

Nurseries and Your Son



For parents of children with
peno-scrotal / proximal
hypospadias and DSD
(differences of sex development)

This leaflet has been co-ordinated and produced by **dsdfamilies**.

It has been written by parents of boys with peno-scrotal hypospadias and DSD, with input from healthcare professionals from across the UK.

With thanks to Lisa, Dilyana, Ruth and Laurie and to Caroline Sanders, Maia Thornton, Rachel Hamblin, Zoe Edwards, Martina Rodie, Phil McNicol, Emma Hewson and Louisa Monzani.

One of the parents who co-wrote this leaflet is a manager at an early care setting in the UK and will be happy to address any questions families may have.

Contact

For suggestions regarding this leaflet or questions about nursery care, please write to **info@dsdfamilies.org**.

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Work, Parenting, Nurseries and Your Child (*)

Early care workers are experts at helping parents start their children at nursery school. They have training and experience in helping all children!

This brochure will help you:

- to feel confident about finding the right nursery for your child
- to know what to say to help the nursery care for your son:

"My son is born with a condition affecting his genital development."

"You may have questions around nappy changes and other aspects of care, and I would like to answer any questions you may have."

"My son's medical history is personal to him. Please be respectful and maintain his right to privacy by not discussing his care outside those that need to know."

(*) Much of this information also applies to other childcare arrangements, e.g. childminders.

Finding a Nursery

Starting nursery can be stressful for any parent. If you have a choice between various nurseries within your area for the starting date you are looking at, visit them!

You should like the indoor and outdoor environment and general feel of the nursery. Have a look at the room where the babies sleep, and where the artwork magic happens for the toddlers. You might want to consider the size of the nursery in terms of how many children they take in, or whether they provide all meals or nappies, and how often all children get fresh air. Do they sound and look inclusive?

As parents you should feel you can ask as many questions as necessary.



FAQ

I am not sure how to approach the DSD subject. Where do I begin?

Once you have settled on a facility you are comfortable with, ask for a meeting with the manager or SENCo (Special Educational Needs Coordinator). You can ask whether his key worker can also attend. You can also write to the nursery - see the examples overleaf.

Professionals in Early Years should be accommodating and empathetic. If they are not, then move on and keep looking for the right setting.

FAQ

How much information should we share with the nursery?

The amount of information you share is entirely your choice. Nurseries do not need to know everything about your child's condition. They need to be given enough information to ensure your child is well cared for.

Share enough to answer the big questions such as: How do I change his nappy? Is there any medication we need to administer? Can he use the bathroom on his own? Do you need me to help him use the toilet?

As your baby grows and develops you too will learn more about his needs, which may change over time. Allowing the staff to know this gives you more flexibility in dealing with future care demands.



Parent to Parent



Naima's story

Before starting nursery, the only person who had changed my son's nappy other than us (his parents) was my mum. Leaving my son somewhere for the first time was daunting enough. Now I needed to have "the conversation" – and talk to a stranger about things I had not spoken about to anyone outside the family, other than medical professionals. As often happens, the anticipation is worse than the reality! It was a big deal for me, but I found it wasn't necessarily as big a deal for anyone else.

If you feel unsure about how much to reveal, start very basic and very simple. Provide the information that is required for care; for example, how best to change a nappy or he needs to sit down to wee etc. If you feel comfortable sharing more information, you can do this in your own time. Once you start to have these conversations, you may be surprised about how knowledgeable you have become about your child's condition and how easily you can respond to any questions!

Points to think about when meeting with nursery staff:

- Difficult conversations often work best if held face-to-face, where this is possible
- Plan a time to meet when you won't be interrupted
- Ask who your son's key worker(s) will be and if they can attend
- If you are apprehensive, don't be afraid to go in with a few notes written down

Yaz's story

I wrote the following to the nursery. I did not go into too much detail and they were great with this explanation. They didn't even ask questions, just reassured me he will be in good hands:

"My child was born with a condition, called a Difference of Sex Development (DSD), which does not require active treatment (may need a surgery at a later time if he wants), but he may look different to other children in the genital area and may not be able to urinate standing up (for potty training). His condition means his urethral opening is not in the usual place, but further down."



FAQ

What should we tell nursery?

The staff are not medical professionals. They need relevant information to help them in the day-to-day care of your child. If you give them too much information, the key points could get lost.

You can start with:

“I want to share a private issue with you about my son and we want to find a nursery that can support him in a thoughtful and caring way.”

“My son was born with a condition that affects the production of the hormone testosterone” (or for some boys: ...a condition that affects sensitivity to the hormone testosterone).

Describe what that means, all children look different – find the words you are comfortable with:

“As a result, he looks different in the genital area” or “As a result his penis / his willie didn’t develop as typically expected.”

Move onto what it means for nursery staff and his care:

“This is not something to worry about, but you may have questions around nappy change and potty training...”

“He does not pee standing up.”

You may be asked some questions like, “What does this mean for when he grows up?” or “Is there surgery for this?” You can answer this however you want, but feel free to say:

“We still have many questions ourselves and are discussing this with his medical team. Our priority now is that he gets the best possible support and care whilst he is here with you in the nursery.”

For some children you may want to clearly state the sex of your child and reinforce it is not subject to interpretation by the nursery staff.

It can be useful to send a follow-up note or an email to confirm what has been agreed in terms of care and thank them for their support in maintaining your child’s privacy whilst at nursery.

FAQ

Is there a risk he will be treated differently to other children there?

Every early childcare facility has an inclusion policy. Inclusion means all children have the right to be treated the same and be able to access the same activities and toys even if adjustments need to be made.

You should get notes every day at handover (plus most likely endless drawings and ‘artwork’!) and most settings have electronic learning journeys for you to view what he has been doing. Also, your child will be assigned a key worker so your child can develop a bond with them, and they will work with you as a family to help with your child’s development and learning.

Education, Health and Care (EHC) Plan

If your son has more complex healthcare needs and penoscrotal hypospadias / DSD is only a part of those needs, you can get help from the nurse at your DSD clinic to contribute to an Education, Health and Care Plan to share with nursery (and possibly with a health visitor). If you think this is something that would really help, ask the specialist nurse of your medical team about this.

FAQ

How do I address toilet issues or concerns about nappy rash specific to my child?

Any good setting will follow your lead and work with the family on potty training; and they should have a care diary which records all nappy changes. Feel free to explain your son may need support or be changed in a different way, take your time to show them this yourself. You could ask the manager to set up an appointment where you can train various staff at the same time on special hygiene needs and so on.

FAQ

I worry other kids will notice something during nappy changes. How will nursery staff ensure his privacy?

Discuss your worries with the nursery manager. The staff are experienced in helping all people with specific concerns. You can depend on them to be discreet with your baby and toddler. Also, most nurseries have individual toilet cubicles for all older children.

More questions about confidentiality and privacy

What is privacy?

We know that families may feel concerned about keeping information about their son's condition private. This is understandable, you want to protect his privacy and not share his story without his permission.

However, there are situations where you need to pass on information to other trusted people to help them look after your child. In this case you could highlight that you would like the information to be shared with only the people who need to know it so they can care for you child.

You may want to emphasise that this is because it is your child's body, and you don't want to share information unnecessarily before he can say whether he would want this.

Should I keep my child at home for his privacy?

As your child's advocate, you must think about his whole life. This condition is only a small part of his life and eventually, it will be a small part of yours as well. Just now, as your child is growing and changing, it seems very important. But he has other more demanding needs such as social, educational, physical and language development to consider.

You can provide him with the contact he needs through caring for him at home, taking him to playgrounds, play facilities, and inviting play dates to your home. You may have already planned to be stay at home parents and if that is your plan, you may feel you have more control over his privacy.

But do not allow fear about his condition to determine whether you go to work or not. You are not alone, and other people have successfully raised children with these conditions and gone to work as well.

All early learning settings offer a whole range of play based activities that aid early childhood development and encourage lifelong skills, so you are not neglecting him by going back to work. And by placing him in a day care setting you can become more skilled in dealing with schools and strangers regarding his condition, and your child may feel more confident when he starts big school.

One of the nursery assistants knows friends of mine. Can I trust them to keep this information private?

Remember, data protection laws in the UK are there to protect everyone's private information. And the nursery will want to work with you in maintaining your son's privacy (see previous pages).

If staff disclosed any child's personal information this would lead to a disciplinary case and even legal action from the parent against the nursery. No nursery wants ill feeling or bad publicity. The manager should take great care to ensure staff behave professionally.

Discuss any specific concerns with the nursery manager, who can put additional processes in place.



More questions about surgery

All information so far is equally useful for parents whose sons have had some hypospadias surgery and those who have not.

Below we focus on a few practical questions regarding any stage of surgery.

How do I address the issue of absence from nursery due to surgery and recovery time? Will the nursery expect us to pay when he is away to hold his place?

Most nurseries continue to charge when the child is absent. You can discuss this with the nursery prior to enrolment and read their terms and conditions before signing a contract. They may be able to make an exception or be more flexible about holiday times.

Other financial help may be available from the government. If you look up 'help with childcare' on GOV.UK you can find out if you are eligible.

If my son is to have a surgery, approximately how long are they off nursery to recover?

That is something only healthcare professionals can tell you, and it will depend on type of surgery. We strongly recommend waiting the full recovery period before sending him into the nursery. This will minimise accidental injury and nappy changing concerns.

How do I prepare nursery for when he returns there after surgery?

Your child needs time to rest and recover. Get the doctor's advice on when he can play without fear of hurting himself. When he is ready to return, speak to the setting about what they can and cannot do.

Remember if the setting does not feel they can keep your child safe after surgery they can refuse to take him until he is recovered enough. This is because they want to keep your child safe from harm. You will need to ask your doctor what toys your son can play on. And you may want to ask yourself how the nursery will limit toy use post-surgery (slides and sit on toys) until he has recovered – children often like to play rough and tumble.

The nursery cannot provide 1:1 support for your child without funding. The ratio for children up to 2 years is 1 adult to 4 children and at 3 or 4 years it is 1 adult to 8 children. It is recommended to send them back to day care when they can join in with all the fun activities. It is hard for a child 4 years old or under to comprehend being careful, and they will copy what the other children are doing.

A note about dsdfamilies

dsdfamilies provides educational, practical and peer support to children, young people and families living with differences of sex development*.

We work to ensure that the experiences of children, young people and their families inform best-care practice and professional training. We do this in collaboration with health care providers and peer support networks for adults and families.

**including Androgen Insensitivity, CAH, penoscrotal Hypospadias, Swyers, 5- α -Ard, some forms of Turner, Gonadal Dysgenesis, Ovotestes, 3-Beta, 17-Beta, SF1, Frasier and many others.*

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www.dsdteens.org

With thanks

