

Welcoming a child with a Limb Difference

INTO YOUR NURSERY



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www.limbbofoundation.co.uk



The fact that you are reading this means that you either have a child with a limb difference in your nursery or one that is about to join you. You may well be apprehensive about how this will work. How will other children react? How much, if any, extra support will this child need?

Hopefully, this booklet will put your mind at rest and be able to preempt some of your questions.

This book isn't a list of do's and don'ts, it's just our way of trying to raise awareness of some of the issues that you may encounter and offering ways that will make life easier for both you as the member of staff and the child with a limb difference that you will be supporting.

We've included quotes from children, parents and nursery staff which you will hopefully find useful.

If you have any questions that you think we might be able to answer or if you just want a chat please get in touch.

info@limbbofoundation.co.uk





LimbBo

Foundation

The LimbBo Foundation was formed in 2018 after the birth of Tommy D (in 2014). We know what it's like to feel isolated and to be honest a bit scared of milestones such as leaving your Limb Different child at Nursery for the first time.

Whilst we in no way claim to have all the answers if we don't know the answer to a question we will know someone who does. We are like a family and all of our parents support each other. Questions could range from what is the best sippy cup to what should I expect after my child's amputation?

The photos in this booklet have been willingly shared by parents who have been there, done that and are now proudly wearing LimbBo T shirts.

If you need any help at all then please email info@limbbofoundation.co.uk and we will make sure it gets to the right Trustee or our Co founder Katie who is our operations manager.



We also have a group of Youth Ambassadors who can give you insight into what nursery and starting school was like for them as well as answer any questions that you might have about living with a limb difference

Before

The child starts Nursery



Talk to the child face to face and if staffing allows then visit them in their home environment as this will allow you to see how the child functions at home.

By watching the child in their home environment you will notice that the parent will allow their child space to do things in their own way. In other circumstances you will be able to see how much and what type of help the child needs .

Let parents visit all of the places that their child will need to access so that that they can check whether there will be any barriers before he/she arrives. There may be barriers that aren't obvious and this is a way of highlighting what these could be.



Types of limb Difference

UPPER OR LOWER LIMB

Your best support here are parents, they are the ones who have been supporting their child and know exactly what they need help with and when they need to be left to get on with whatever they are doing. It's a learning curve for both of you, they have to learn to let go and this means removing a layer of 'protection' for their child - they are effectively handing this over to you and will welcome questions. You won't be seen as being interfering but as caring so ask away - they are the experts and will be keen to share with you. They will also be scared and worried (the same as any parent when their child starts nursery but with an added layer of worry!)

There are so many limb differences it would be impossible to describe them all here, just go with what parents are telling you and ask the children themselves because even at this age they know what they can do on their own and what they may need some support with at first.



“

I want nursery to call me or ask me if they are not sure how to adapt something - I'm always willing to help

”

LimbBo parent



How do I refer to the child's limb difference?

Although there are types of Limb Difference no two children will have an identical difference

Upper Limb



Many children refer to their limb different arm as their 'little arm' or their 'born arm'. Some refer to it as a 'baby arm' or a 'special arm.' There are lots of variations - again you need to be led by the family in this. The only thing we would ask is that you don't allow others to refer to it as 'their poorly arm' or something that implies their arm has something wrong with it - it's just different not damaged.

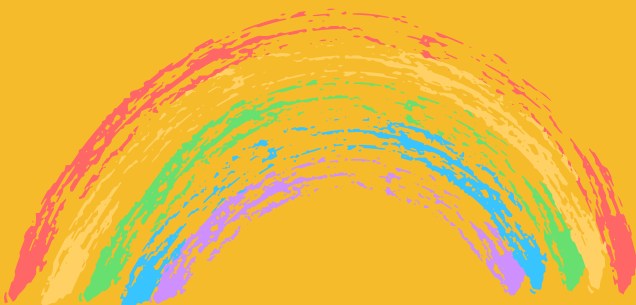
How do I refer to the child's limb difference

Lower Limb

As with the upper limb difference terminology, please ask parents how they refer to their child's limb difference and follow their lead.

The medical terminology when talking about a lower limb difference is to refer to the child's 'residual limb'. Obviously, this is a bit of a mouthful for children and many of our children refer to their 'stump', 'stumpy' or 'leggy'. However, this is a key thing to find out when first meeting families as they may have their own way of referring to their lower limb difference, their prosthetic, and unaffected limbs.

It is possible to buy dolls which have a prosthetic leg - this will really help with normalising limb difference and allowing children to talk whilst playing.



Lower Limb Difference Surgery

There are a whole range of lower limb differences but this isn't the place for us to describe all of them. Parents will be able to tell you the medical name for their child's limb difference and sites such as www.stepsworldwide.org will have more information should you wish to have a deeper understanding.

What you do need to be aware of is that the child joining you may have already had to undergo surgery. This could be minor, several surgeries, leg lengthening or even amputation. Again, it's impossible to cover all types of surgery as each child is an individual and their treatment will vary.

If a child in your care is scheduled for an amputation, it's good to prepare the other children for this change.

“

We were able to talk the other children through why 'J' looked a bit different but would soon have two legs. You kept us in the loop with everything and this was extremely important for our own understanding. It also gave us the confidence to challenge him

”



A child may need to take time out of nursery for an operation but every child recovers differently and therefore there is no set time frame for when they will be able to return to nursery.

Tips from Parents



“

Ask about any specific funding they can access eg 'F's' nursery gets some disability funding which they use for any special equipment he might need

”

“

Listen to the child if they need a rest from their prosthetic. Check with parents about building in breaks from wearing it – especially if it's a new prosthetic.

”



“

Mobility is going to vary, from making amazing progress to barely being able to wear their prosthesis as they grow and stop fitting properly. It's a constant roller coaster!

”

“

Speak to the child's Occupational therapist (if they have one) or contact your local authority to see if they can support you with equipment





ADVICE from A PARENT

'Advice for nurseries: Ask, ask, ask! Don't be afraid to ask. Ask parents what language they use to describe and label their child's difference (and stick with it!), be aware that the nursery child might need some adult support around inquisitive children at that age (so keep half an eye on them in new social settings!).

Ask parents how they respond to questions about their child's limb difference and try to follow their approach. Parents are inherently protective, and parents of children with disabilities and differences can feel even more so. At such a young age it's the parent's responsibility to model responses and behaviours to their child, and handing their child into the care of another adult can be extra daunting.

Reassure the parents that you'll follow their example and wishes as much as is possible and will do your best to support their approach whilst their child is at nursery. As their carer you become the responsible adult and your role in modeling positive attitudes, responses and approaches can be key to that child's development.'



Parent comments

“

An Occupational Therapist can advise on accessibility and on how nursery activities might need to be adapted to include everyone, involving parents too.

”

“

He is very confident with active play, he has no problem accessing anything at soft play or the park. Playing in open spaces is harder for him as he can't run as fast as others his age so gets left behind.

”



“

He is so used to falling over that he just gets up and carries on, even if he's hurt himself. So he might need someone to check that he's ok.

”

“

Limb difference books in all rooms to help other children learn about Limb difference.

”

“

As a parent I would say that S can do more than anyone would think and that will amaze you, be mindful but don't hold her back, if she wants to try then let her

”

Books



Specifically about limb difference

Limb different character but not solely about limb difference

Generic books about difference and equality

- What happened to you & You are awesome – James Catchpole
- Airick Flies High – Eric Gaffney
- Different is Awesome – Ryan Haack
- The Abilities in me – Limb Difference Gemma Keir
- When Charlie met Emma – Amy Webb
- Uniquely me – Trace Wilson

- The Roller Coaster Ride –David Broadbent
- Splash!–Clare Cashmore
- Chops series – Matthew Jenkins
- Rae's first Day – Danny Jordan
- Phantom Castle –Charlotte Middleton
- Going Viral – James Catchpole – released in 2024

- All about diversity – Felicity Brooks & Mar Ferrero
- The perfect fit – Naomi and James Jones
- It's ok to be different– Sharon Purtill
- Know me by my name – Kirsty Webb
- Marmaduke the very different dragon –Rachel Valentine & Ed Eaves
- Giraffes can't dance –_Giles Andreae

<https://literacytree.com/a-book-list-for-books-with-positive-images-of-neurodiversity-or-disability/>

Tips for Upper Limb Difference



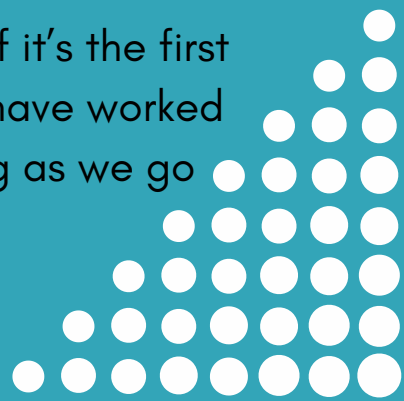
There is a real balance here – obviously we want our children to be as safe as possible but we also want adults to understand that even if you think they need help – they might not want or need you to help them.

There will be times when you want to step in as it looks like they are struggling, take a breath and watch – we've all learnt to stand back and it's hard because your instinct is to help – unfortunately that sometimes means that you will just do it for them. We had times when Tommy said he was cutting something out and the adult took it off him and did it – when asked how he felt he just shrugged and said 'she's better at it than me' but I **was** doing it.



Once you get to know the limb different child in your care you will learn from them. One teacher told us after a few weeks 'I feel much better now I know I'm not going to break him'

It's ok to say to parents if it's the first limb different child you have worked with – we are all learning as we go along!





If you look at the children on these pages even the youngest child who is only 6 months old, has worked out a way of doing something. They often use their little arm or elbow joint to hold something or to keep it steady. They will always find their own way.

If a child has an above elbow limb difference it can be more challenging than a below elbow difference as the elbow acts as a natural 'holding' place. However, our children will always work out a way of doing something







Feet for stability



**Finding
our own
way**



UpperLimb Different children may well be able to ride a bike by just resting their little arm on the handle bars, but in order for them to sit up straighter and find it easier to balance we will happily send you a LimbBo bike adaptation free of charge.

Contact Bianca@limbbofoundation.co.uk





Koalaa prosthetics have created an adaptation for young children to use bikes or ride ons - these are a sort of cross between a prosthetic and a toy to introduce our children to prosthetics in a positive way.

please get in touch with them

This is called the Joeyy

For babies and toddlers under 3 years old with Below Elbow, Through Wrists, partial hands and fingers.

When they're not whizzing along with the walker, your little one can cuddle up with their snuggly Joeyy.

hi@yourkoalaa.com
www.yourkoalaa.com



UNDER



JOEY!

Tips for lower limb difference

These are just ideas not a list of do's and don'ts – many of our parents have shared what they have found helpful.



Try to make games collaborative or adapt the games so that a child with a lower limb difference doesn't struggle to keep up. e.g J likes to play tag where he is in the middle and the children run from one side to the other past him and he can tag them on the way rather than doing all the chasing.



If they have forgotten how to put their prosthetic on and off or want to be reminded of anything they need to feel confident to ask and not be afraid to say.

Top tip – if you are changing clothes for a child with a lower limb difference who wears a prosthetic – put the trouser on the prosthetic before putting it on 😊

“ Ride on toys were good for ‘J’ before he had his prosthetic leg or when he wanted a break from it. Also a trike with a handle which can be pushed will allow them to rest if they need to. ”



Talk to parents about how long their child has had a prosthetic and how often they might need an activity which isn't weight bearing. Each child and each prosthetic will be different .

Do children use a walker or a wheelchair – can you speak to OT's about this?

“ Its very tempting to bring out the kid gloves and check insurance policies etc. It's biting the bullet and saying to ‘J’ that everyone is different and we all have days where we have a blip - we just start again the next day ”

Childminder for a lower limb child ”



“

One thing I've really noticed is that they always make messy play activities accessible and within reach for 'V' (She's not yet at the stage where she is able to confidently wear her prosthetic leg at nursery')

”

Are there activities which can be done whilst sitting on the floor?

Between the age of 3 & 4

This page isn't based on any medical research but on our lived experience. Between the age of 3 and 4 children will begin to be aware of their limb difference. They will begin to question why? When will it grow? Can I have 2 hands? Why did I have an operation?

Previously extrovert children who have seemed accepting of their difference may suddenly start to hide their hand (sleeves pulled down etc)



Similarly, other children may suddenly be aware that the classmate they have worked with for months is 'different' and may start to question.

We've seen this happen several times. Tommy is now ten and has much younger cousins. He has been around them since they were born, they have walked alongside him, holding his little arm. He has played with them, helped them up when they've fallen. When 'B' was 3 and a half she literally did a double take, her head jerked round, she walked over to Tommy, held his little arm and said 'where has your hand gone?' Please be aware she wasn't being unkind or rude she genuinely wanted to know where his hand had gone. (This is a completely different response to children mocking others) Be ready for this and explain in the way parents have asked you to. We always taught Tommy that he was 'born like this'. He said this so many times at school that the other children called it his 'born arm' Young children are very open and once they realise that this difference is just 'how it is' they are in the main, accepting of it.

Your child has a limb difference

www.limbbofoundation.co.uk



"
'Don't worry
it's reyt'

You can take the girl out of
Barnsley but ...



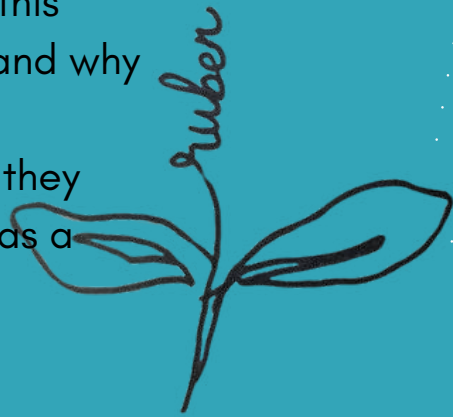
ONE OF OUR HOSPITAL
POSTERS WITH QUOTES FROM
OUR CHILDREN

Painting cards

FOR SPECIAL OCCASIONS

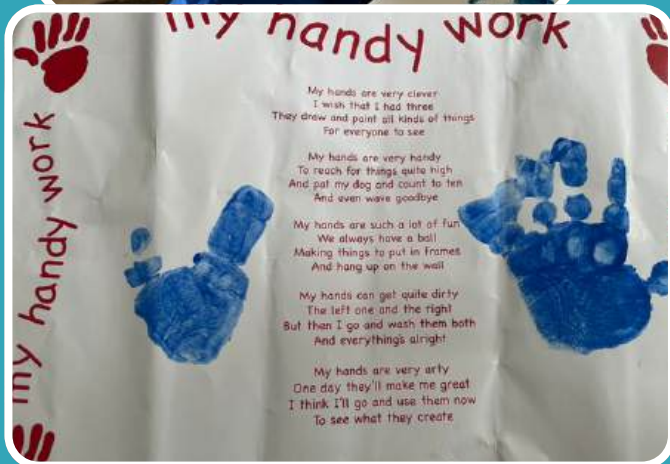
This is a plea from all of us at LimbBo. We had a card sent home made with two hand prints one left and one right. When we explained this wasn't Tommy's, the nursery didn't understand why we were upset.

Please can you let children print with 'what they have' a hand and a little arm that will print as a circle or whatever shape it is.



If the child has a lower limb difference- it's ok to print their foot twice or just once but not their foot and another child's foot to make it fit.

SAME FOOT PRINTED TWICE



Prosthetics for upper limbs

The role of prosthetics for children with an upper limb difference is completely different to those for lower limbs. A child with an upper limb difference might not need or want a prosthetic. It could be that it is used for cosmetic purposes which gives emotional support or it could be one of the myoelectric ones which work on muscle sensors (NB these aren't suitable for very young children and actually getting one is either costly or means a very long wait on the NHS)



In many cases our children chose not to wear prosthetics or to only use them for certain activities

Speak to parents and ask if the child uses a prosthetic at all or if they have 'devices' which help them.

See tips on next page.



lightmyfire.com

Munchkin Tip and Sip
Weighted Straw
Trainer Cup



Recommended by parents as it has a weight in the bottom and children can drink from any angle

Spork - sturdy and cuts well
recommended by Tommy D



What wellies are we all using to fit a prosthetic leg?



Snow boots are easier to put on because they open lower or we cut a line down the back of an old Welly and duck taped it up once.

Not sure about the chunkiness sorry, maybe velcro snow boots instead of zip so it's wider

kolma ultra light eva kids wellies
We've used these for years. Depending on leg we've had to take liner out and cut around the top. But they are really flexible and stretch unlike normal wellies, and bargain price. Amazon

Useful ideas - also check out
www.activehands.com



Autumn -
lego figure
with a limb
difference.

Checklist

☐

Home visit

☐

How to refer to limb difference

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Feeding/eating - equipment

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What do they need help with

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Toilet training and equipment

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Accessibility for wheelchair use

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Prosthetic care

☐

Inclusion - books

☐

What questions do you have?



This is for you and the family to decide upon together - its meant to be helpful not add lots of work so use it how you feel its appropriate!



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INTO YOUR SCHOOL



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Transition
booklets for
schools are
available

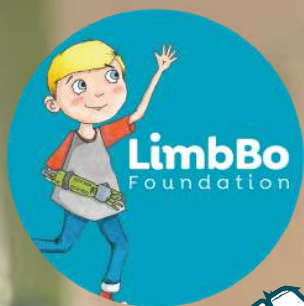
”



Welcoming a child with a Lower Limb Difference

INTO YOUR SCHOOL





OUR LIMB DIFFERENT CHILDREN



ENJOYING LIFE TO THE FULL

