

Indian Academy of Pediatrics (IAP)



## GUIDELINES FOR PARENTS

# Care of a Child with Chronic Liver Disease

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### 11 FAQs on CARE OF A CHILD WITH CHRONIC LIVER DISEASE

1. In chronic liver disease, what problems should I anticipate and when should I be worried that the disease is progressing?
2. My child is talking irrelevantly or becoming drowsy. What should I do?
3. My child is developing swelling of feet and abdomen. What should I do?
4. My child just vomited out some blood or passing black stools. What should I do?
5. My child has developed fever. What should I do? Can I give paracetamol?
6. My child has a nose bleed or skin bleed. What should I do?
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11. My child has had a liver transplantation recently. What precautions should I take?

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# Care of a Child with Chronic Liver Disease

## Q1

**In chronic liver disease, what problems should I anticipate and when should I be worried that the disease is progressing?**

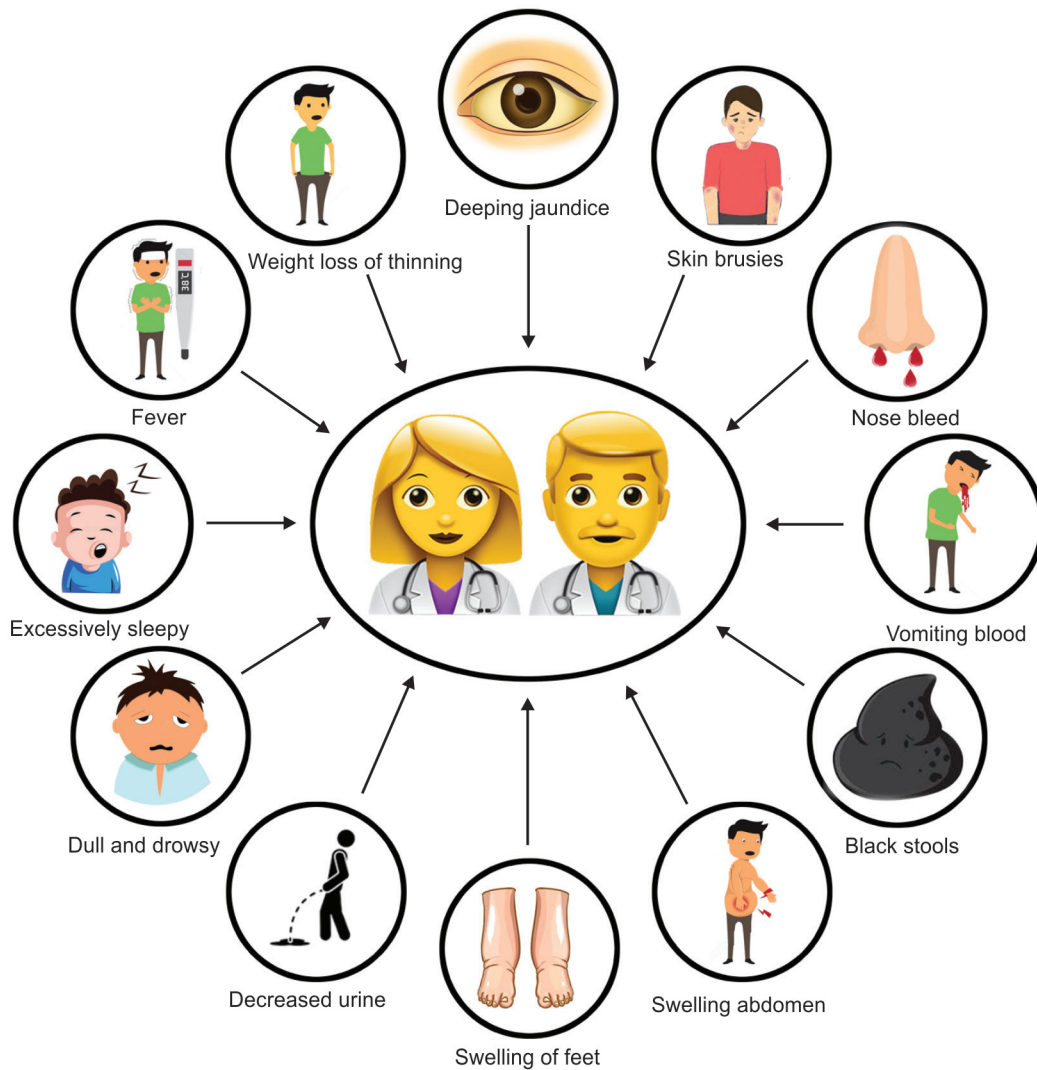
Chronic liver disease is a long-term damage effect to liver. It is like a war where natives are defending their land from intruders. The intruders can be kept on a check with effective weapons and medicines. Intruders can be viruses, toxins, heavy metals or body's own immune system. If the intruders succeed, then they take over the liver. Biologically, an enlarging scar and inflammation slowly replaces the normal liver tissue. Hence, the liver functions slowly and ineffectively as compared to healthy individuals leading to a final point where the liver stops working completely (**Fig. 1**).

Early symptoms are:

- Mild jaundice (yellow eyes and darker urine)
- Fatigue and appetite loss
- Weight loss
- Swelling of feet
- Itching of body (in some cases)
- Mild changes in blood tests (liver function tests) without any symptoms

Progressive and worrying symptoms (*red flags*) are:

- Deepening of jaundice
- Skin bleeds after minor bruises or without any trauma at all
- Repeated nose bleeding or bleeding while passing stools
- Sudden and repeated bloody vomitus or black tarry stools



**Fig. 1:** Symptoms of chronic liver disease.

- Progressive swelling and fluid in abdomen
- Change in behavior and sleep, forgetfulness, confusion, drowsiness, and tremors
- Progressive thinning of limbs
- Decreased passage of urine

Patient needs to be taken to emergency (*alarm signs*) if the following occurs:

- Sudden and repeated bloody vomitus or black tarry stools
- Progressive swelling and fluid in abdomen
- Change in sleep, drowsiness, confusion, and tremors
- Decreased passage of urine

Children with chronic liver disease must be regularly seen by liver specialist to identify potential complications and prevent life-threatening emergencies.

## Q2

### **My child is talking irrelevantly or becoming drowsy. What should I do?**

- Advanced chronic liver disease may affect the brain and sensorium, most importantly due to loss of salts, fall in sugar levels, diarrhea, and constipation. It may also occur if there is an associated infection or just after a bloody vomitus.
- Till you reach the doctor, stop proteins in the diet and give oral rehydration solution (which is used for diarrhea), if child is able to feed. If drowsy, do not attempt feeding and lay the child on left side of body.
- This is a medical emergency and it is advisable to seek help from your doctor/specialist at the earliest.
- Doctor will advise admission and tests.
- If medical attention is delayed, then child may become drowsy and unresponsive.

## Q3

### **My child is developing swelling of feet and abdomen. What should I do?**

- Advanced chronic liver disease may cause pooling of fluid in the body and inside abdomen. This may cause decreased passage of urine, increase in weight, and difficulty in breathing and ambulation.
- Till you reach the doctor, stop extra salt in the diet. Do not start any medication unless consulted with the doctor.
- This is a medical emergency and it is advisable to seek help from your doctor/specialist at the earliest.
- Doctor may advise admission and tests.
- If medical attention is delayed, then child may have abdominal discomfort, poor feeding, develop fever, and become drowsy.

## Q4

**My child just vomited out some blood or passing black stools. What should I do?**

- Advanced chronic liver disease may cause rupture of enlarged veins in the food pipe (esophagus) due to high internal pressures. This will cause bleeding into the gut. Sometimes analgesics may cause bleeding too.
- Till you reach the doctor, do not give any analgesic drugs such as ibuprofen, aspirin, and mefenamic acid. Lay the child on the left side of his body and allow the vomit to drain out. Do not compress the abdomen. Keep calm and do not panic.
- This is a medical emergency and it is advisable to seek help from your doctor/specialist at the earliest.
- Doctor will advise admission, tests, endoscopy, and blood transfusion.
- If medical attention is delayed, then child may vomit blood again, develop swelling of abdomen or feet and become drowsy.

## Q5

**My child has developed fever. What should I do?  
Can I give paracetamol?**

- Advanced chronic liver disease may cause infection in any part of body.
- Till you reach the doctor, only give paracetamol for fever. No other antipyretics or analgesics should be given.
- Dose of paracetamol should be discussed with your doctor beforehand on routine follow-up visits. Paracetamol can be given three to four times a day in its regular doses. Intermittent spike of fever should be controlled by sponging.
- It is advisable to seek help from your doctor/specialist at the earliest.
- Doctor may advise admission, tests, and antibiotics.
- If medical attention is delayed, then child condition may worsen and he/she may become drowsy.

## Q6

### **My child has a nose bleed or skin bleed. What should I do?**

- Advanced chronic liver disease may cause bleeding due to abnormal bleeding and clotting factors. Usually, these bleeds are small in amount and do not present as emergency.
- To control nose bleeds make the child sit up or stand. Tilt the child head forward and pinch his/her nostrils together just below the bony center part of nose for 10 minutes. Do not stop applying pressure to keep checking if the bleeding has stopped.
- Till you reach the doctor, get preferably intravenous than intramuscular vitamin K administered from a nearby health setup.
- It is advisable to seek help from your doctor/specialist at the earliest.
- Doctor may advise admission, tests, and blood transfusion.
- If medical attention is delayed, then child condition may have recurrence of bleeding.

## Q7

### **Is there any role of alternative medicines to reduce the jaundice? Are there any medicines I need to avoid?**

- Alternative medicines (herbal, homeopathic, and others) are promoted as liver tonics. These must be avoided as they can cause worsening of liver disease.
- The above drugs do not reduce jaundice and should not be given as a desperate measure.
- Drugs such as ibuprofen, nimesulide, mefenamic acid, and aspirin must be avoided as they can cause bleeding into the gut.
- Drugs such as diuretics (furosemide and spironolactone), beta-blockers (propranolol and carvedilol) and laxatives (lactulose) should be titrated only after consultation with a doctor.

Q8

**What can I give to eat or drink in this condition?  
Are there any dietary restrictions  
(general or disease specific)?**

- For diet, it is important to consult a dietician from time to time.
- Adequate amount of water intake is necessary.
- Regularly timed meal is important.
- Additional bed-time and early morning snack after waking up is encouraged.
- All patients require a high calorie and high protein diet, when they are well and having no danger signs.
- Medium chain triglycerides is a special kind of fat which is important for growth. This is to be prescribed and titrated by the dietician.
- Multivitamin, iron, and health supplements must be prescribed by the doctor or dietician.
- In specific situations, there are modifications:

<b>Drowsy child</b>	<ul style="list-style-type: none"> <li>• Decrease overall protein intake till patient comes to normal senses</li> <li>• Avoid animal protein (meat, poultry, and egg)</li> <li>• Encourage plant and dairy proteins (lentils, beans, milk, and curd)</li> <li>• High fiber diet to avoid constipation</li> </ul>
<b>Distended child</b>	<ul style="list-style-type: none"> <li>• Decrease salt intake. Do not add extra salt in diet. Consult detailed diet charts</li> <li>• Decrease milk intake if child complains of bloating and discomfort</li> </ul>
<b>Bleeding child</b>	<ul style="list-style-type: none"> <li>• Give liquids instead of solid feeds as they are tolerated better</li> </ul>
<b>Febrile child</b>	<ul style="list-style-type: none"> <li>• Increase fluid intake</li> </ul>
<b>Specific diseases</b>	<ul style="list-style-type: none"> <li>• Consult doctor for the same</li> </ul>



## Q9

### Can I let my child play outside in active sport or go to regular school? What precautions should I take?

Children with chronic liver disease have poor muscle mass and growth. On one hand, they may feel excessive tired. On the other hand, physical activity is essential for them to increase muscle mass and continue growth. Parents should seek a fine balance between the two.

Children should be encouraged to attend school regularly like other children.

The child should:

- Try and participate in all school and sport activities.
- Inform teachers and parents, if he/she is unable to perform.
- Take snack and toilet breaks regularly.

Parents should:

- Regularly sensitize teachers about ongoing problems.
- Seek regular feedback and progress from teachers.
- Provide contact and functioning phone numbers for school authorities.
- Provide contact number of child's physician.
- Provide child's blood group to the school authorities.

Teachers should:

- Allow regular snack and toilet breaks to the child.
- Avoid giving any excessive strenuous activity to child.
- Keep extra vigilance personally or through a responsible classmate.
- Alert parents immediately if any alarm signs.
- Call the school doctor or nurse for help.
- Be sympathetic, if school absenteeism or assignment completion is a major issue.

School doctor or nurse should:

- Provide immediate emergency airway and breathing management.
- Check blood sugar and blood pressure in case of emergency.
- Liaison with the child's physician for safe referral.

Contact sports (e.g., cricket, football, and basketball) are best avoided, if child has:

- Large spleen
- Bleeding from any sites
- Undergoing regular endoscopies

Safe sports requiring minimal caution are running, badminton, swimming, cycling, etc.

- Indoor activities and board games have minimal hazard.

## Q10

**My child has been advised liver transplantation. What precautions should I take before the transplantation?**

- Completion of required and special vaccination of the child.
- High calorie and high protein special diet
- Multivitamin supplementation
- Optimal management of complications
- Hygiene, adequate rest, sleep, and avoid over-crowded areas.
- Avoid contact sports till the time of transplantation.
- Positive attitude and emotional support from family persons, teachers, and friends.

## Q11

**My child has had a liver transplantation recently. What precautions should I take?**

The general precautions are:

- *Medication:* Administer medicines yourself for good compliance and maintain medicine diary.
- *Hygiene:* Wash hands with soap and water before eating, bathe regularly, maintain oral hygiene to prevent caries and brush teeth daily, keep finger nails trimmed.
- *Food:* Vegetables and meat thoroughly washed in running water and boil them. Peel off skin of fruits, salads, and vegetables before consuming them. Avoid raw vegetables, meat, and poultry. Check expiry dates of dairy products. Avoid preservative foods.
- Clean filtered potable water for drinking. Maintain adequate hydration.
- Maintain weight of the child in the normal range.
- Regular follow-up with transplant team.

For first 3 months, post liver transplantation additionally:

- Avoid overcrowded places such as cinema, restaurant, departmental stores, etc.

- Avoid contact with animals and birds to prevent infection.
- Avoid contact with people suffering from infectious diseases such as flu, pneumonia, TB, hepatitis, chickenpox or measles.
- Regular deep breathing exercises.
- Avoid prolonged bed rest.
- Ambulation necessary.

Report to the doctor immediately if any *alarm signs*:

- Fever
- Cough
- Jaundice
- Vomiting
- Appetite and weight loss
- Increasing abdominal distention
- Bleeding from any sites
- Swelling at surgical sites