

Indian Academy of Pediatrics (IAP)



GUIDELINES FOR PARENTS

Chronic Disease in Children

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22 FAQs on CHRONIC DISEASE IN CHILDREN

1. My child is diagnosed with a chronic disease. What is a chronic disease? How common are chronic diseases in children?
2. What will be the impact of chronic disease on my child at different stages of life (viz., neonate, infant, childhood, and adolescence and adult life)?
3. What will be the effects of chronic disease on child growth, day-to-day activities, schooling, and social life?
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22. When to seek urgent medical attention (Red Flags)?

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Chronic Disease in Children

Q1

My child is diagnosed with a chronic disease. What is a chronic disease? How common are chronic diseases in children?

Chronic disease is defined as one which lasts >3 months. Chronic diseases may persist for months, years or lifelong, and need treatment and care.

Around 10–15% children worldwide suffer from chronic diseases. Below are a few examples of chronic disease:

- *Lungs and upper respiratory tract:* Bronchial asthma, cystic fibrosis, allergic rhinitis, chronic sinusitis, chronic suppurative otitis media (CSOM)
- *Heart:* Congenital heart disease, rheumatic heart disease, cardiomyopathy, and hypertension
- *Blood and bone marrow:* Thalassemia, sickle cell disease, leukemia, and lymphoma
- *Kidney:* Nephrotic syndrome and chronic kidney disease [chronic renal failure (CRF)]
- *Liver:* Cholestatic liver disorders, chronic hepatitis, cirrhosis, portal hypertension, and chronic liver diseases
- *Brain:* Hydrocephalus, postinfectious sequels, poststroke, malignancies and tumors, epilepsy (seizures disorders)
- *Developmental and behavioral:* Global developmental delay, cerebral palsy, autistic spectrum disorder, attention deficit hyperactivity disorder (ADHD)
- *Gastrointestinal system disorder:* Celiac disease, gastroesophageal reflux disease (GERD), Crohn's disease, ulcerative colitis, and chronic constipation
- *Endocrine:* Diabetes mellitus and hypothyroidism
- *Skin:* Allergic dermatitis, seborrhea, and winter eczema
- *Urogenital:* Hypospadias and intersex disorders
- *Facial:* Cleft lip and cleft palate

- *Orthopedic*: Osteomyelitis, osteopetrosis, bone tumors and malignancies, deformity or absence of limbs/digits (congenital), developmental dysplasia of hip, and loss of limbs/digits (due to accidents)
 - *Chromosomal*: Down syndrome, Turner syndrome, Klinefelter syndrome, and Fragile X syndrome
 - *Nutritional*: Obesity, undernutrition, anorexia nervosa, bulimia, micronutrient deficiency, macronutrient deficiency, and micronutrient toxicity
 - *Psychiatric*: Depression, bipolar disorder, and obsessive compulsive disorder
 - *Hearing, vision disorders, and other disabilities*—since birth or later due to accidents/diseases
 - *Inborn error of metabolisms*: Galactosemia and phenylketonuria
 - *Storage disorders*: Gaucher’s disease, Pompe disease, Niemann–Pick disease, and Tay–Sachs disease
 - *Immunodeficiencies*: Congenital and acquired
 - *Environmental*: Lead poisoning and after-effects, survivors of nuclear radiation exposure and poisonous gas exposures, and pollution effects
- The list is not exhaustive. There are many other diseases in various systems which are chronic diseases. This is just an overview of common disorders.

Q2

What will be the impact of chronic disease on my child at different stages of life (viz., neonate, infant, childhood, and adolescence and adult life)?

Chronic diseases will affect the child’s life at every stage.

Neonatal and Infant Period

During neonatal and infant stage, they are unable to understand the disease but they may experience pain, separation anxiety, while going through treatment. This can have impact on their emotional well-being.

Sometimes, parents may find it difficult in giving them medicines at scheduled time and comply with the treatment plan. With time, they find ways to deal with these issues with patience and perseverance. The treating team will also guide in this aspect.

Preschool Age

In preschool age group, child will start understanding the limitation imposed by the disease and its treatment. Slowly, they would accept the treatment and the need for continuous follow-up.

Schoolchildren

A school-age child will start feeling the impact of limitations and restriction in life. They would also start seeking answers from parents and treatment team. Sometimes, they will feel left out in school and in social situations due to limitation imposed by the disease or the treatment protocols. Their queries are to be answered in a manner appropriate to their age and understanding.

Adolescents

Adolescents understand their condition better but sometimes they would become defiant and ignore the advice of parents and treatment team. Periodic counseling and keeping them motivated would ensure that they adhere to the treatment.

Regular communication with the adolescence is of utmost importance and the treatment team should make efforts to communicate with them.

They may feel restricted in living a life which prevents them to act like their peer group. Peer influence is the biggest factor at this age. It will also depend on the disease and the way parents handle the effect it has on their child. They should be trained in lifeskills.

Parents should have regular heart-to-heart talks with them, and understand their concerns and guide them appropriately. They may take help of counselor and psychologist.

Q3

What will be the effects of chronic disease on child growth, day-to-day activities, schooling, and social life?

Chronic diseases can affect the growth and development. This has to be monitored by treating team. Proper management can decrease the adverse effects. The restrictions in day-to-day activity and social life depends on type of diseases, stage of disease, severity of disease (e.g., during exacerbation), and other factors. Whatever day-to-day activity and social interaction is possible, child must be allowed to take part for having best experience of life.

Coping mechanisms of the parents, family, and child have direct impact of outcome of the disease. Lifeskill training should start early. Motivation techniques can be applied by parents by learning it themselves. Parents must act like a coach for the child. They have to take care of their wellbeing—physically, emotionally, and socially—and provide the best help to child.

Q4

Chronic diseases usually need life-time treatment/ follow-up. How to make child accept daily/regular treatment and adherence to it in different stages of life (viz., toddler/childhood/adolescents)?

- Chronic diseases need very long or even sometimes lifelong treatment. Child has to be explained about the disease in age-appropriate manner. Treatment adherence is of utmost importance for the best results.
- Once the child understands that with treatment his quality of life would be better he/she would adhere to it.
- It will also need motivational counseling and self-responsibility as the age advances.
- In preschool age, onus is mostly on the parents to ensure that the treatment is continued regularly.
- Once the child understands, the responsibility can be shared by the parent and the child and later as the child graduates from adolescent to adult life, the responsibility can be shifted to him/her.

Q5

How to remain motivated and to help our child to lead near normal life?

It is important that one sees the bright side, interact with other parents having children with similar or any chronic disease, attend group counseling and join parent forums, if any.

Most of times disease-specific groups and forums exist and your physician can guide you, e.g., thalassemia, cystic fibrosis, celiac disease, leukemia, and many more. Moreover, many hospitals conduct group counseling sessions and children interaction sessions these days.

Parents can meet other parents who are going through different phases. This can help them to learn from their experiences.

Child should be encouraged to participate in activities, camps, and group meetings for similar children so as to realize that they are not alone. There are many like them and coping well. They can also be provided with biography of role models who were having similar diseases, who were successful and have contributed to the society.

Q6

How to mentally and emotionally prepare my child for expected/repeat medical procedures?

Repeated or unexpected medical procedure can cause stress in the child. He/She has to be explained and counseled before every visit to hospital to get the best result. They also have to be mentally prepared that they may need some new procedures or investigations from time to time, as the treatment plan demands. This will motivate them to adhere to advice of treating team and may accept the procedure easily.

Q7

What will be the impact on our child schooling? What special efforts should be made for child to attend a regular school, and how to make up with missed days?

Chronic illness definitely disrupts child's schooling.

- Parents should meet the principal, classteacher, and counselor in the school.
- Explain to them the disease, and potential problems the child is likely to face (mood swings, feelings of fatigue, activities to do/not to do in school, in case of emergencies what needs to be done, who is to be informed—preferably a written plan would be best).
- Discuss with classteacher and counselor as to what other children should be conveyed to in regard to the child's condition, so that they can get to understand the child and support him/her instead of bullying/teasing.
- Discuss with teacher about missed days, homework, how to get it posted to home and be assessed by them. This has become a lot easier with the current practice of using digital media platforms. A plan has to be prepared with the school team regarding this, for promoting a regular schooling. Home-schooling can also be given as an option.

Special services arrangement can be made at the school or near school (instructors/physical therapy/physicians on call for emergencies). Classteachers and school medical team should be made aware of it. This has to be discussed with the authorities at school.

Q8

What are the ways to avoid the teasing or bullying at school/in other setting? How to teach my child to handle these issues?

- Parents should take the help of schoolteachers to apprise the fellow students about child's condition and make them ready to accept child's limitation and help the child and not to bully. They can be encouraged to be care buddies for the child.
- Parents have to prepare the child mentally to answer the queries raised by other children and to handle bullying. It has been observed that children who have accepted the diagnosis, and have a positive outlook and are emotionally stable, are well equipped to handle these situations.
- Explaining the child about disease, role-playing at home setting by parents, e.g., taking the role of child can prepare child better in handling these situations.
- Time-tried techniques of handling teasing/bullying can be used. Child needs to be taught these by parents/teachers/counselor/psychologist. These techniques are:
 - Ignoring
 - Convert to humor
 - Take a stand
 - Explain
 - Taking help of elders, if needed

Q9

How much information regarding disease needs to be divulged to child at different stages of life?

It is a great dilemma for parents on how much information is to be divulged to the child. Parents should try to be open and honest but give age-appropriate information in a positive manner so that the child should be hopeful and motivated. The child has to be told about limitation and restriction but also be apprised of positive side.

If parents are unable to answer the child's queries regarding the disease properly, then help of the treating team, especially pediatrician and clinical psychologist should be taken.

Q10

There are a lot of advices related to my child's condition online/offline and it is quite confusing. Even family and friends keep giving their advice off and on. How to handle these information for best use for my child?

Yes, there are a lot of online advices. Some are reliable, some are unreliable and unscientific. Discuss with treatment team before acting on any online information.

Regarding advises from friends and family members, thank them for it and that their concern, but follow discussion with treating team especially pediatrician.

One may find some new development or treatment, while going through online sources. Discuss with the treating team about the merits of the treatment.

Best sources are professional organization such as the Indian Academy of Pediatrics (IAP), the American Academy of Pediatrics (AAP), Indian Medical Association (IMA), and so on. One can also visit disease-specific official organization and association websites/social media pages. Treating team can give suggestions in this regard.

Q11

What will be the impact of the chronic disease in our child on our family (parents/sibling/grandparents)?

- Yes, there will be impact on whole family. Each family member will be affected in a way or other. The stress and anxiety of newly diagnosed disease will affect everyone.
- The child will need care and support from everyone in family. The other family members such as parents, grandparents, and sibling will get less time for self and from others.
- The best way to deal with this is that every person in the family should support the child treatment. Everyone will be involved with one another and will not feel left out. It will be better for child also as he/she will feel connected to everyone. It is important that everyone is on same page in matter of caring and expectations from child.

Q12

**Should we take any professional counseling?
If yes, from where?**

Yes, professional counseling can be taken, if needed. The treating team can guide the parents. Many hospitals have made family groups and disease-specific groups for meeting between parents of other children under treatment and usually a clinical psychologist is part of team.

Q13

How the disease will impact other sibling life?

- The sibling usually feels left out and ignored and this may make them feel jealous and hatred toward the child. They too should be given time by parent. They would feel better when they are listened to, and their anxieties are addressed sympathetically.
- They are worried for self and their life as compared to other children as they fear they will have similar disease. They also fear loss of diseased sibling. They also feel sometimes left out as parents are engaged with the sick child.
- It has been seen when siblings are made part of treating team and responsibilities are assigned to them, then these types of problems are less seen.
- Similarly, other members of family need time. If responsibilities are shared with in family members, then each member can contribute to the care of the child.

All the above-discussed approaches can help one in coping with disease directly and indirectly help the child to lead a fruitful life. A well-adjusted parent leads by example and facilitates the child and family members to cope up with the condition.

Q14

What will be the financial impact of disease on family and what are various resources, we can get help from (Government/NGO/Crowdfunding)?

- Treatment costs and loss of wages, etc. can cause financial strain on the family's resources, also may disrupt the work schedule. There are many schemes of government, guidance can be taken from social welfare department officer, Office of Chief/Block Medical Officer of district/block, treating physician, district administration, Office of Local Member of Legislative Assembly (MLA) and Member of Parliament (MP). One can even write to Prime Minister Office (PMO)/Chief Minister (CM) Office for special grant for rare diseases.
- Many nongovernmental organizations (NGOs) are helping by crowdfunding for specific diseases.
- Sometimes fund generation drives are done by the hospitals to help patients.
- Parents can start your own crowdfunding drive by connecting with crowdfunding agencies/with friends and their social network.
- Disease-specific societies, help-groups, and forums also do help and guide in financial issues.

Q15

What types of disciplinary methods I need to apply when my child does not listen to me or overshoot limits?

- It is very important to practice discipline when child overshoot the limits. Use effective and positive-parenting methods.
- Do not fear to discipline child, whenever needed as discipline provides structure and security, children learn to control own behavior and perform best in life.

Recommended Discipline Techniques

- Praise appropriate behaviors.
- Explain them where they are overshooting limits.
- Use time-out with younger children.
- Use restriction and withdrawal of privileges for older children.
- Discipline practices need to be consistent by parents (individually) and between parents. One has to be firm in discipline and lead by example in many situations.

Q16**How to set limits/set-up expectations in day-to-day life?**

Parents need to set limits/expectations from child by involving child in making their decisions. One can sit with the child and discuss what is expected from him/her. Make rules by involving him/her, by stating that if child overshoots limits, then the parent can withdraw privileges/apply timeout.

Q17**How to schedule the daily routine of child with chronic disease?**

Set the routine with child taking while discussing in age-appropriate manner. Explain to the child the benefits of setting routine and lead by example. Waking time, sleep time, and meal times are to be set properly, as it will be easy for the child to follow routines. Rest of things like going to school, homework, and playing time can also be incorporated in set routines.

Q18**What responsibilities at home can be given to child?**

Assign to the child age-appropriate responsibilities (keeping limitations due to disease in mind). It is very important for child to lead near normal life, feel as valued member of home and society. It helps child to taste success and happiness in small things in day-to-day life at home.

Q19

What should I do to keep myself physically, mentally, and emotionally healthy and fit, while taking care of my child with chronic disease?

It is very important for the parents to take care of themselves. It is like, during a flight you are advised by airhostess, that in case of emergency, you have to help yourself first, especially in case of oxygen before helping others.

Parents have to be in the best possible state physically, mentally, and emotionally, so that they can help their child in coping and managing himself/herself in the best manner.

Take care of following:

- Time for self/me time (as short as 15 minutes twice a day) can be enough
- Do meditation/yoga/exercise/play/sitting still in nature, whatever you like
- Take care of your diet/nutrition
- Have someone to talk—must have a patiently listening ear (friend/family member/relative/helplines)
- Have someone to share some responsibilities when needed (family/friends)
- Involve in some social group activities or spiritual discourse/retreat
- Practice gratitude and gratitude meditation

Q20

How to deal with social pressure/social stigma? How to seek help from relatives and friends?

Parents have to accept the situation as it is a new normal for them. There is no social stigma attached to any disease unless one gives into that feeling. One has to understand that it is a disease and it needs treatment. Professional help from counselor or psychologist should be taken if one feels bothered and stressed by social pressures.

You should be ready to take help from friends and family when needed and whatever being offered. It eases life and takes stress of doing everything alone. A lot of people are there in our life who are ready to help when asked for. Many of them openly offer their help themselves. One should be ready to accept the help offered and pay with gratitude to them.

Q21

Sometimes there is discussion about child's deteriorating condition/ financial impacts/other issues at home with family members or those who visits us. I am scared that my child may be overhearing that and may feel stressed after that. What to be done?

- All family members and treating medical team should work like *"a close-knit team"* **(Flowchart 1)**.
- If some conflicts arise, it is always better to solve them by discussing and finding out solution.
- It is advisable to have such discussion at a place where child will not be able to overhear it, preferably at a place other than home or with treating team at hospital when child is not there.
- Parents and other family members have to be aware of this when they are talking on phone as child is likely to overhear it, misinterpret it and get unusually worried or affected emotionally or mentally.
- If child shows concerns or signs that he/she has overheard a conversation and is feeling worried, then best thing to do is to have open conversation about issue and explain it in an appropriate manner.

Q22

When to seek urgent medical attention (Red Flags)?

There are few absolute red-flags where urgent/immediate action needed:

- Refusal to continue treatment—not taking medicine, not doing rehabilitation therapy
- Not able to have oral intake or refusal to eat and drink
- Stopped communicating with family and treating team
- Inconsolable cry
- Hitting, vandalizing property, fighting with others or family members
- Verbalizing about death and end-of-life
- Suicidal thoughts and tendency
- Suicidal attempt and self-harm activities
- Hostility toward others—family members, others, even animals
- Any general danger sign—not breathing well, lethargy, seizures, disease-specific danger sign as explained by treating team

Flowchart 1: Parents are at center stage with children in treatment team and others in family.

