

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



Fact Sheet



Preparing for an Amputation

Talking to Your Child

For a child facing a lower limb amputation, the future can be a scary place full of questions. Will it hurt? Will I be able to walk? How will I cope at school? Will the other children like me? Will I be able to play all their games? Will I get teased?

Your child will begin a period of physical and emotional adjustment before the amputation takes place – and you can help them prepare for this. Deciding when you choose to start talking about the procedure with your child will depend very much on their age, personality, and level of understanding.

With a very young child, reading children's books featuring characters with a missing limb can help the child identify with characters that look like them and face similar challenges. Reading can also be a good way of encouraging your child's peers and siblings to understand and embrace their differences. Likewise, regular role play about 'Teddy goes to hospital' and playing with adapted dolls or toys, can help to prepare emotionally.

A child of six or seven can be involved in discussions from quite early on and an older child may even join in the decision-making process for aspects of their aftercare and choice of prosthetics. Always make it easy for them to talk to you and encourage them to ask questions no matter how tough those questions might be, and be honest and straightforward with your answers. Your child will appreciate honesty and will often understand more than you think. A clear answer, no matter how difficult it may be to say, will avoid your child playing out their own scenarios in their imagination - and possibly imagining a far worse outcome! If necessary, get help in preparing your answers: talk to other families, your consultant, physiotherapist and hospital paediatric psychologist, if they have one.

Whatever their age, your child will feel a range of emotions, from anger or confusion about why this has happened to them, to being worried about physical differences and their impact on friendships. There may be times when your child will blame you as the decision maker and this could be a recurring theme through their development. Don't be afraid to ask others for support.

Giving Your Child Confidence

Helping your child to feel good about their body and how they look, is the best preparation you can give them to face the challenges they have ahead: give lots of positive messages and focus on the good, rather than the bad. This attitude will be reinforced by how you as a parent behave and respond, to them and others. Show them that you accept your body and encourage them to accept, respect and love theirs.

Remind your child that we are all different, physically and emotionally, and that we all have our unique personalities and abilities. Reinforce that "difference is normal" and that every child will have the same hopes and fears about their own differences and what the future holds, as they do. Reassure your child that lasting friendships will be strengthened by similarities and personalities, much more than they'll be affected by any physical differences.

Always encourage them to "have a go" in any activity they show an interest or ability in. Focus on their strengths and praise their efforts rather than the outcome. And always focus on what they will be able to do, which is almost everything!

It is inevitable that peers will ask your child about their limb difference, so it is best to prepare them in advance and encourage them to give their own answers. Practicing their answers with you, their medical team, family members or teachers, will give them confidence and a sense of empowerment. They may even come up with their own amusing alternative stories about their limb loss; this is all part of the process.

Talking to Your Child's School

It's important that as many people as possible are available to help your child face the challenge of amputation. Depending on their age, one of their biggest concerns will be how they'll cope at school and how their classmates will react. Talk to your child's school or nursery teacher and SEND (Special Educational Needs and Disability) Coordinator in advance and bring in some books and adapted toys, so they can talk openly with your child and their peers.

Talking to Consultants

It's essential to understand as much as possible about your child's surgery and rehabilitation. Preparing a list of questions that you want to discuss at your hospital appointments will make it more likely that you get the answers you need. Don't be afraid to ask those questions! There's often a lot of information given in a typical hospital visit, so do ask if a handout is available: alternatively, take a notebook to write things down. And remember to ask about things you don't understand. If you don't ask any questions, your doctor will assume you understand everything! If possible, bring your partner or a friend with you, as another pair of ears. If there are two of you, you're more likely to get a balanced perspective and you can discuss what you heard afterwards.

Your Emotions

It is quite normal to experience feelings of grief during this process - but this will ease, as you begin to see your child adapt and flourish. The process will be distressing and overwhelming at times; it may even get better before reappearing again as your child experiences different challenges. It's important not to dismiss any feelings of grief. Be kind to yourself and allow yourself time to work through your own feelings. Remember, it is still okay to have fun and laugh and not feel guilty. And please don't compare yourself with others - everyone has different coping mechanisms!

Sources of support

Our helpline (01925 750271) 9am until 5pm on weekdays, for questions, medical enquiries and practical support. Email info@steps-charity.org.uk with a specific request or fill in a contact form on our website.

The Steps closed Facebook Group <https://www.facebook.com/groups/1730693800550369/> is a friendly and safe way of discussing your worries with other parents, sharing tips and finding emotional support.

Our Family Contact service identifies someone else who has been through a similar situation and who's happy to talk about their experiences, on a one-to-one basis, to offer support and encouragement.

Resources

Books and Films

Just let me put my legs on ...Kenzie Le Turley; a young boy shows everyone that he is more than capable of doing anything anyone else can do, once he has his legs on!

Goose's Story, Carrie Best; A girl and her dog discover an injured Canada Goose, and learns about overcoming adversity (this book is also used as a teaching tool)

Molly the Pony, Pam Kaster; A heart-warming story about a little horse who loses her leg in an accident and how she thrives against the odds. (this book is also used as a teaching tool)

How to Train Your Dragon; A TV series, later cinematically adapted, featuring Hiccup; a young boy with a metal prosthetic leg and his dragon, who's missing tail made it impossible to fly until Hiccup's ingenious intervention.

Websites

<http://limbs4kids.org.au/> An Australian site for child amputees, lots of useful advice.

<http://www.cafamily.org.uk/> UK based organisation for families and professionals caring for disabled children.

<http://www.newlifecharity.co.uk/> UK organisation providing advice and funding for disability equipment.

www.citizensadvice.org.uk advice on benefit application and other topics such as discrimination and taking time off work to care for your child

www.gov.uk/government/publications/equality-act-2010-advice-for-schools guide for schools to avoid disability discrimination and help children back into school setting

<http://limbpower.com/> aims to help engage amputees and individuals with limb impairments in physical activity, sport and the arts to improve quality of life to aid lifelong rehabilitation

steps-charity.org.uk

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We don't take walking for granted...



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 give with confidence