

Down syndrome (DS)

From **birth to three years old** what can I expect?

<p>What kind of professionals might my child need for his/her first few years of life?</p>	<p>Primary Care Physicians (Pediatricians) will help to manage your child's care consistently. Refer to their expertise in times of transition or change as well.</p> <p>Cardiologists will monitor your child's heart.</p> <p>Ear/Nose/Throat Doctors (Otolaryngologists) will be able to evaluate problems in any of these areas.</p> <p>Audiologists will be able to evaluate for hearing deficits.</p> <p>Optometrist/Ophthalmologist can evaluate eye function and health.</p> <p>Endocrinologist can evaluate thyroid function, a common problem for children with disabilities.</p> <p>Gastrointestinal Specialist can help if intestinal problems were to arise.</p> <p>Physical Therapist: see "therapies" for a complete description.</p> <p>Occupational Therapist: see "therapies" for a complete description.</p> <p>Speech Therapist: see "therapies" for a complete description.</p>
<p>What conditions may affect my child?</p>	<p>Heart Defects are seen in about 50% of children born with DS. Surgery will often be needed immediately after birth and in some cases again at age 2 or 3.¹ Consult with your doctors to determine the proper course of action for your child.</p> <p>Developmental Delays will be seen in most all areas of development including gross motor skills (crawling, walking, etc.), fine motor skills (holding toys, feeding him/herself, etc.), cognition, and speech.</p> <p>Intestinal Issues are very prevalent, and if problems arise a GI physician as well as a dietician may be needed to resolve the problem. Around 13% of children with DS will have some sort of intestinal problem.¹</p> <p>Decreased Immunity is common, so be aware that your child may be sick more often than other children.</p> <p>Hearing Loss is present in about 75% of children¹. Be sure to have your child's hearing tested.</p> <p>Seizures are seen in 5-10% of patients with DS.¹ Infantile spasms are the most common seizures observed in infancy.</p> <p>Eye disease is seen in roughly 60% of children with DS.¹ It is important to get your child's eyes checked as well.</p> <p>Respiratory infection is an increased risk for children with Down syndrome. As a parent, be aware that your child has this susceptibility and be sure to seek medical attention if he or she begins to show signs or symptoms¹ such</p>

	<p>asa prolonged cough, shortness of breath, or excessive coughing without relief.</p> <p>Thyroid disorders most commonly arises during school ages. About 15% of children with DS have a thyroid condition¹, most common being hypothyroidism. Your thyroid can be important in regulating your body systems as well as in maturation and puberty. Be sure to check with your physician if your child begins to show symptoms such as: decreased growth rate, constipation, lethargy/tiredness, decreased muscle tone, and dry skin/hair.¹</p> <p>**It is important to know that these conditions are more common in individuals with DS, but a diagnosis of DS does not mean that your child will develop them.**</p>
<p>What kind of surgeries will my child need? When?</p>	<p>Medical complications your child may face over the years can require surgical treatment, but the diagnosis of Down syndrome does not, in itself, dictate any specific surgical treatments. The following are conditions often seen in conjunction with DS and of which you should be familiar.</p> <p>Heart Surgery: Often, children born with Down syndrome will have associated heart problems. Heart conditions most often seen in children with DS are an Atrioventricular septal defect or a ventricular septal defect. These conditions are most simply defined as a hole in the heart where there should not be one. Development of your child’s heart was in some way incomplete, and so, when born, will not be able to transition as smoothly to his or her own heart system. Depending on the size of the hole, surgery can be done immediately after delivery if the child is in good health, or the surgery can be postponed until the child is older and stronger. ²</p> <p>Intestinal Surgery: Often, children with DS have a higher incidence of bowel and intestinal problems. At birth, there is a chance that the bowel will not function properly, and thus surgery may be needed immediately. Occasionally surgery will be needed to remove blockages or parts of the intestine not functioning properly. Surgery is only necessary in the severe cases. Often, many other options will be available in order to avoid invasive procedures.³</p>
<p>What kind of assistive devices are available?</p>	<p>Assistive devices will vary with each child. There are many devices available to make everyday tasks easier. Here are just a few that you may find helpful.</p> <ul style="list-style-type: none"> -Orthotics (particularly for the foot) -Adaptive Toys -Adaptive handles for spoons, cups, etc. to allow for self-care <p>From 0-3, children with DS can often use the same sorts of strollers, car seats, etc. that normally developing children will use.</p>

<p>What kind of therapies are available?</p>	<p>Drug therapy – If your child has some of the associated conditions, drug therapy may be appropriate. Examples are as follows:</p> <p>Cardiac Defects: Drug therapy to be determined by your cardiologist.</p> <p>Gastrointestinal: Almost all individuals with DS will need to regularly take a stool softener to maintain normal bowel function.</p> <p>Hypothyroidism: a thyroid supplement may be necessary. Consult your doctor to learn more.</p> <p>Physical therapy – Often, children with DS will have delays in motor development as well as overall motor control. EI therapy services can help your child improve motor outcomes such as crawling, walking, and overall mobility. Occupational therapy – Teaching your child how to interact with their environment. The OT will help your child with grasping, eating, and playing.</p> <p>Special braces/Orthotics – For musculoskeletal problems, usually this service will be provided by your physical therapist or by an orthopedist.</p> <p>Speech therapy – Speech therapy can help your child if they have any issues with eating or swallowing. A speech therapist will also focus on the child’s ability to communicate – carrying on a conversation, making important facial expressions, speaking more clearly, etc.</p> <p>Alternative therapies have been explored but have little research to prove or disprove their effectiveness. Be sure to approach any “cure all” therapies with caution. The following are therapies you may encounter:</p> <ul style="list-style-type: none"> -pituitary extract -glutamic acid -thyroid hormone -5-hydroxytryptophan -sicca cell therapy (proven to be a dangerous therapy) -growth hormone administration -orthomolecular approach (combination of vitamins, minerals, enzymes, and amino acids) ⁴
<p>What else can I do?</p>	<ul style="list-style-type: none"> -Make sure your child is eating well and getting the nutrients he or she needs. -Maintain high activity levels. -Seek financial aid for help with the extra costs. -Seek counseling for yourself, your child, and your family. -Enjoy your child!
<p>What sort of expectations should I have for my child’s physical development?</p>	<p>It is important to know that children with Down Syndrome will often progress at their own rate through development. They may keep up with peers in some areas, and fall behind in others. Often children with DS will progress quickly for the first few years of life, and then “plateau.” This plateau can include slowing of development and even a regression of skill. Find how your child learns best and utilize those methods to help your child succeed will help your child decrease the plateau effect. ⁵</p>
<p>What sort of expectation should I have for my child’s</p>	<p>Children with DS often have intellectual delays. Delays can be on a very large scale, from mild to severe. It is important to work with specialists to understand how to develop your child’s skills so that he or she can reach full</p>

intellectual development?	potential.
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For **ages 3-12**, continue to refer to the above chart, but the following is important information for the next phase of life.

<p>What will my child do for school?</p>	<p>Going to school is important for emotional and social development of your child. Your child has a right to attend public school and receive the same education as every other child. If he/she does have a disability that will affect his or her ability to learn, they will most likely qualify for special education assistance.</p> <p>A few important terms should be understood before entering your local school system.</p> <p>Least Restrictive Environment (LRE): It is required by law that every student be placed in his or her least restrictive environment. The general education classroom is defined as the LRE, and from there a child’s team (teachers, therapists, etc.) will determine the level at which this child will function optimally. This may be in a general education classroom with an aide, a separate classroom for some or all classes, and everything in between.</p> <p>Inclusion: The public schools have begun a trend known as inclusion, in which those with disabilities are no longer always separated from other children. Whether this is done in all classes or in select electives, it is meant to provide both a social and educational advantage for your child.</p> <p>Individualized Education Plan (IEP) The IEP will be specially designed to fit the needs of your child. It is through this forum that teachers, professionals, and parents can communicate with one another in order to create functional and meaningful goals for your child.⁶ As a parent, it is important that you are involved in these IEP meetings. Be sure to voice your concerns and hopes for your child. And be certain that you communicate with your child’s team throughout the year, not only at the annual IEP meetings. You also have the right to disagree with the IEP team, so be sure to be your child’s advocate throughout the process. ⁶</p> <p>More information about transitioning to school can be found on the following websites: National Down Syndrome Society US Department of Education</p>
<p>Any new associated conditions to be aware of?</p>	<p>Seizures can also become a problem as children begin to age. Most commonly, the individuals with DS that develop a seizure disorder will have tonic-clonic seizures (seizure of the entire body).⁷</p>

	Leukemia can also be a concern. Children with DS are more likely to develop this condition, but still only around 1% of the population with DS is affected. ¹ Be aware of this increased risk.
What therapies should we continue?	Your child should continue to receive therapies in school, if seen as appropriate and necessary by their teachers and related professionals. Continuing physical therapy can help he or she continue to improve his or her motor skills and balance. Occupational therapists will be beneficial in developing skills for school such as writing, dressing, and eating in socially acceptable ways. Speech therapy will offer your child a continuing opportunity to improve his or her communication skills. If you begin to see deficits or regression in your child's abilities do not hesitate to take action.

Now that my child has reached **the teenage years (13-18)**, is there anything to worry about?

Any new diagnosis to consider?	Sleep Apnea may become a problem in this age group. Sleep apnea is defined by a temporary break in normal breathing during sleep usually caused by a blocked airway. It is estimated that 50-75% of children with DS have or will develop this condition. ¹ Symptoms may include snoring, restless sleep, frequent awakenings, and daytime mouth breathing. Be aware of this condition and get medical assistance if needed. ¹
Will puberty be a problem for my child?	Puberty, as with any child, is a difficult time. Children with developmental delays tend to have an even harder time with this transition. It is important to teach your child about this transition and do all that you can to help them understand this new transition of their body.

What about my child's **adult life (19 and beyond)**?

Any new diagnosis to consider?	Often, people with DS will prematurely develop dementia . Nearly 25% of individuals with DS over the age of 35 show clinical signs and symptoms of Alzheimer's-type dementia. ⁸ Being aware of this high incidence rate will be important in getting your son or daughter the appropriate help.
Anything else to consider?	It is important to keep your child socially involved even after the high school years. Options such as community living, group homes, or assisted living may be appropriate and beneficial for your child and should be explored. Healthy eating and active living are just as important, if not more important, for individuals with DS. A healthy lifestyle can help to decrease the occurrence of disease and keep the individual able and willing to participate in community activities. Individuals with DS are now living long, healthy lives thanks to advancements

in medicine. Be sure to enjoy each stage of your child's life!
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