

# PARENTS SUPPORT GUIDE



# CARING FOR A CHILD WITH A RARE CONDITION

As parents, you can most likely remember vividly the day you received a prenatal diagnosis, followed by the uncertainty that feels like an eternity.

You may find yourself becoming an expert in brand new information while trying to prepare for a newborn yet cope with the emotions and difficulty of it all.

Our hope is to provide you with a guide to help you and your family through the process by sharing some practical strategies and suggestions throughout your pregnancy until birth. We truly hope to serve you and your family through this time.

Some of the information provided in this guide may be different based on which country you live in. Please talk to your clinicians for more location-specific resources and information.



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## FINDING OUT ABOUT YOUR BABY'S CONDITION

- A prenatal diagnosis often occurs around the time of an anatomy scan around 18-22 weeks gestation. At this time, your care team may have referred you to a maternal-fetal medicine expert or perinatologist to gain more information.
- Receiving a prenatal diagnosis can trigger difficult, unexpected, and powerful emotions. Some emotions you may experience are:
  - Guilt, anger, frustration, isolation, shock, confusion, extreme hope, adoration, joy, confusion, depression, or anxiety
  - You may even feel emotionless.
- It is important that as you are finding out information about your baby, you feel supported. Helpful professionals can be:
  - Genetic counselors
  - Perinatal psychologists
  - Social workers
- These can all be helpful people to walk alongside you and advocate for your needs. Additionally, knowing the medical team who is not only taking care of you during pregnancy but also of your baby after birth can help reduce anxiety and create a consistent plan of care.
- When it comes to your care, if possible, make sure you are in the care of physicians who have familiarity with your child's diagnosis and the imaging tools necessary to best care for you.



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Imaging tools such as ultrasound, fetal echocardiogram, and fetal MRI can be useful for gaining as much information as possible about the baby.

- Diagnostic genetic testing by amniocentesis can also be valuable in helping identify the underlying cause of the baby's diagnosis and can help set an individualized plan for the care of your child.

## ANNOUNCING YOUR PREGNANCY AND TALKING ABOUT YOUR PREGNANCY

- You may have already announced to your circles that you are pregnant prior to getting a fetal diagnosis. Or in some cases, you may receive a diagnosis around the time when you would be announcing. Neither is easy.
- Once you have gathered information about the baby's condition, decide who in your support system you feel most comfortable sharing the information with and how you may feel best sharing it. Some feel best making a social media post to spread awareness and to tell many people at one time. Some may feel they only need to tell their immediate support circle. Some parents may choose a designated point person to share updates about the pregnancy. Topics of discussion may include:
  - Uncertainty about prognosis
  - Emotions you are feeling
  - Baby showers, gender reveals, or celebratory events
- If there is thought that the baby may initially be in the neonatal intensive

care unit (NICU), some parents choose to have a "welcome home" party or "Sip and See" party after the baby is home.

- This may be helpful if you are unsure about newborn clothing sizing or the specific needs that your child requires that may be better addressed after they are born.
- Remember that the story of your pregnancy is your story, and you can choose to share it in the way that feels most comfortable to you.
  - A change in the place where you may deliver may need to be discussed with family members or friends to help watch other siblings during the delivery time, especially if in a hospital that is further away.
  - If a home birth was originally planned, this can be hard, but with the right support and time to process it all, the safety of you and your child becomes a priority without a doubt.

## YOUR FEELINGS

- As new information about your prenatal diagnosis comes forth or, in some cases, not enough information, emotional responses can range. These feelings are all normal, and you should not feel bad if you are experiencing negative emotions. Be kind to yourself and try to reflect on why you're feeling a certain way.
- It may also be helpful to talk to other people about your feelings. This can include your family and friends, though some parents express that they are uncomfortable speaking to their

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loved ones. If that is the case, you can also speak to professionals who have experience in talking to families with rare diseases.

## CARING FOR YOURSELF

- When navigating such strong emotions, it is common for individuals to forget to take care of themselves or not to know how to care for themselves.
- Remind yourself that taking care of you is taking care of your unborn baby, and it is okay and encouraged to ask for help.
- People will want to help you but may not know how. Creating a list of ways that they can help (cleaning the house, cooking meals, babysitting other children) can give them purpose and give you time to take care of yourself.
- A prenatal diagnosis often brings about feelings of uncertainty and anxiety. "What if the doctors are wrong?" "What if it's worse than expected?" "What if..." practicing mindfulness techniques can be a valuable tool to keep us present in the moment. Some additional ways to practice mindfulness include breathing exercises and guided meditation for a few minutes throughout the day. There are also smartphone apps for meditation.
- When we feel uncertain, it can also make us feel helpless or out of control. Focus on what you can control. You can control your next meal, your sleep routine, and the time you spend on the internet. Take note of these things. If you find yourself having trouble with any of the daily tasks of caring for

yourself, it can be a sign to check in with a therapist for more support.

- Moving our bodies is also a way to care for ourselves. Unless otherwise instructed by your care team, exercising as you did before the diagnosis should be fine. Prenatal yoga classes, spin classes, and taking walks are all ways that you can care for yourself. Consult with your team about any restrictions on movement.
- In summary, try to spend some time doing the things you loved doing before being pregnant. These activities will give you time to focus your energy elsewhere and give you a mental break from some of the negative thoughts you may be having.

## GETTING SUPPORT FROM FAMILY AND FRIENDS

- It can be helpful to discuss your feelings with your partner if you have one and figure out what ways you both can work together to support each other through this hard time.
- Asking others for help is not a sign of weakness; on the contrary, it shows that you have acknowledged the difficulties of your situation and that you need support from other people. Not everyone you know may offer their support because some people are not sure how to respond to these situations appropriately. If you feel that a loved one has distanced themselves from you, you could try opening communications with them to see if that helps. However, if this does not seem to work,



try giving them some more time and space; meanwhile, focus your attention on people who are supportive.

- If you have friends or family coming over, it is perfectly acceptable to not want to always discuss your baby's diagnosis. In these situations, you can simply let the other person know that you would like not to discuss it today, but still are looking forward to meeting them.
- Be honest with yourself and others about what types of support you want from your loved ones. They may not feel comfortable overstepping into your life, so if you are clear about how they can help, that may make things easier.

## INTRODUCING SIBLINGS TO THEIR BROTHER/SISTER'S RARE CONDITION

- Children at different developmental stages may need different language surrounding their sibling's medical condition. Data has shown that children are more perceptive than we know and think, and so while you may think you are hiding your emotions well, your child at home likely knows something is going on.
- Speaking in simple concrete terms and neutral language is helpful.
- Avoid using words like "baby brother is sick" because children may associate being sick with needing to be in the hospital and think they need to enter the hospital every time they are sick.

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- If you are able, utilize a child life specialist within your medical team to learn about tools to talk to siblings.
  - It may also be helpful to use a picture book to help you introduce your newborn baby's diagnosis to other siblings.

## MEDICAL TREATMENT

- In some cases, medical treatment is available before birth; talk to your medical team about the risks and benefits of what that treatment may look like and how it can impact your family.
- For many conditions, there is no treatment available before birth

which can be frustrating and give you feelings of helplessness. It is okay to acknowledge those feelings. Remember that taking care of yourself is taking care of your baby.

## GOING OUT IN PUBLIC

- Being pregnant with a baby who will require medical care can make taking trips to the market or trips in public triggering as you may worry that someone will ask an intrusive question.
- Sometimes it can be helpful to have a script handy of what you may say if a random passerby asks, "when are you due" or "what are you having." It is okay





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to acknowledge that these questions may elicit conflicting emotions.

Give yourself grace in this space.

- Additionally, it is ultimately up to you what information you want to provide others.

## GOING TO A BIRTHING CLASS

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- Talk to your care team about if your birth plan will be altered by your child's diagnosis. Sometimes certain conditions require C-section deliveries; for other conditions, it is perfectly fine to have a vaginal delivery.
- Acknowledge that a birthing class for individuals who may not have a medically complex baby may not be the right fit for you, but maybe it will also be the support you need. If you find it is causing negative emotions, perhaps turn to online support groups for parents experiencing the same issues or ask your care team if there is a specific group for families undergoing a fetal diagnosis. If those are not available, many online classes focus on newborn sleep techniques or post-partum care for mothers, and those may be helpful in finding a practice that works for you.

## JOINING SUPPORT GROUPS

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- It may benefit you and your family to join patient support or advocacy groups. Hearing the stories of other parents and learning what they did

when they were in your situation (or a similar situation) can help you cope as well as give you guidance on what to expect. It is important to understand that with rare diseases, each patient has their own unique journey, so something that they did or were told by their clinicians may not necessarily apply to you and your baby.

- Nowadays, support groups are often available online, which gives you the flexibility of not having to commute to different locations. Also, with online meetings, you may have the chance to talk to families worldwide.

## LIVING LOSS

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- Living loss refers to the ongoing emotional pain and grief experienced by individuals who have a loved one with a chronic or severe medical condition, disability, or mental health issue. This concept highlights that the loss experienced by the family or caregivers is not confined to the death of the person but extends throughout the person's life due to the challenges and changes brought about by their condition. Living with someone who has a long-term or debilitating condition can be emotionally and physically draining. The sense of loss may arise from the changed expectations for the future, the loss of the person they once knew before the illness or disability, and the constant adjustments that need to be made to accommodate the person's needs. Caregivers may experience grief, frustration, sadness, and a range

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of other emotions as they navigate the complexities of providing care and support. Recognizing and understanding the concept of living loss is important as it validates the emotional struggles of caregivers and family members. It emphasizes the need for support and resources to help them cope with the ongoing challenges they face while caring for their loved one.

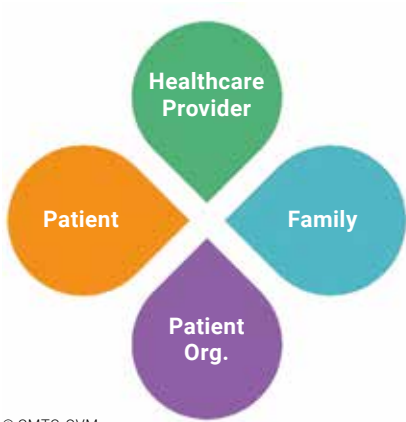
## LOSS

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- For a parent who is dealing with the sudden loss of a child, it is understandably normal to have questions and feel lost in what feels surreal and unfathomable.
- Take as much time to process it all and to be with your loved ones. Keep an open mind to the advice that your clinicians may give you as they are on your side. They may suggest speaking to chaplains, social workers, or other trained professionals. Even if you may not want support at this time, think about your family who may be feeling confused and conflicted about losing someone they loved also.
- You do not get over losing your child, but you can certainly get through it. You can once again find joy and purpose in your life while always remembering your child.
- Parents have expressed that the healing process after losing their child is one that will need to be tailored differently to each family. In some cases, parents prefer returning back to their usual regime and work.

- “This helped me feel some normalcy again and I was able to help others. The embrace of others was comforting and the feeling of contributing to society made me have a sense of purpose again.”  
– *Jennifer Ortiz Cutshall*
- When you begin this process alongside your family, remember to be patient and keep an open mind. There are many people going through hardships around the world that are finding their way back to a “new normal” just like you... and who knows, you may be the person to inspire them.

## FINANCIAL SUPPORT

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- Having a baby with a rare disease might have a financial burden on you and your family depending on your health insurance and other forms of medical coverage available. The costs of visiting specialists, fetal imaging, therapeutics, traveling, and lodging can add up to a substantial amount.
- Patient organizations may have financial assistance available for which you can apply for. If you attend any support group meetings, you can always ask other parents how they dealt with their finances or if they know of any programs that provide monetary assistance. You can also ask social workers in your clinical team if they have any additional resources or organizations that can help offset some medical costs. Based on which country you live in, there may also be a federally funded assistance program.



- Palliative care is aimed at optimizing one's quality of life by aiding in reducing pain and discomfort. It may be important to reach out to a specialist who has expertise in this field to help with your child's care. We have provided the URL for a webpage that discusses palliative care and the importance of having someone being part of the interdisciplinary team who has experience in this.
  - <https://www.ninr.nih.gov/newsandinformation/conversationsmatter/conversationsmatter-patients>

## RESOURCES:

- - Postpartum support international is a great resource that is available globally and has weekly support groups for fetal diagnosis patients. You may visit at: [www.postpartum.net](http://www.postpartum.net)
  - To find patient advocacy groups and to connect with other families who are affected by a similar diagnosis, you can ask your team of clinicians for local groups or check out the following websites:
    - <https://www.naevusglobal.org>
    - <https://rarediseases.org/for-patients-and-families/connect-others/find-patient-organization/>
    - <https://globalgenes.org/rare-concierge/>
    - <https://www.cmtc.nl/en> (for vascular malformations)
  - If your clinical team has a child life specialist, you can also reach out to them for more specialized information.



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