

ADVICE FROM RARE DADS

TOP TIPS FOR RARE PARENTS

GUIDANCE FROM DAVID ROSS AND ADAM JOHNSON:
HOW TO NAVIGATE PARENTHOOD AND LIFE WITH A RARE DISEASE

1 Time as a parent

Having a rare disease can take over your life in many ways, things can be challenging but you are still you. It is important to make quality time to just be a parent with your child and remember they don't see your disease they see their Dad or Mum.

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Allow time to adjust

Just as you have needed time to adjust to living with your rare condition let your children process the information you give them. Don't be worried if they don't express their thoughts straight away, it can be a lot to take in and time is needed to process this.

2 Feel the feelings

There are so many corresponding emotions and feelings that go along with chronic illness and rare diseases. Give yourself permission to feel all of them when they arise. Sometimes writing down what you are going through can help to express your feelings.

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Go with the flow

If you can't do the activities you used to do with your children, go with the flow and find ways to tweak things so you can still have fun and spend time with them even if this time looks different to how it once did.

3 Ask for help

Asking family and friends for help can feel like you are failing or you may feel you don't want to burden them, but it is really important to reach out if you are struggling physically or mentally. If you want to find support outside of your family unit there are charities and communities to help you. Check out David's Ross's blog post here for signposting: bit.ly/MensMentalHealthMeetings

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Pace yourself

Somedays may be tougher than others. Don't try to do too much, your family will understand that you need some time to recoup and rest before jumping back into the full swing of family life. They won't judge you so don't judge yourself.

4 Accept the help

Accepting help when it is offered is not always easy. But if a family member or one of your children is offering you help with a physical task or with emotional support accept it. They are offering it because they want to!

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Make connections

Reach out to other parents who are going through the same thing, they might have advice and strategies for coping that you haven't heard of before! Take the time to build relationships with people who understand your process.

5 Communicate

Don't be afraid to let your children know about your condition. Children are often more aware than we realise and talking things through with them in child-friendly way can really help them process what is going on. Start a dialogue and be honest and as they get older they will appreciate being involved in your journey bringing you closer together.

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Time for play

Living with a rare condition means that serious issues and appointments take priority in your life. Try and find the time to enjoy yourself and your journey as a parent. Have fun with your children and cherish the good times.

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MAGAZINE

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