

Top tips from the Small Steps Team



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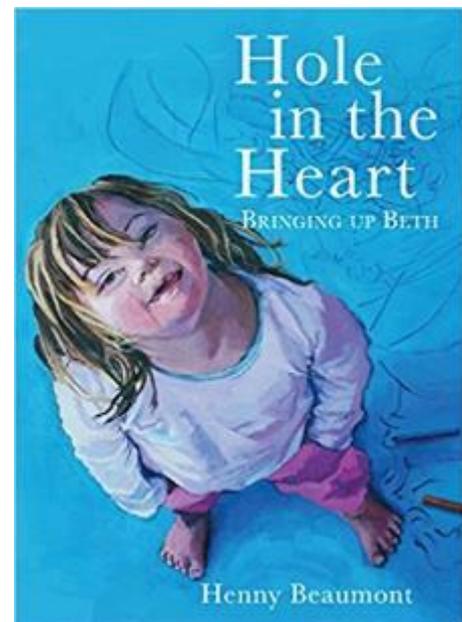
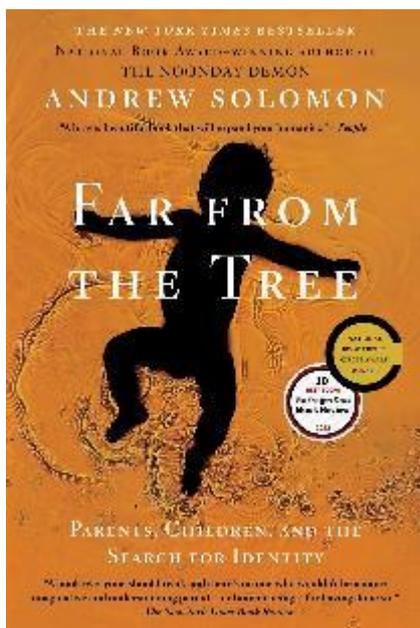
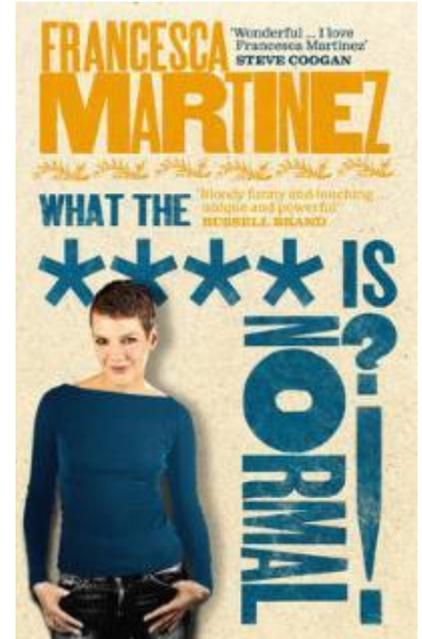
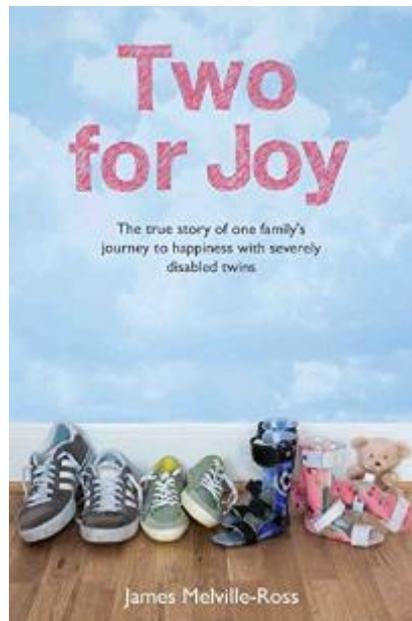
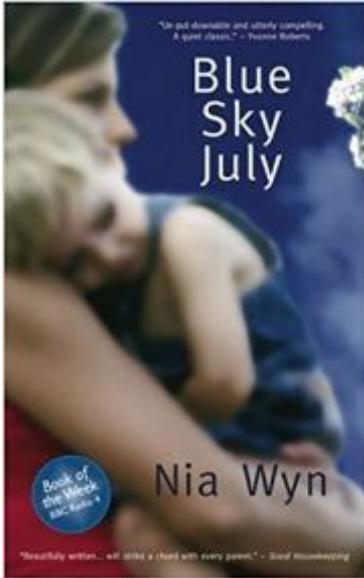
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Top tips from Anita (Head of Small Steps)

1. Introduction, practical activities

Feel free to speak to her for further details ☺

2. Books



Top tips from Bettina (Practitioner – Conductor)

1. **It's fine to take breaks between activities.**

Our 2 hours sessions are very interactive and packed with lots of activities. If your child need some 'time out' feel free to sit down on the side and have some water, read a book or just have a cuddle.

2. **Makaton** signs are brilliant and a great opportunity for your child to express her/ himself.

Use it consistently at home as well. Sometimes children find their own way to use a sign – it's absolutely fine using the signs their way as long as it's consistent and always stays the same.

3. **Conductive Education** what we use at Small Steps is a holistic approach. One activity can improve so many aspects of the child development. – gross motor, fine motor, self-care, communication, social interaction etc.

So when we 'just sing a song' it's not just singing. It's all about active learning: keeping symmetrical position, keeping feet flat, listening, looking, following instruction, copying action, attention, focus, turn taking. – many ways to learn new things when singing.

4. **It's important to practice standing and walking** on the right way.

Children are learning a bad pattern of movement when they are not fully weight bearing because they lean backwards, crossing their legs or walking on their tiptoes - this is what we want to discourage. So do sit to stand: keeping feet flat, knees in the middle, arms straight, push the ball / ladder forward and then stand up. Standing: keeping knees hip width apart, hips in the middle, back straight.

Walking: helping at shoulder or at arms but keeping them shoulder high or lower (because when they practice STS they pull themselves up with their hand and when they walk it's close to the natural walking).

5. **Be positive** – you always can find one thing to be proud of.

Session can be a bit hectic. We all have good and not so good days. But we always can find at least one thing what went well on that session. Maybe it's just reading a book, tidying up something, shaking hand with a friend – but every small step count. So be positive. 😊

Top tips from Kas (Practitioner – Physio)

1. Posture and Alignment

Remember to have a little look at what your child's body parts are doing in every position.

You can think **top-to-toe**:

- **Head**
- **Trunk**
- **Arms**
- **Hips**
- **Legs**
- **Feet**
- Are they in the **middle**?
- Do they look **symmetrical** or about the **same** on **both sides**?
- What can I do to help them? For example, **encouraging** and **asking** them to **correct** their **posture**, **physically helping** them yourself or using **pillows, blankets, towels** and other equipment to help keep their body in line.
- You can think about a stick girl/boy 😊

<http://apcp.csp.org.uk/documents/parent-leaflet-promoting-physical-development-lying-sitting-2015>

2. Repetition

Little and often

- Don't worry about blocking out 2 hours per day for practicing skills and activities.
- **Remember** you can **repeat activities throughout each day**, repeating short tasks like:
 - **Looking** at and **following** your **favourite toy**;
 - **Bridging** and lifting hips up when **changing nappies**;
 - **Rolling or crawling** across the floor to get to the other side, before being picked up or to get to where you want to go;
 - **Lie to sit transfer**: actively tucking chin down/ lifting head up, rolling to side, pushing through arm, pulling with hand etc;
 - **Sitting** with legs straight when **reading a book** or **playing** with a **toy**, actively stretching the backs of your legs (hamstrings);
 - **Turning** the **pages** of your **favourite book**;
 - **Clapping** your hands together when you're happy;
 - **Looking, pointing, reaching** or **signing** to **make a choice**;
 - **Makaton signing** with manual support if needed, "more", "please" etc;
 - Practicing **4-point kneeling**, pushing through your hands and weight-bearing through your arms and hips;
 - Practicing **throwing, swiping, holding objects** and **letting them go**;
 - **"Tidying up"** together, **looking, reaching, picking up, holding, putting in, letting go** etc;
 - **Shoes and socks on/off**: active participating, bending leg, looking at feet, reaching etc;
 - **Feeding**: finger feeding, reaching and holding, hand-mouth coordination.

3. Affordable sensory toys

www.cheapdisabilityaids.co.uk

4. Information and advice for families with disabled children (and adults)

www.contact.org.uk

5. Health and Wellbeing

Remember “Me Time”

- Remember to **look after yourselves** and to **put yourselves first** sometimes
- Hobbies – **what do you enjoy doing**
- Seeing/speaking to friends
- Practicing yoga, meditation and appreciation
- Playing sports
- Watching movies or tv series
- Playing games/apps
- Reading books
- Try talking therapies
- Join Small Steps Facebook group

Ideas:

- Try to block out just 10-20 mins for yourself everyday
- OR
- Once a week for maybe an hour - you could write down different things you'd like to do for yourself, put them in a jar and pull one out every week

Top tips from Ruth (Communications, Marketing and Office Manager)

1. Finding support and information online

There are loads of help and support websites out there... but these are three that I think are really good: Firstly the **Cerebra** website – a fantastic resource, with a huge array of information and 'how to' guides for families from managing stress and advice on challenging behaviour, right through to guides on Education Health & Care Plans and navigating Carers Assessments: www.cerebra.org.uk/help-and-information/guides-for-parents/

Another great website for searching for support, advice and information for your family is the **SEN Direct** website www.sendirect.org.uk/ You can search for available services by postcode, so you don't have to trawl through listings that aren't relevant to you. It has a huge directory of services from 'Overnight and Breaks Away' right through to 'Education & Learning' and loads more.



Sky Badger is a charity that finds help and adventure for disabled children and their families across the UK. They have listings of everything from disabled sports clubs to sibling groups to 'make a wish' charities advice on how to fill out forms etc. www.skybadger.co.uk/

2. Grants and financial assistance



Having a child with additional needs can be expensive and it's often difficult for families to fund essential items for their disabled child. There are some organisations that give grants to families to help finance holidays, mobility equipment or sensory/play equipment and more. Here are a few worth looking at:

The Family Fund: www.familyfund.org.uk/

Caudwell Children: www.caudwellchildren.com/

Newlife: www.newlifecharity.co.uk

Variety Children's Charity: www.variety.org.uk/what-we-do/equipment-grants

3. Benefits

There are several benefits that you may be able to claim as the parent of a disabled child:

Disability Living Allowance (DLA) for children, can help with the extra costs of looking after a child who is under 16, has difficulties walking or needs much more looking after than a child of the same age who doesn't have a disability. See the Government website here for more information and how to apply: www.gov.uk/disability-living-allowance-children

If your child is in receipt of the Middle or Higher rate of Disability Living Allowance, you may be eligible to claim **Carers Allowance** too: www.gov.uk/carers-allowance

4. Getting around

If you are in receipt of the Higher Rate Mobility Component of the Disability Living Allowance you can apply for a **Motability Grant** to fund a car or wheelchair accessible vehicle on behalf of your child. Find out more here: www.motability.org.uk/about-charity/motability-scheme/

You could also be eligible for a **Blue Parking Badge**, to enable you to park in disabled bays and for free in certain places. You're automatically eligible for a Blue Badge if your child is registered as blind or gets the higher rate of the mobility component of Disability Living Allowance (DLA). A child under 3 who needs to be close to a vehicle because of a health condition can also be eligible for the Blue Badge. For more information on how to apply take a look here: www.gov.uk/apply-blue-badge



You could apply for a **Taxicard**, which offers subsidised travel in licensed taxis and private hire vehicles to London residents with serious mobility impairments or who are severely sight impaired. It enables those who have difficulty in using buses, trains and tubes to get out and about. The scheme is paid for by your local council and Transport for London. It is administered on their behalf by London Councils, with a contractor providing taxis and Private Hire Vehicles. To find out more and apply go to:

www.londoncouncils.gov.uk/services/taxicard/apply-taxicard-your-borough

5. Help from your local authority



Every **local authority** (local council) must protect and promote the welfare of children in need in its area. To do this, it must work with the family to provide support services that will enable children to be brought up within their own families. The local authority can provide a range of services for children in need. These can include:

- day-care facilities for children under 5 and not yet at school
- after-school and holiday care or activities for school age children
- advice, guidance and counselling
- occupational, social, cultural or recreational activities
- home helps and laundry facilities
- assistance with travelling to and from home to use any services provided by the local authority
- assistance for the child and family to have a holiday
- family centres
- financial assistance usually in the form of a loan, see below
- respite care
- looking after the child

The local authority must publish information about the services it provides for children in need and their families. Take a look at your council's website to find contact details of your Children's Services Department to find out what they can offer you.



You are entitled to request a **Carer's Assessment** from your local authority if you wish. This assessment is usually carried out by a social worker. Its aim is to see whether you have any support needs and if so, whether the local authority needs to provide any support services to you. This could be, for instance, help with the housework to free up time to spend with your disabled child, or respite care to allow you to have some time to yourselves. If your child's social worker hasn't

offered you an assessment, or you don't have a social worker, contact your local authority's children's services department and ask for one. You'll find the contact details on your local authority's website and you may also find information on carers' assessments there as well. For more information see the NHS website www.nhs.uk/conditions/social-care-and-support/carers-assessment/

It is possible to apply for a **Disabled Facilities Grant** from your local authority to help fund changes to your home if you need them, for example to widen doors and install ramps or improve access to rooms and facilities such as a downstairs bathroom. The first thing to do is to contact your local authority to book an assessment, you will find these details on your local council's website. Or you could ask your child's GP, nurse, social worker or other health or social care professional to refer you to an occupational therapist. You can self-refer to a social services occupational therapist by contacting your local council to arrange an appointment.



You can find out more about Disabled Facilities Grants here: www.gov.uk/disabled-facilities-grants

And finally...

All this form filling can be very daunting... but there are agencies out there that can help you complete these applications so don't be put off! Someone at your nearest **Citizens Advice** www.citizensadvice.org.uk might be able to sit with you and help you with the form, or even fill it in for you. You can also call **Contact** (for families with disabled children) helpline if you have questions - they're experts in DLA for children. **Contact (for families with disabled children)** Telephone: 0808 808 3555 - Monday to Friday, 9:30am to 5pm - Calls to these numbers are free.



As with everything, it's always best to get advice and recommendations from others who've been there! So, if you haven't already, I would recommend signing up to our Small Steps **Facebook Family Forum**. This is a closed group just for Small Steps families, so it is a safe space to share. You can request to join here:

www.facebook.com/groups/smallstepsfamilyforum/

If you've any questions about the above or anything else, don't hesitate to drop me an email and I'll do my very best to help! ruth@smallsteps.org.uk

Top tips from Nicola (Business Manager)

1. Please complete a **Gift Aid** form if you haven't already done so. There is no obligation to make a donation to Small Steps, but if you do and you are a UK tax payer, we can claim an additional 25% from HMRC on top of your donation at no extra cost to you.
2. Please let us know if your employer has a **community or charity fundraising scheme**; we have been very successful over the years with applications to companies that our families have worked for eg. Network Rail, KMPG, Google, Deutsche Bank etc. Some firms also have 'matched giving' schemes where your employer will match any donations you make.
3. We have also been fortunate to have been supported by schools attended by siblings, cousins, nieces and nephews. Please do **nominate Small Steps to your PTA** if you can!
4. If you or a family member would like to set up a **regular standing order** to Small Steps, you can do this by contacting your bank. Please ask for the Small Steps bank details or talk to Nicola or Ruth about standing orders.

Pop in to the office and see us! We love to see you all at the end of the session 😊

Top tips form Cilu (Practitioner – Conductor – Teacher)

On closing this evening, I would like to focus the attention on you, lovely parents. Now that you have listened to my colleague's clever tips and took some notes I just need you to relax, have a sip of your wines and listen as I mumble something from the heart.

My speech was inspired by Jason Beaumont who has Cerebral Palsy and was one of the keynote speakers at the recent Conductive Education conference in Nottingham. He spoke about his early life and emphasised how Conductive Education has shaped his future, and how grateful he is to his parents for putting him through all the therapy early in his life. He didn't see his CP as a disability, but more like an obstacle and a challenge what he needs to overcome. It made him stronger and even more determined to thrive in life. During his teenage and early adult life he has set several goals for himself and didn't stop until he has achieved them or came really close to achieving them. He is now in his early 30s, has a beautiful wife (who has been his rock) and a job what he loves. He said when his own son was born it suddenly dawned on him how much harder it must have been for his parents when he was born with additional needs and their world was falling apart...

I know your journeys are all different and unique, but you are all here for the same reason. To create a better future for your child/ren, help them and support them on every step of the way!!! Perhaps the sleepless nights of researching and endlessly seeking and attending of different therapy/ educational settings and support groups week on week out, or when 'just' spending quality time with your family, children and loved ones. All this is wonderful because with that you are giving everything you have and doing everything you can!!

You should all be feeling a sense of achievement, satisfaction and pride because what you do is making a difference (even if you cannot see it now) in your child's life, and you are setting them for a brighter, better and a more positive future. I thought I say this because no-one ever tells you how fantastic and amazing you are, but Bettina and Kas just did! So again, **well done to you all, you are doing a smashing job!!** Cheers to that! 😊

Now let me finish by reading out the final paragraph from Jason's speech at the conference:

"I have always been certain that Conductive Education has been the best thing that I could have done at my early stages and will always be thankful to my mother for taking me through it.

Finally, I would like to say a few words I would say to my younger self and perhaps to those who are in my younger position now. Disability is not the end, disability provide an opportunity to prove yourself against all doubt, of which there will be plenty. You may not reach the destination you so desire at the beginning, but there is always a way to get as close as you possibly can, if you truly want to. Do not think you are settling for second best, for it is you that will provide the first rate effort to those around you and some will see this. Put the effort in and do not fear if you may not succeed at one thing for in the words of the late Prof Stephen Hawking; 'however difficult life may seem; there is always something you can do to succeed at.' With that in mind, you can go from here to anywhere."

Top tips from Fran (Practitioner – Physio)

Fran's top tips were ideas of how to get the most out of your child's NHS physiotherapy provision (although the tips could also be applied to other NHS therapy provision, such as Occupational Therapy and Speech and Language Therapy).

1. Establish good communication links with your child's NHS physio:

- NHS physios are very busy and can often be hard to get hold of
- Ask to have the physio's direct email address and use it (even if to pre-book a telephone conversation)
- Find out when the physio is likely to be in the office so that you can call them at this time
- If you are finding it difficult to get hold of the physio by phone, try to set up pre-booked regular 'telephone clinics' with them at a mutually convenient time

2. Set joint goals for your child:

- Think about goals that you would like your child to achieve (what skills are they on the cusp of achieving / what are realistic long-term goals / what skills would make a real difference to your child or to family life)
- Talk to your physio about these goals and make sure they listen to you – you know your child best!
- Find out when the physio will be writing your child's physio EHCP report and make sure you agree with the proposed physical targets they are going to write in the report

3. Request blocks of treatment for your child:

- Due to large caseloads it may be challenging for your child's physio to provide continuous regular treatment sessions, however they may have capacity to provide intermittent 'blocks' of treatment sessions
- Try requesting a block of treatment to work towards a specific target, or to address a specific concern you may have – if you are specific then your child is more likely to receive a treatment block

4. Request joint therapy sessions:

- If you are feeling bombarded with numerous therapy appointments for your child, try requesting joint therapy sessions, such as a block of joint physiotherapy and occupational therapy sessions
- This can often work really well and provide higher quality treatment sessions for your child

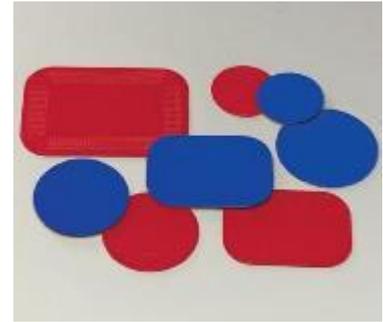
5. Make sure you receive adequate training from your child's physio:

- Make sure you know how to confidently carry out your child's physiotherapy programme
- If you are unsure how to carry out a physiotherapy technique with your child don't be afraid to ask for further guidance and repeated training
- Make sure everyone who has regular contact with your child (grandparents / nursery staff / etc) receives physio training so that they can also carry out your child's physio programme with them
- Enquire about parent workshops / training sessions that your child's physiotherapy service may offer

Top tips from Eszter (Practitioner – Conductor/Teacher – Team Leader)

1. Dycem mats

They come in different size and shape and are very helpful to keep feet flat, bottom back, put it under cups and plates...



2. Hippy Chick / Hip Seat Carrier



Hippy chick helps you keep your posture straighter when you carry your child. It is a belt that you put around your waist including a seat, so your child is sitting on it and not your hips.

3. Stretch your back after the sessions

Because you lean a lot during session, it's very important for you to stretch your back and do the opposite direction...



4. Knee pads



When you find kneeling on the floor uncomfortable, wearing knee pads can relieve discomfort.

5. Breath fresh air

Very important to let fresh air in your house. Even in winter it's recommended to regularly open the windows for short periods of time.



Top tips from Sam (Practitioner – Physio)

1. Footwear

APCP leaflet <http://apcp.csp.org.uk/documents/parent-leaflet-choosing-footwear-children-updated-2016>

2. Orthotics

Ask your physio to be at the appointment OR write down what they think your child needs from the orthotic eg: heel strike / foot position / more knee control. Ask them questions – make them explain.

Basically the orthotic should help your child's walking and standing. If it doesn't then insist on a review.

3. Trikes

A bike can be a great way for children to get some cardiovascular exercise and stretch and strengthen their legs. There are trike companies who do adapted trikes so many children can be accommodated. It is best to research what is available and then try them out at an appointment with the reps so they can try some different adaptations.

<https://www.rifton.com/products/special-needs-tricycles/adaptive-tricycles>

<https://missioncycles.co.uk/special-needs/>

<https://www.quest88.com/adaptive-cycling.html>

KIDZ exhibitions (held regularly during the year) have some trikes on site that you can look at and try – as well as lots of other useful stuff

www.kidzexhibitions.co.uk

There are charities which specifically help to fund equipment such as trikes. (they are super expensive) The trike companies can usually supply a list of these. You will need a supporting letter from your physio or OT and a quote from the rep outlining what adaptations are needed.

4. Peanut pillow

Use on the floor or in the buggy / seating to keep the head in midline and chin tucked down.

Lots available on internet – type in plagiocephally pillow or make one of your own

Only use when they are supervised

5. Outreach Service

Parent leaflet (separate) p17

Top tips from Mylène (Charity Support Assistant)

1. Ways to communicate with us

For letting us know about absences or general enquiries:

Via our landline: **020 8704 5935**

Via email: info@smallsteps.org.uk

Via our new text messaging system: **+44 7860 003526**

For any further information or advices about your child, sessions, contact your session leader or any practitioners:

bettina@smallsteps.org.uk, cilu@smallsteps.org.uk, eszter@smallsteps.org.uk, fran@smallsteps.org.uk,
kasane@smallsteps.org.uk, samantha@smallsteps.org.uk

For any further information or advices about fundraising, donations:

ruth@smallsteps.org.uk, nicola@smallsteps.org.uk, anita@smallsteps.org.uk

To see our latest news, and interacting with us:

Website: <http://www.smallsteps.org.uk/>

Twitter: <https://twitter.com/SmallStepsTweet>

Facebook: <https://www.facebook.com/smallstepssfp>

Instagram: <https://www.instagram.com/smallstepscharity/>

Display in the foyer.

2. Ways to fundraise at no cost

One of the easiest way to raise money for Small Steps without costing you a penny, is when you order online. The only thing you have to do is to create an account on one of the following portals, select your shop you want order from and the charity you want to support. Make sure you always go through one of the links before doing your orders.

Easyfundraising: <https://www.easyfundraising.org.uk/causes/smallstepsputney/>

"It doesn't cost you a penny extra!

When you shop online the easyfundraising way with one of our 3,191 shops and sites they give us a commission for your purchase. We turn that into a donation and give it to your good cause. Easy!"

Give as you live: <https://www.giveasyoulive.com/>

"Raise free funds for charity, just by shopping online

Sign up and support any UK charity

Choose from over 4,100 stores to shop with

Click through to the store from our site & shop as usual

We donate to your chosen charity - for free!"

INREACH / OUTREACH AT SMALL STEPS



Did you know?.....

We are aiming to provide an **outreach service** for families with children who currently attend or have recently attended Small Steps.

This may include.....

- Regular **newsletters** to keep families informed of news and events
- Membership of the **facebook** family forum for advice and support
- **Nursery visit** to give advice and support staff.
- **School visit** to give advice and support staff.
- Workshops / talks in school or nursery to staff and / or children to increase awareness of condition and conductive education.
- Workshops / talks to other professionals involved eg: physio teams / GP's etc
- **Report for EHCP** and support through the process
- Attendance at **TAC meetings**
- **Networking with other families** in the same area or at the same school / nursery to share experiences and give advice
- **Parent workshops** every half term, in the evenings on a variety of topics
- Summer and Easter **holiday club**
- Signposting



We welcome anyone involved with your family to come and visit Small Steps and observe a session and meet the team.

If you think we may be able to help with anything, please give us a call on **020 8704 5935** or email samantha@smallsteps.org.uk . We will consider all requests for outreach support and discuss with you what we may be able to offer, taking into consideration logistics and staffing availability.

Small Steps SFP
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