

Please call the hospital with any questions at (801) 536-3500. If you are unable to reach the hospital and you feel it is an emergency, call 911 or go to the nearest Emergency Room.

Questions about Transition? Contact your  
Care Coordinator:

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Not First Steps 01/07

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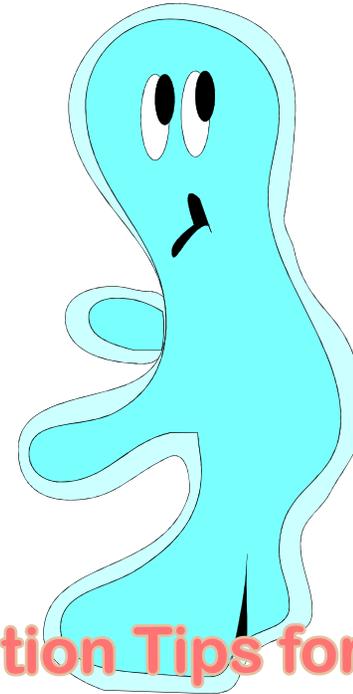


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# A New Start

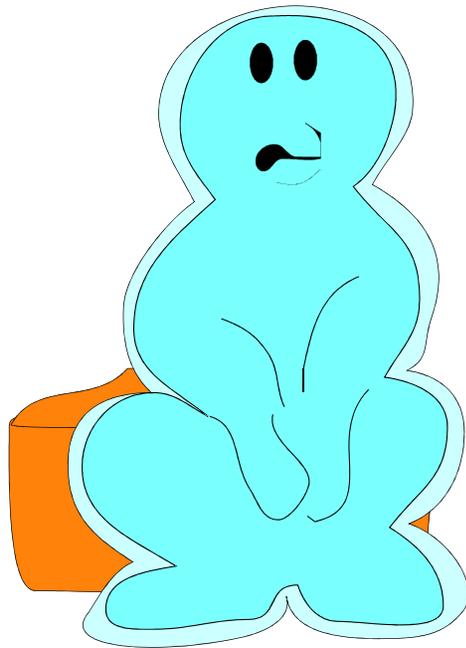


**Transition Tips for Parents  
of Newborns or Newly  
Diagnosed Children with  
Disabilities**

## How do I cope with the news that my child has a disability?

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- Recognize that you may feel a sense of loss when you find out that your child has a disability or special health care need. Lean on your support system including family, friends, neighbors and members of your religious community for strength.
- Take comfort in the fact that although having a child with a disability may be new to you now, after awhile it will become routine.
- Recognize that there will be moments when you will feel that you cannot make it. Keeping a clear sense of where you want to end up and how best to get your child there will make the difference.
- Celebrate everything! Every milestone, every new skill learned and each new day warrants a celebration. There will be many more good days than bad ones if you focus on the positive.
- Remember that the love you have for your child will provide you with the strength to learn and do what you need to for your child and your family.
- Keep in mind that a hard life can still be a good life. You will be amazed at how much you will learn, the people you will meet who will make a positive difference in your child's life and how strong you are.



- Plan ahead in order to prevent a crisis. Fill prescriptions before running out, avoid Friday afternoon or end of the day requests and stay up to date on immunizations and medical screenings. Learn the signs and symptoms of health problems and take action early.
- Be an active member of your child's health care team. Ask questions, share concerns and advocate for your child.



- Create a “portable medical summary” that includes your child’s diagnoses, medications, allergies, prior treatments, surgeries and contact information for all his health care professionals. Update the summary as changes occur.
- Request that a copy of your child’s medical record be sent to you for his portable medical summary and to your child’s medical home after each health care appointment.
- Learn as much as you can about your child’s disability. Use books, other parents of children with disabilities, professionals and the Internet as resources.
- Do your part to help others help you by organizing your information, keeping your medical appointments, updating contact information and completing necessary paperwork.
- Find out the best time to call or ask questions. Leave clear and complete messages including your child’s name, date of birth and a phone number where you can be easily reached.

## How do I stay strong for my child and my family?

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- Treat yourself like a long distance runner. You are in this for the long haul. Finishing the race means taking care of yourself physically, emotionally and spiritually.
- Do not forget to meet your own needs as well as your child’s needs. Children with disabilities need healthy caregivers. Continue to eat healthy foods, exercise, ask others for help if you are not getting enough sleep and keep your regular medical appointments.
- Recognize that stress can take a negative toll on your well being and subsequently the well being of your child. Stay involved in activities that bring you pleasure. Create ways to fit in exercise and other stress reducing activities.
- Stay connected with your friends, family, church and community.
- Nurture your inner spirit through worship, meditation, volunteering, relaxation or play.
- Recognize that depression may occur and may get worse without help. You may want to see a counselor.



- Find a mentor, another parent of a child with a disability, who can teach you what she has learned on her journey. Consider joining a local support group for parents of children with disabilities or look into Internet support groups. Contact your local Parent Training and Information Center for more information. [www.taalliance.org/centers/index.htm](http://www.taalliance.org/centers/index.htm)
- Make time for yourself. Schedule time for yourself each day while your child is at school, sleeping or being attended to by someone else to do the things that bring you comfort and relaxation. You may also want to schedule formal breaks each week where you can have extended time to do something special for yourself.
- Accept help when offered. Let others, including the professionals in your child's life, show their love for you and your family by helping.
- If help is not offered, ask for it! Remember that asking for help is a sign of strength. Your child will learn that it is ok to ask for help by watching you.
- Continue to do those things that give you faith and hope for the future.



## How do I find and best utilize resources to help my child?

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- Learn about resources in your community. Do not assume that what you need is not out there. Ask other parents and professionals about available resources.
- Let professionals know what you need including resources, services and support. Tell professionals what you can and cannot do and let them know when you need help.
- Find out what the rules and boundaries are in the agencies you use so you can understand what professionals can and cannot do.
- Find out who opens doors and can say yes. Be persistent, if one person cannot help you, keep asking around.
- Don't immediately take no for an answer, try asking a new question. Learn from bad experiences by changing your tactics. Appeal denials as soon as you can.
- Respect what others can and cannot do. Advocate, don't irritate. Use negotiation, not confrontation.
- Think outside the box and help others to do so as well. Expect positive results and avoid negative people with limited visions.

## How do I use health care efficiently?

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- Find a medical home for your child. A medical home consists of a pediatrician or family doctor and his team who will work in partnership with your family to assure that your child's medical and non-medical needs are met. Your medical home can help you access and coordinate specialty care, educational services, out-of-home care, family support and other public and private community services that are important to the overall health of your child. [www.medicalhomeinfo.org/states/index.html](http://www.medicalhomeinfo.org/states/index.html)



- Allow your child to experience the consequences of a poor choice as well as a good choice. This will help her to learn to make good choices in the future.
- Provide space for your child to learn to do without you. Your child will not become more independent by having a parent who does everything for her.
- Transfer responsibility for self-care to your child in small steps, when your child is ready.
- At an early age, teach your child to talk with health care providers by asking questions and giving health care updates.
- As your child grows and understands more, teach and re-teach her about her disability and health care management.
- Get your child out of the house and involved with various activities such as school and church functions, community events and family outings. Remember, she is an important part of the community.
- Find and support friendships both with children with disabilities and those without. Invite neighbor children and school peers over for play dates, join a support group for families of children with disabilities and tap into family resources such as cousins and other relatives.



## How do I build hope for my child and our family?

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- Live the life that you would have lived before the diagnosis to the greatest extent possible.
- Recognize that much of what you wanted for your child's future can still happen, it may just have to be adapted. Try to avoid a "cannot do it" or "will not be able to do it" attitude.
- Create a vision for your child's future and begin to dream new dreams.
- Encourage your child to dream and plan for her future. Ask her what she wants to be when she grows up. Accept any of her answers, even if they seem unattainable. Future goals, whether attainable or not, enable your child to see herself as a productive contributor to her future.
- Focus on your child as a person, not the disability or condition. Family members and professionals will take their cues from you.
- Focus on your child's special gifts and abilities. Work on what you can make stronger and learn to accept what cannot be changed.
- Expect positive outcomes. When one door closes, often another opens.

## How do I keep my family strong?

- Balance the needs of your child with a disability with the needs of brothers and sisters.
- Create special one-on-one time with each of your children.
- Support all of your children's involvement in activities outside of the home such as school, church and other extracurricular activities.
- Understand that your other children may be experiencing mixed feelings about having a sibling with a disability. Look for resources that can help them deal with these complicated feelings. Contact your local Parent training and Information Center for more information. [www.taalliance.org/centers/index.htm](http://www.taalliance.org/centers/index.htm)
- Remember, your child is part of a larger family. Try not to make him more special or different from anyone else in the family.
- Include your child in all family activities, including chores, to the greatest extent possible.
- Discipline your child with a disability when he misbehaves just as you would any of your other children. The type of discipline you use may be different, but he should still have consequences for his actions.



- Work at staying connected with your spouse or partner. Create time for the two of you to be together without the children.
- Laugh together with your spouse or partner as often as you can. Remember that you can cry together too. Avoid blame and do not stay angry for long.
- Share the load of carrying for your child with your spouse or partner. Allow your other children to be involved in the care routines of their sibling with special needs, as much as they would like and are able.

## How do I support my child's independence?

- Encourage development of life skills at each stage of development such as washing hands, dressing, fixing a snack, shopping and managing money.
- Think about "function." What does your child need to function more independently? Options may include therapy, equipment or assistive technology. For example, your child may be able to brush her own hair with an adapted brush that has a longer handle.
- Learn what you can do to support your child's development. This could include purchasing developmental toys, participating in therapies or simply giving your child the time and space to learn at her own pace.
- Recognize that most activities can be adapted for your child and accept that some cannot. Be creative in thinking up ways to adapt activities. Think outside of the box.
- Let your child make choices whenever possible. Start with small choices such as what shirt to wear, what healthy snack to eat or what book to read first. Move onto more complex choices from there.