

# Understanding Children and Chronic Illness:

Protecting your child's emotional health



Educational health information  
from the Department of Pediatrics  
at National Jewish Health™

**nj4kids**™

---

National Jewish Health™

Dedicated Care from  
America's Best Pediatric Specialists

**nj4kids**<sup>TM</sup>



**National Jewish  
Health**<sup>TM</sup>

Science Transforming Life<sup>®</sup>

[njhealth.org](http://njhealth.org)

# Understanding Children and Chronic Illness:

## Protecting your child's emotional health

An educational health series from the Department of Pediatrics  
at National Jewish Health

### IN THIS ISSUE

What is chronic illness?	2
What shows positive emotional health in children and teens?	3
How do physical health and emotional health affect each other?	4
What can you do to develop positive emotional health in your child?	6
How can chronic illness affect your family?	7
What can you as a parent do to help?	8
Should you discipline your child even when he or she is sick?	9
What can you do to help positive illness management?	10
What are age appropriate expectations for your child?	11
Developing an Action Plan for Chronic Illness	13
When should you consider counseling/therapy?	19
What types of services are available at National Jewish Health?	20
Glossary	21



## What is chronic illness?

Chronic illness is an illness that may last throughout a person’s life, although the frequency and severity of symptoms can change. There can be periods of time when the illness is “quiet.” There are also periods of time when the illness is more active, and symptoms may be worse. Examples of chronic illnesses often seen in children and teens include asthma, atopic dermatitis, allergies to foods and/or the environment, and diabetes. A chronic illness usually cannot be cured, but it can often be well managed to allow the person to lead an active life.

## What are your goals?

Even with a chronic illness such as asthma, your child can still do the things other children his or her age can do. Goals that families have for children with a chronic illness often include being able to:

- Develop and keep friendships
- Run, play, and do sports
- Sleep well at night
- Attend school most of the time
- Need few or no hospital visits at all
- Control symptoms of chronic illness using medicines with as few side effects as possible
- Feel comfortable when handling the management of the chronic illness

**What are your goals? List them below:**

---

---

---

---

---

---

---

---

---

---



## What shows positive emotional health in children and teens?

Some examples are:

- Getting along with others
- Participating in enjoyable activities
- Doing good work in school, at play, and in taking medications
- Being happy most of the time
- Being able to ask for what they need and to say how they feel
- Handling daily frustrations appropriately
- Being able to be comforted when upset



## How do physical health and emotional health affect each other?

Mental health and physical health impact one another. Increased physical symptoms can cause a rough time on the child's emotional health. Chronic illnesses can interfere with children's happiness and how they feel about themselves. When children are distressed and unhappy, their illness may be harder to control. Many things having to do with a chronic illness can affect the child or teen's emotional health. Some examples include:

- A child or teen may need to complete medical tests. These can be invasive and scary.
- A child or teen may be sad and grieving because of a doctor's suggestion to remove a pet from the home, or to limit his or her activities

- A child may feel "different" than peers
- Medicine side effects can affect children's mood, and how they feel about themselves and their bodies
- Infants and younger children, when sick, can be clingy, lethargic, sad, fussy, mad, tearful, withdrawn

As stated above, children and teens often feel unhappy when sick. These mood changes often improve quickly as your child begins to feel better physically. However, when a child or teen with a chronic illness has mood changes that continue or return, this may signal a problem that needs professional attention. The good news is that it can be helped!

When children are distressed and unhappy, their illness may be harder to control.

Areas to keep an eye on are:

- Changes in eating and sleeping habits
- Changes in school performance
- Mood swings
- Negative self-comments about the way he or she looks or feels
- Not cooperating with medical care
- Displays of strong fear or anger

Some children and teens can become very upset and scared about medical tests. Talk with your child's healthcare provider about how best to prepare you and your child for these tests. For instance, before the test occurs, your child may tell you whether or not he or she wants an explanation of the test, or see the medical equipment, or the room in which the test will take place.

In addition, pay attention to whether your child or teen:

- Starts to withdraw from friends and family
- Shows less interest in things he or she previously enjoyed
- Looks unhappy, sad or angry
- Fights with siblings and friends
- Begins to talk about death

If you are worried about changes that begin to happen, talk with your healthcare provider about getting professional help.

The Healthcare Team at National Jewish Health can help you and your child understand and cope with the tests that may be recommended.

**Talk with your child's healthcare provider about how best to prepare you and your child for medical tests.**



## What can you do to help develop positive emotional health in your child?

Adults can do a lot to help develop good mental health in a child with a chronic illness:

- Provide routine, predictable times to talk or “check-in” with your child
- Help your child to know that unhappy feelings are acceptable and normal
- Show that you understand your child or teen’s feelings by saying things like: “Dealing with your illness is tough” or “Taking medications every day is very hard, and something your friends don’t even have to think about”
- Provide ways to help your child get rid of bad feelings, and reward him or her when he or she does. Some examples are using puppet play to act out feelings, or making an “anger corner” in the home where younger children can rip up newspaper, hit pillows, or stomp and yell, “I’m mad at my illness.” Older children and teens may want to write in a journal, draw, exercise, hit a punching bag, or learn relaxation

techniques to release their feelings.

Creative arts can also provide a helpful outlet to children with a chronic illness.

- Reward your child routinely for taking prescribed medications. Remind him or her that after he or she does, fun activities can follow such as bike rides, playing with a friend, or going to that bowling party or movie.

Make sure that other adults who care for your child or teen know about your child’s illness and the medical plans that are in place. These can include schoolteachers, religious leaders, coaches, or extended family. Work together to encourage, support, and reward the good choices your child makes. Examples are: when children with allergies avoid things to which they are allergic, or when kids with asthma rest during physical activities when they are feeling “tight.”





## How can chronic illness affect your family?

Chronic illness can also affect your family in many ways. Some of these include:

- Parents may have increased worry and stress
- Sleep may suffer
- Family sadness and/or anger may increase
- Healthy siblings may get less attention and become jealous
- Increased time may be spent on organizing an Illness Action Plan and seeing that it gets used. This can be frustrating and may take time away from fun family activities.
- Parents may have less time for each other and for social activities outside the home
- Plans for dinners or vacations may get cancelled
- Planning for future fun times may be more difficult due to the unpredictability of the illness
- A child's decreased cooperation over medicine taking and treatment can lead to conflict within the family
- Money problems can occur

Chronic illness can affect your family in many ways.



## What can you as a parent do to help?

Parents can help a lot! Some examples include:

- Focus on fun family activities when your child is healthy
- Siblings often feel “left out” or jealous of the time and attention the sick child receives from parents, even during doctor visits. Explain to siblings about how much has to be done because of the illness. Remind them frequently that they are loved equally.
- Ask your other children what might help them to feel better, particularly during an acute period of your sick child’s illness
- Provide routine quality time to all your children, not just to the one with an illness
- Have each parent alternate providing this quality time, as each parent should be equally involved with all the children, as well as with the medical care of the ill child. Single parents can alternate quality time between each child.
- Talk openly with your family about the stress of chronic illness. Set an example for your children by telling them how you feel about it.
- Work hard at not allowing your ill child to feel responsible or guilty for the added stress or expense
- Learn deep “belly breathing” to calm your children and yourself whenever the stress of the illness seems too much
- Find babysitters you trust with your child’s daily routine and special needs so that you have time for yourselves



## **Should you discipline your child even when he or she is sick?**

Absolutely. Knowing what to expect helps reduce worry in children. Structure and consistency are an important part of raising an emotionally healthy child. This can be difficult under the best circumstances, let alone when your child is ill. Therefore, basic expectations should stay the same

regardless of illness. If parents do not give clear expectations and set limits, children may begin to “use their illness” as a way to avoid doing what you expect of them. But remember that expectations may change when your child is very ill.

**Structure and consistency are an important part of raising an emotionally healthy child.**



## What can you do to help positive illness management?

Teaching children about their illness, symptoms, triggers, and treatments can help make their care both safe and effective! This will help reduce some of your worry. It is important to handle the chronic illness as only one of life's challenges. Likewise, managing the illness should be just one part of your child's daily routines — not the only focus.

It may also help to have Illness Action Plans written out for others who care for your child, like providing a written action plan for school, camp, childcare, and friends/family. By understanding your child's chronic illness and any special needs he or she might have, other adults will be better able to care for your child safely.

In the following sections you will find information about developing an Illness Action Plan (IAP) to help best manage your child's illness. You will also find an example of an IAP with instructions on how to complete it. Talk with your child's healthcare provider to make sure one is developed exactly to fit your child's needs, as the older your child gets the more responsibility he or she can take for his or her illness.

Lastly, remember, if you see signs that your child is struggling emotionally with the stress of the illness, talk with your healthcare provider about getting professional help.

Teaching children about their illness, symptoms, triggers, and treatments can help make their care both safe and effective.



## What are age appropriate expectations for your child?

It is always best to take a family approach. We all do better when someone we love helps us stay healthy. While parents will always have a role in their child's health, that role will vary. For instance, with increasing age, the older child and teen will take on more responsibility and the adult will move slowly into more of a guidance role. The following are some general guidelines that can be used based on whether your child is preschool age, school age, or a teen.

### Preschool Years

Preschool years are all about gaining your child's cooperation and beginning to teach him or her self-care techniques.

Your child should be expected to:

- Cooperate with medicines and therapies
- Use correct technique when taking medicines and therapies
- Respond to adult guidance when symptoms happen
- Begin to identify symptoms, and tell an adult when something doesn't "feel right"

### School Age Years

School age years are all about learning and speaking up for oneself.

In addition to the preschool expectations, your school age child should be expected to:

- Know the dose, time and correct use of medicine
- With the help of an adult, seek ways to remember medicines and therapies. For example, have a daily routine, such as taking morning medications with breakfast, and evening medications with dinner, which can help him or her remember.

## School Age Years (continued)

- Discuss treatment of symptoms with the adult helper
- Identify things that make the illness worse
- Begin to independently avoid or control things that make the illness worse, like avoiding exposure to allergens, like to animals to which they are allergic

## Teen Years

Teen years are about being able to do all of the things listed above plus having the ability to make wise decisions. Be careful! Many parents believe that teens can be totally responsible for themselves. However, it is in the teen years when action plans often fall apart. Just because teens often look and sound like adults doesn't mean they always think or act like adults.

In addition to the preschool and childhood expectations a teen should also be able to:

- Learn medicine actions and side effects
- Plan and take routine medicines and therapies using reminder techniques, such as a written medicine schedule or an alarm wristwatch or cell phone
- Pack medicines to take with him or her. Consistently having a packed travel pack may be helpful.
- Identify when a medicine needs to be refilled from the pharmacy, and then tell an adult helper

- Meet with the adult helper on a routine basis (at least weekly). When you meet discuss the details of the action plan, and how the action plan is going.
- Avoid and/or control things that make illness worse, at home and school and friends' homes
- Identify severity of symptoms, treat the symptoms, and know when to contact the healthcare provider

These tasks may be inconsistently managed by the teen. Teens often need closer supervision during times of stress and/or illness. Because symptoms may be identified one time and disregarded by them at another time, supervision by a parent or adult helper is very important. As the adolescent demonstrates consistent responsibility taking, adult supervision can be slowly decreased, and the teen's status and privileges increased. You may go from watching him or her closely to just being needed to answer a question.

So remember, expectations vary depending on the age and developmental level of your child. At all ages though, parents or adult helpers always play an important role whether your child is preschool age, school age, or a teen.

**Expectations vary depending on the age and developmental level of your child. At all ages, parents or adult helpers always play an important role.**



## Developing an Action Plan for Chronic Illness

Illness Action Plans (IAPs) can be developed for all chronic illnesses. For instance the American Academy of Pediatrics recommends that children with asthma have an action plan to help with controlling their asthma illness. IAPs help you know what to do every day to manage your child's chronic illness, like which medications to take, and when. In addition, it will help you know exactly what to do when your child's illness is getting worse, and when your child is having more frequent symptoms. Knowing what to do, and when, is important for managing any illness.

Ask your child's doctor about developing an IAP for your child. This should include steps to take for regular care and for when your child is getting sicker. Make sure your child's healthcare provider helps you to put down in writing everything that goes into the IAP, no matter what the illness. Make sure to ask all of your questions of the healthcare provider; **you** are the consumer.

As we said in the last section, these plans can then be shared with school nurses, physical education (PE) teachers, babysitters, relatives, and others who care for your child.

Knowing what to do, and when, is important for managing any illness.

### How to Fill out Your Child's or Teen's Illness Action Plan with your Healthcare Provider

An example of an Illness Action Plan is included for you to discuss and develop with your child's healthcare provider. Below are instructions about what should be included in each section.



Ask your child's doctor about developing an Illness Action Plan for your child.

**DESCRIPTION OF THE DIAGNOSIS** List the child's diagnosis here. Things like asthma, eczema, food allergies, and diabetes should go here.

**DAILY CARE NEEDS** List the medicines, treatments, and equipment your child might require while at school/daycare, or on overnights, and the times they should be taken. For teens it may include rescue inhalers when going on dates. Things to avoid, such as specific foods or possible triggers, should also be included. Include tips to improve cooperation such as providing rewards and distractions as appropriate for your child. Some examples of rewards include a sticker chart for positive reinforcement, and using bubbles, games, or stress balls to help with distraction. Adolescents may enjoy later bed times, increased allowance, or "overnights" as their rewards.

**WARNING SIGNS** List signs that caretakers can look for to tell them your child is having difficulties. Don't forget to include such things as asthma peak flow zones if appropriate or signs of allergic reactions.

**ACTIVITY LEVEL** List any special requirements or accommodations your child might need at school such as taking medication before physical activity, breaks during PE, an elevator pass, or getting more time to walk between classes.

**AN EMERGENCY ACTION PLAN** If symptoms continue to worsen after regular steps are taken, it is important to have the necessary medications on hand and a step by step action plan, including when to go to doctor visits, to the emergency room, or when to make 911 calls.

**CONTACT INFORMATION** List people to call in an emergency and their phone numbers.



## Developing an Action Plan for Chronic Illness

### Illness Action Plan (IAP)

Below are some examples of what should be included.

Diagnosis (What is the illness, condition?)

---

---

---

Daily Care Needs (List all your child's medications and treatments here)

---

---

---

Warning Signs (Are peak flows low? Is your child's skin red or irritated? Is your child in pain? Is your child scared?)

---

---

---

Activity Level (When should your child not do recess or PE?)

---

---

---

Emergency Action Plan (What should you do if the child is not getting better and needs to go to the hospital right away? Who should be called in the family?)

---

---

---

Contact Information (Names and telephone numbers to call if your child is sick at school or at an overnight)

---

---

---

### What do you do once the Illness Action Plan (IAP) is developed?

Once the IAP is developed:

- Provide a written copy of the action plan to adults caring for your child, especially babysitters and key school personnel
- Meet with the adults caring for your child such as the child's teacher and nurse and explain it to them. Make sure these adults know what to do and feel comfortable following the IAP. Your child may be able to help demonstrate some of his or her care. For school, agree on a "signal" between your child and teachers so that your child can obtain medical care without disrupting the class or feeling as if everyone is watching him or her.
- Check with your child regularly to see how the action plan is working. Make sure your child knows what to do.
- Check back with the adults caring for your child to see how the action plan is working
- Have extra copies of the plan to provide professionals in case of an emergency



Check with your child regularly to see how the IAP is working.

### What are signs that the Illness Action Plan is working well?

Remember, most of the time your child should be able to:

- Run, play, and do sports
- Sleep well at night
- Attend school most of the time
- Control symptoms of chronic illness using medicines with as few side effects as possible
- Control chronic illness or allergies with no (or very few) hospital visits
- Accept the steps of his or her chronic illness care plan, even if it annoys him or her to do it

If the above positive signs are not true of your child, talk with your healthcare provider about the action plan.

### When should you be concerned?

Some signs of poor illness management are easier to notice than others. Signs that the Illness Action Plan needs to be adjusted vary with age and development. These signs may include:

## Developing an Action Plan for Chronic Illness

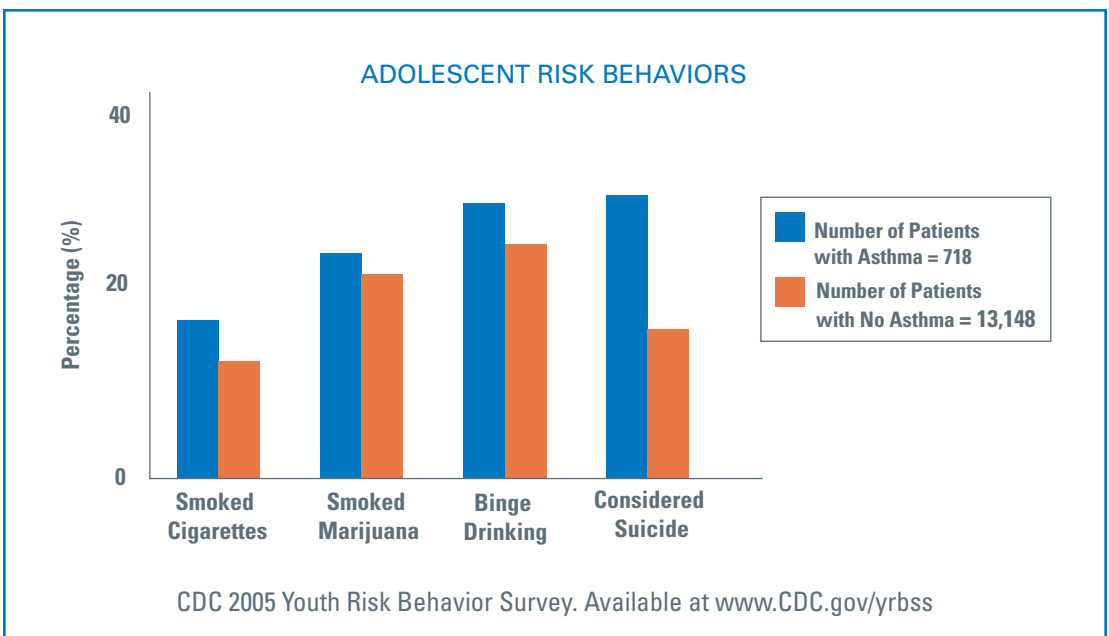
- Increased symptoms of the chronic illness/condition
- Decreased cooperation with illness care
- Overlooking and/or denying symptoms
- Exposing oneself to triggers, like foods or animals to which they are allergic
- Missing school and/or activities
- Withdrawal from family and friends
- Mood changes

### Why is the Illness Action Plan not working?

Studies have shown that older children with a chronic illness are more likely to experience symptoms of depression and engage in risk-taking behaviors such as using cigarettes, drugs, and alcohol. They may be angry about the illness and about all of its responsibilities, and how the illness sets them apart from other children and teens their age.

Here are some other reasons for a failed action plan:

- Denial (“I feel fine today. I don’t need my medications.”)
- Lack of a routine for daily care such as taking regular medication at consistent times
- Lack of praise, rewards or privileges from the caretakers for good daily care by the child/teen
- Forgetting to renew prescriptions



### How can you improve the Illness Action Plan (IAP)?

As a family, you can do many things to help take charge of your child's illness. If things are not going well, it may be time to step back and take a fresh look at how the IAP has been developed. Some steps you can try include:

- Reorganizing the routine for daily care so that it is more workable and convenient for family members
- Setting up clear expectations and time frames for completing the daily care with or by your child
- Setting up rewards, including encouragement and praise for good daily care by the child
- Clarifying behavioral limits and consequences, and holding the child accountable for poor daily care
- Encouraging age appropriate responsibility taking. Praising mature behavior.



If the IAP is not going well, try setting up rewards for good daily care by the child.



## When should you consider counseling/therapy?

Consider counseling and therapy if there are changes in your child's daily functioning.

You may notice:

- Changes in eating and/or sleeping
- Not wanting to see friends
- Missing or avoiding school
- Grades that are dropping
- Lack of treatment cooperation, or medication refusal
- Changes in behavior or mood
- Expressing strong emotions like anger or tearfulness, which can lead to the worsening of symptoms or to poor illness management
- Trouble coping by the child or family members

It may help to talk with your healthcare provider about when and how to seek counseling and therapy. It is often beneficial to meet with a therapist who works routinely with children, families, and chronic illness.

It is also often helpful to meet with a therapist during the testing or early assessment stage of the child's illness. This allows for family discussion about the illness, to raise your concerns about the possible negative impact on your child and family, and to learn ways to prevent illness-related stress.

Sometimes we forget that the mind and the body have to work together if we want to feel better. Interventions such as biofeedback and hypnosis can help children and adolescents master relaxation/breathing techniques, and improve their overall self-care so that they can be in better control of their illness. These tools can also help reduce emotionally triggered symptoms. You may also want to discuss with your healthcare provider accessing other services in your community, such as your child's school nurse, the support of a visiting home nurse, or finding respite care for parents and grandparents.



## What types of services are available at National Jewish Health?

The Department of Pediatrics at National Jewish Health emphasizes the importance of teaching patients and their families how best to manage their disease. The Pediatric Behavioral Health (PBH) clinicians are an essential part of the National Jewish Health multidisciplinary team, working together to help children and families cope more effectively with the chronic illness. This teamwork is important for the patient as it makes communication and planning easier. After completing medical evaluations at National Jewish Health, including a visit with a clinician from our PBH team, most patients return home with a better outlook on life and themselves.

The PBH team also works with children and families addressing other emotional/behavioral issues not having to do with chronic illness. You do not have to be a medical patient to be seen by the PBH group. We can provide general assessments, brief (one session)

quality of life assessments (QAL), psychiatric assessments, psychological testing, and routine individual, family, and group therapy. We use a variety of modalities that can include art therapy, play therapy, hypnotherapy, relaxation and biofeedback, eye movement desensitization and reprocessing, and cognitive behavioral approaches. Many of these services involve brief assessments and interventions, and psycho-educational teaching. Our PBH team continues to develop new programs to help improve the quality of life of each medical patient and their family. At National Jewish Health we work with people from all walks of life and from various parts of the world. We know that different people have different beliefs about medical procedures, medications, and therapy. Your concerns are addressed with the utmost respect.

**Call us at 303-398-1260 if you would like more information or are interested in setting up an appointment.**

# Glossary

**ACCOMMODATIONS** Changes to make things easier and safer

**ACCOUNTABLE** Checking to make sure things get done

**ACUTE** When symptoms are severe and often

**AFFECT** Change in a good or bad way

**ALTERNATING** Taking turns

**CHALLENGES** Tough things to face

**CLINICIAN** Therapist

**CONFLICT** Arguments, disagreements

**CONSISTENCY** Doing things the same way each time

**CONSULTING** Giving help when you are asked

**CONSUMER** The person who buys the service or product

**CURED** Fixed completely, no symptoms ever

**DEMONSTRATES** Shows

**DISREGARDED** Not paying any attention to symptoms

**EMOTIONAL** Having to do with feelings

**EXPOSURE** Coming into contact

**FORMATS** Ways counseling is done

**FUNCTIONING** The things your child does

**GRIEVING** The process of feeling angry and sad over a “loss,” and that it’s not fair

**GUIDANCE** Suggesting what to do

**INDEPENDENT** Doing things on one's own

**INVASIVE** Something which enters their bodies: shots, probes

**LETHARGIC** Tired, no energy

**MODALITIES** Types of therapies

**NEGATIVE** Bad, critical

**PHYSICALLY** Having to do with the body

**PREDICTABLE** Knowing when it is going to happen

**PROFESSIONAL** Someone with training

**QUALITYTIME** Fun time together

**RESPONSIBILITY** Things one needs to do

**SEVERITY** How bad it can get

**SIBLINGS** Brothers and sisters

**STRUCTURE** Organizing ways to do things

**SYMPTOMS** Signs of illness

**TRAUMATIZED** Scared and upset for a long time

**WITHDRAW** Doesn't want to be around anybody



# Notes

# Notes

**Call Pediatric Behavioral Health  
at 303-398-1260 for more information  
or to set up an appointment.**

**[njhealth.org/pbh](https://njhealth.org/pbh)**

**[njhealth.org](https://njhealth.org)**

**nj4kids**<sup>TM</sup>

For more information:  
1400 Jackson Street  
Denver, Colorado 80206

[njhealth.org](http://njhealth.org)



**National Jewish  
Health**<sup>TM</sup>

Science Transforming Life<sup>®</sup>