Diagnosis during pregnancy Fact Sheet

Updated May 2026



steps
We don't take walking for granted

Steps is the leading charity working for all those whose lives are affected by childhood lower limb conditions

Support for childhood conditions of the lower limbs



Steps has created this guide to help signpost you to resources for information and support if you are pregnant and have been informed that your child may have a lower limb condition.

Many families have been where you are now. It can feel overwhelming at first, but support, treatment options and experienced professionals are available. You do not have to manage this on your own.

Steps are here to offer support and advice to make this journey as manageable as possible. Steps is the leading charity working for all those whose lives are affected by lower limb conditions. Everything we do is about valuing and supporting individuals, families and carers affected by conditions which have an impact on the legs, hips or feet.

We offer advice and support, and can link you with families who have had a similar journey to you.

Reactions

Following a diagnosis or potential cause for concern, it's normal to feel shock, sadness and even anger. It's important to take time to think, to absorb the news and to accept your new circumstances. Initial concerns may diminish as you start to learn more about your child's condition. If these feelings become overwhelming, speak with your midwife, GP or hospital team for additional support.

Your medical team are an essential first point of contact and will be on hand to answer your questions and help you understand your next steps.

Talking to others who have been through the same experience can help address any fear or practical issues you have, and Steps can help to connect you with other parents.

Any worries about the reactions of friends and family will fade as the day-to-day practicality of having a newborn takes over.

In time, families find that while their child's condition may bring challenges, it is a small part of the much bigger journey that you are starting as a family. Children with lower limb conditions regularly go on to lead active, fulfilling and happy lives.

Hospital Visits

For many parents, learning that their child requires hospital treatment can be an extremely stressful time. *"How will my child cope with an operation?"*, *"What happens with the anaesthetic?"*, *"Will I be able to stay with them?"*. These are very common questions that might be going through your mind. Steps has produced a guide for parents and carers "Preparing for your child's surgery", to answer some of the questions that might come up during this worrying time and to help you prepare your child (and yourself) for admission and surgery.

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Steps Charity Groups:
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The Leading Charity for Lower Limb Conditions

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Support services

Every hospital and local services are different, don't be shy about asking hospital staff any questions you may have – they'll be happy to help.
Find out what is available where you are. Some hospitals offer support services such as:

1: Patient Advice and Liaison Service (PALS):
Providing advice and information about the NHS and about health-related matters.

2: Family Support Service:
This team offers practical guidance, emotional support, and information to help families navigate their child's care and access the services they may need. They may also be able to help you access additional financial support.

3: League of Friends:
Their purpose is to improve the care and comfort of patients, visitors and staff.

Hospital related expenses
Again, every location is different, ask if your hospital offers the following, or if they are available nearby:

4: Free or reduced hospital parking:
Some hospitals may let you park for free, or at a reduced rate, if you are visiting your child.

5: Free hospital meals for parents:
When you are visiting your child in hospital, it's important to keep your own strength up. Eating away from home is expensive and some hospitals may provide free meals to parents who are visiting their sick children.

6: Accommodation and Ronald McDonald House:
The Ronald McDonald House Charities help families stay near their sick children while they are in hospital. There are 14 Ronald McDonald Houses across the UK, all located close to specialist children's hospitals. Families can get some crucial rest, a sense of normality and support from other families, all in a "home from home" environment.

The charity tries to help any family they can, although families who have to travel the furthest to be with their sick child get priority. For more information phone Ronald McDonald House on 0300 011 1113 or visit the Ronald McDonald House Charities website.

Steps is here to help

Whether you need condition-specific information, practical guidance or emotional support, Steps is here to help you. We are the UK's only national charity which supports the most common and much rarer conditions affecting the legs, hips and feet. Our valuable experience and respected medical board can help families make confident and informed decisions at what can be a confusing and difficult time.

We offer a wide range of services to help and support all those affected by childhood lower limb conditions. We are continually reviewing and developing resources, including condition guides and informative videos.

We have our own YouTube channel and social media presence which includes a Facebook group where parents can share experiences and knowledge in a safe and supportive environment.

If you are affected by, or would like to learn more about the conditions we support, please call our contact number on 01925 750271.

We don't take walking for granted!

Support

Contact Steps: +44 (0) 1925 750271 to answer any practical questions you have.

Email: info@steps-charity.org.uk with questions.

Family Contact Service: If you want to talk to someone who has been through a similar situation, one on one.

Facebook Group: A closed group where you can talk about your worries, share helpful tips, and find emotional support.

CBeebies' Dr Ranj offers simple, useful hints and tips about preparing your child for a hospital visit for procedures or tests. You can find his 'Get Well Soon' video series on BBC iPlayer.

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