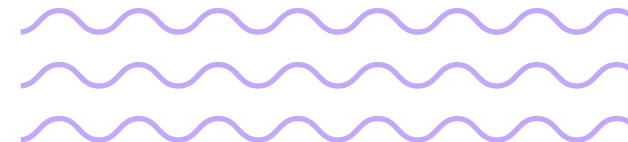
Waltham Forest Parent Forum is a parent carer forum, run by parents and carers of children and young people with special educational needs and/or disabilities (SEND). We wanted to help remove the isolation and barriers you may be facing.

We have put this booklet together for parents to pass on their supportive, positive parenting comments and top tips and for them to show that you are not alone,

We hope the support of their words can bring you knowledge, confidence and courage on your journey as a family. You are a great parent and you will be an amazing advocate for your child.

We are all there for you.

Anything is possible when you have the right people there to support you.



SAYINGS

Everyone is different, but everyone is special

Listen to your child

The diagnosis is not the end, as it may seem. You have lived with this so far and you will only continue to grow and help your child be the best they can be!!

You are doing a great job; we all get overwhelmed

Take every day as it comes. No two days are the same.

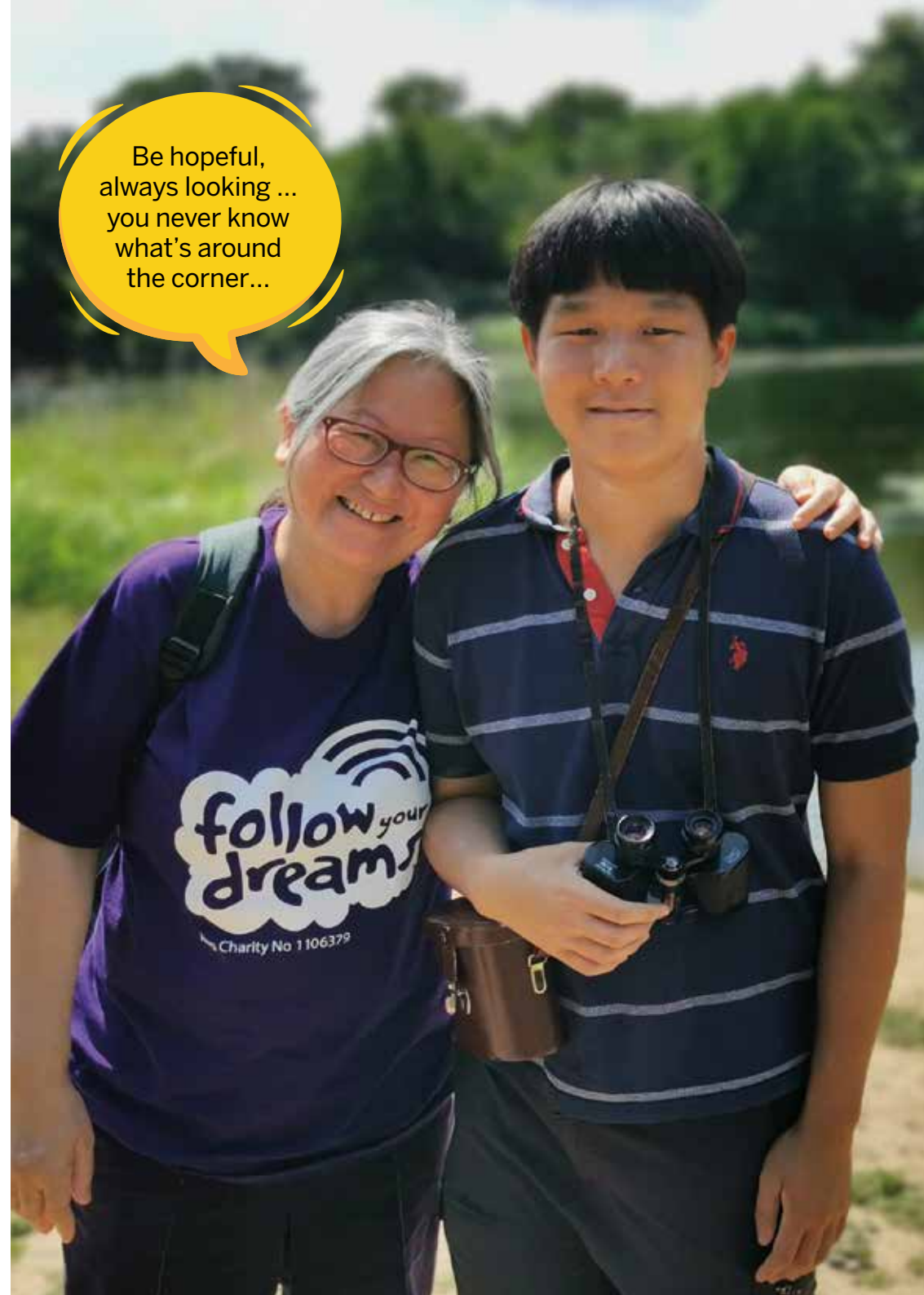
Your child's SEND does not define who they are, but makes them exceptional

Welcome to the wonderfully special club that no-one asks to be in

Trust yourself

Your child's silence is your invitation to be their voice. Be the best one you can be.

Be hopeful, always looking ... you never know what's around the corner...



TIPS



▶ Your child will help you appreciate the small wins in life! You'll learn to live in the moment and relish celebrations, big and small. You may feel tired, you may feel angry, you may even feel like you can't do this anymore. All these feelings are valid. Don't let anyone, not even your own conscience, tell you otherwise. We all feel this way every now and then and why wouldn't we? We've been chosen on this special journey, where everything requires extra effort. So, whenever you feel you're running out of fuel, do what you need to do to recharge yourself. If it means letting your child have longer screen time than usual, then let them. For you can only give your child your best when you feel your best! You got this! All my love...

▶ Always do your own research and question everything you are not sure about.

▶ A few years ago, I went to an Autism workshop. The speaker was a gentleman who wore a snazzy holiday print shirt and said that he was also autistic. He mentioned something so memorable that I have treasured to this day. He said: "Do not introduce your child to others with their deficit." He said if someone were to introduce me to someone else, I would like them to say, "Hey this is Dave... (for example) he's my friend who wears nice shirts." The idea is that you wouldn't introduce anyone with their shortcomings and disability at first. Their disability doesn't define who they are.

▶ Pick your battles (especially with your child).



▶ Child with lots of appointments in lots of places? Get a huge lever arch folder and store medical reports, letters, etc as soon as they come in. And then take it to every appointment. Digital versions work well too, but remember medical settings rarely have accessible Wi-Fi and you might need a report in a hurry.

▶ The help and support you find from other parents is invaluable and priceless, don't be afraid to reach out.

▶ Accept support. It took me a long time to realise this. Accepting help is not failing, it's recognising that I am not alone.

▶ Gather a support network around yourself, family members, friends or a local support group. They will be invaluable if things get tough.

▶ It can feel like sometimes there's just too much to learn or understand straight after the diagnosis. Don't try to do everything at once. Focus on small things, one step at a time.

▶ Ask which groups/workshops you can attend and go to at least 2 soon after diagnosis. They will allow you some time to talk with other parents, listen to experts and start coming to terms with the diagnosis, which may have come as a massive shock to you. It'll be emotional but it can be a really isolating time and you need to know that you're not alone with your experiences.





Be persistent with schools, healthcare providers, etc. I have made the mistake of not following up on stuff quickly and time certainly slips away if you don't keep your eye on things!

Self-care is paramount. Take regular time to look after yourself physically and mentally, even if it's just for a short time every day. I attended Sarah Fisher's NVR course in January 2019 and, after some general introduction to NVR, she dived straight into self-care. It had a massive impact on me - at the time I was really struggling (classic post-Christmas holidays exhaustion!) and Sarah's emphasis on self-care prompted me to face up to my mental health issues and to seek help. It was a real turning point for me, as taking regular time for myself to have therapy, or do a hobby, or do exercise, or sit and watch Midsomer Murders, no longer feels selfish - those things make me a better parent because I'm more relaxed and find it easier to keep things in perspective. Most of the time...

Remember that some things are under our control, whereas others are not. I read a bit of Stoic philosophy these days. It wouldn't appeal to some, but this is a key Stoic theme, and it really helps me to manage my expectations of myself, others and the world in general.

Join as many groups as possible for advice, and remember, knowledge is your ultimate power.

Look after yourself as well as your child.

Join Waltham Forest Parent Forum (WFPF)! It's excellent! Lots of help, support and a listening ear!





Waltham Forest Parent Forum

If you are a parent or carer of a child or young person with special educational needs and/or disabilities (SEND) aged 0-25, live in Waltham Forest, and want better services for them and support for you and your family...

THEN JOIN US NOW!

Find us: walthamforestparentforum.com

Email us: walthamforestparentforum@live.co.uk

Call us: 07794 298496 or 07528 433640

LOCAL SUPPORT

Life with a disabled child brings unique challenges, which is why it is important to find support. There are many organisations and websites, locally and nationally, which can offer support.

LOCAL OFFER

The Local Authority must have a website dedicated to special educational needs, which includes everything that is available in the area to support families of children with SEND.

www.walthamforest.gov.uk/schools-education-and-learning/local-offer-special-educational-needs-and-disability-send

SENDIASS: Special Educational Needs and Disability Information, Advice and Support Service

All local authorities must fund an information and advice service to offer support about education, health and social care issues to young people and parents. The provider of the service may change as contracts are renewed so it is always best to check on the local authority's website for further details.

www.walthamforestsendiass.org.uk

CARERS FIRST WALTHAM FOREST

Carers FIRST is a not-for-profit organisation supporting people who look after a relative or friend who - due to ill health, physical or mental illness, disability, frailty, or addiction - cannot manage without their support. They provide information, advice, guidance, emotional support, training and activities, giving carers an opportunity to have a break from their caring role and help them to get the support they need.

www.carersfirst.org.uk

FLOURISH SPECIALIST EDUCATION SERVICES (formerly SENDSUCCESS) support children and young people with vision impairment, those who are deaf or hard of hearing, those who have learning difficulties or those with autism spectrum conditions. They work closely with schools, giving them the tools and knowledge to enable their pupils to thrive within a mainstream or special school environment.

www.flourishspecialisteducationservices.org.uk

NELFT (North East London Foundation Trust) provides an extensive range of community and mental health services for people living in Waltham Forest including health visiting, speech and language therapy, children's physiotherapy, occupational therapy, the Child Development Nursing Team, the Continence Advisory Service, the Community Learning Disability Team (CLDT) and the Child and Adolescent Mental Health Service (CAMHS).

www.nelft.nhs.uk/home

CAMHS

The Child and Adolescent Mental Health Service (CAMHS) is the specialist mental health team providing support to children, young people and their families. The service is available to families with children & young people from birth to their 18th birthday. The service offers help to children and young people who are experiencing emotional, behavioural or mental health difficulties.

www.nelft.nhs.uk/camhs-home

For those over 18, there is an adult Mental Health Single Point of Access for referrals.

www.nelft.nhs.uk/waltham-forest-mental-health-single-point-of-access



HENRY

The Henry service is the current provider that supports families with children aged 0-5 to provide the best and healthiest start in life for their children.

Their family services cover three key themes:

- Infant feeding – breast, bottle or mixed
- Healthy eating
- Oral health

As the service provider may change when contracts are renewed, please check availability with your local Family Hub

www.henry.org.uk

As the service provider may change when contracts are renewed, please check availability with your local Children and Family Centre.

FAMILY HUBS (formerly Children and Family Centres) provide a comprehensive programme of activities and support for parents and young people of all ages through:

- * Best Start in Life activities for 0 to 5 year olds,
 - * Support through the Space4All programme for young people aged up to 19 or 25 for young people with special educational needs and disabilities,
 - * Early Help Service's wide range of support for parents.
- Based in the heart of neighbourhoods, Family Hubs offer everything from health and housing services and employment support to creative play and parenting programmes, plus much more.

Family Hubs are open 6 days a week and including an accessible out-of-hours phone line.

www.walthamforest.gov.uk/families-young-people-and-children/family-hubs



NATIONAL INFORMATION AND ADVICE ORGANISATIONS

Cerebra - the national charity helping children with brain conditions and their families (www.cerebra.org.uk)

Contact - for families of disabled children- a charity which offers support and advice and support and which campaigns for better services for children and young people with SEND (www.contact.org.uk)

Mencap - a UK charity for people with a learning disability (www.mencap.org.uk)

Scope - a disability equality charity in which provides practical information and emotional support (www.scope.org.uk)

Sunshine Support - award winning SEND consultants (www.sunshine-support.org)

Council for Disabled Children - a charity that calls for better services for SEND children and young people (www.councilfordisabledchildren.org.uk)

Special Needs Jungle - News, info, resources & informed opinion about Special Educational Needs, disability, children's physical and mental health. (www.specialneedsjungle.com)

IPSEA - Independent Provider of Special Education Advice (www.ipsea.org.uk)

SOS!SEN - The independent helpline for special educational needs (www.sossen.org.uk)

SENTAS - Special Educational Needs Transport Advisory Service (www.sentas.co.uk)

Mind - a registered charity supporting people experiencing a mental health problem (www.mind.org.uk)

Youngminds - Children and Young People's Mental Health Charity (www.youngminds.org.uk)

Eric - The Children's Bowel and Bladder Charity (www.eric.org.uk)

Sensory Spectacle - offer workshops, online training and immersive learning experiences to give a unique insight into the lives of people with Sensory Processing Difficulties (SPD). (www.sensoryspectacle.co.uk)

Spectrum Gaming
Spectrum Gaming is an online community for autistic young people which also has resources for parent carers (www.spectrumgaming.net)

Autism Understood
A website about autism, for autistic young people, created by Spectrum Gaming. (www.autismunderstood.co.uk)

Condition Specific Help - If you want to find out more information about your child's condition, the charity, Contact, have a useful A-Z of conditions which provides helpful information and links to condition specific support groups. (www.contact.org.uk)

