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# Returning to School After Cancer Treatment

When a child or teen is diagnosed with cancer, families and parents will face and need to cope with many problems, including the impact of a child's cancer diagnosis and treatment on regular school routines. A child's cancer diagnosis and treatment can interrupt regular school routines. Many children are able to continue their education during treatment and then will go back to school full-time at the end of treatment. See <a href="Helping Your Child Manage School During Treatment">Helping Your Child Manage School During Treatment</a> for information on keeping up with school before treatment ends.

Most children are able to return to school full-time after they complete cancer treatment. Going back to school is a priority because it can give children a sense of normalcy and is an important part of their social and academic development. Some children feel excited about returning to school, while others feel upset or anxious. These are all normal reactions. Going back to school might be a challenge or a relief. It might give your child the comforting message that they have a future and potential for a full recovery from cancer.

The transition back to school can be just as hard for parents. Parents might think school is going to be overwhelming for their child. They might worry their child will get infections, become overly tired, or be teased for being different. All of these concerns are normal. Most pediatric treatment centers know that families might need help to make sure the transition goes smoothly. Children's hospitals may have education coordinators and teachers that make sure your child has the right support at school.

This piece will guide you through key steps in planning for the return to school after treatment ends, some common problems after returning to school, and things you can do to help.

# Start planning early

After your child is diagnosed and long before any plans are made for them to return to school, you might have talked your child's teachers, school principal, and school counselor about the cancer and the treatment plan. When your child is ready to go back to school, it is important to communicate early with the school and the cancer care team early. Here are some of the steps you can take before treatment ends to help get ready:

- Talk to the cancer care team about when they think your child will be able to return to school after the end of treatment.
- Once you have a planned return date, ask the cancer care team what resources will help plan for school re-entry. The school re-entry services might include nurses, teachers, psychologists, social workers, and child life specialists. If there is a rereentry program, ask them what they will do to support your child's return to school. They might be involved in meetings with the school, arrange visits to the classroom, or communicate special needs to the school and teachers.
- Reach out to the school principal, teacher, nurse (if there is one), and school
  counselor to let them know when your child might return full-time. They might have
  forms for you and the cancer care team to complete.
- Arrange a meeting with the principal, teachers, and school nurse to make sure
  everyone knows what to expect. The cancer care school re-entry team members
  might participate and help guide this discussion, depending on the kinds of support
  they provide.
- Some children might not be ready to return to school for full days the first week, so
  it could be helpful to think about how long their school day should be in the
  beginning. It may take them a few weeks or a month to build up their energy levels
  after cancer treatment. Talk to your doctor and cancer care team about these
  needs before you meet with the school leaders.

#### What the school should know

Meeting the teacher, principal, and school nurse (if there is one) before the child goes back to school is very important and can help everyone know what to expect. If your cancer care team offers support for retuning to school, ask if they will be at the meeting. If they will not be present, ask them to help you write a letter explaining any expected changes in the child's routine and future plans. You'll want to write down these things for the school's records:

- Any medicines the child will need to take and how to give them
- Special devices the child will use and how to use them
- What kinds of problems to watch for and report to you
- Any special precautions that need to be taken or information you need to know, for instance, if a fellow student develops chicken pox or some other illness that might be a problem for your child
- Emergency management of possible problems
- Medicines, treatments, or activities that your child can't have or do
- Whom to call with questions and emergency contact information
- When your child can meet the teacher, principal, and school staff before they go back to school. Ask if your child and have a classroom visit.
- Share any plans or potential needs for a 504 plan or Individualized Education Plan (IEP) if your child has learning problems or needs other kinds of assistance. (See What is an IEP or 504 plan?)
- Any special accommodation needs such as wheelchairs, walkers, help with certain physical activities, or needs for other special devices
- Make sure they know that you'll want your child to be treated like everyone else as normally as possible--except for any special needs

# Common challenges when your child returns to school

Once your child returns to school, you might find that not everything goes as planned. Going through cancer treatment was a big change. It is not unusual for your child to need more support emotionally or academically. You might find there are new physical changes that cause problems, or that the emotional adjustment is a challenge. Some treatments can also affect how children learn and think. Be sure to ask your child every week or so about any concerns they are having after returning to school. Some might need to be addressed quickly, especially if your child is feeling upset about them. Other changes due to cancer treatment may surface later. For more information, see<u>Late</u> Effects of Childhood Cancer Treatment.

#### Some children might not want to go to school

Finding excuses to miss school could be a sign that your child is struggling with some part of going back there. If your child is tearful before and after school or every Sunday night, that might be a sign that they are having a hard time with the change. Older kids and teens might not want to go back to school because they look different, or because their long absences have changed their social standing with friends. If your child does

not want to go to school, it is important to understand what is bothering them. Here are things you can do to understand the reason they are avoiding going back.

- Ask you child to help you understand what is hard for them about going to school
- Make sure they know that they do need to go to school and set limits on staying home from school
- If they stay home from school they may avoid what is upsetting them, but it isn't going to make things better
- Talk with the teachers and school counselor about your child's feelings, they may also have some ideas about what can help
- If the problem is physical, related to school work being too difficult, or other factors the sections below include information about solving common challenges likes these
- Talk with the cancer care team if your child is saying they feel sick, it might help you
  and your child feel more comfortable to get checked out

#### Talking with other children about cancer

Other children may have questions for your child about cancer. It can be hard for children to know what to say in these situations. It usually helps to talk with your child before they go back to school about what to say, so they are ready if it happens.

- Some cancer care teams will send a team member to the classroom to answer these questions, so you might want to check with them first.
- Explain to your child that friends may not understand much about cancer and might say and ask some strange things.
- Give them examples of some questions kids might ask, including: "What is cancer?", "Are you going to die?", "Can I catch it?", and "Can you still play?"
- Talk with your child about how to answer each of these questions. It may help younger children if a nurse or teacher explains to the class that cancer is not contagious and no one did anything to cause it.
- Tell your child they can respond to many questions without a long explanation. For instance, they may say: Thanks for asking, but it's kind of hard to talk about this at school. I don't know the answer to that. Maybe you can ask the teacher or the nurse about that. Depending on the situation, the child might want to use one of these answers then change the subject in a friendly way, maybe with talk about school, an offer to play, or another non-cancer-related topic.
- Know that every child has their own coping style. Helping them figure out what feels

best for them before they go back to school will help them handle questions from friends and classmates in a way that feels OK to them.

### Managing physical problems at school

Physical problems after cancer treatment can affect a child's ability to get around and perform at school the way they did before their cancer diagnosis. Schools might need to accommodate a child's physical needs after cancer treatment. Here are some examples of physical problems and ways to handle them.

If your child is having problems with fatigue or weakness

- Your child may need 2 sets of books, one for home and one for school.
- Ask the school principal and cancer care team about excusing your child from certain physical education activities to avoid severe fatigue during later classes.
- You might be able to have your child take brief rest periods or shorter school days may be needed.
- Teens may need locker assignments closer to classrooms to get to class on time.
- Some children may need more time on tests, quizzes or reduced assignments because of fatigue.

If your child is having problems with appetite, thirst, or using the bathroom

- Dry mouth caused by treatment could mean the child needs to carry a water bottle.
- Children who have bladder or bowel problems after treatment may need long-term bathroom passes so they can take care of these needs without calling attention to the problem.
- Children who are having trouble gaining weight or are underweight may also need a longer lunch period and have extra snacks.

# If your child is having trouble with schoolwork and learning

Most children adjust well to school after cancer treatment. But cancer and its treatments can cause emotional and cognitive (ability to think and reason) changes, which can affect your child at school. You can help your child by watching for problems, so they can be dealt with as soon as possible, before they become hard to manage. Some

changes after treatment that affect learning can last a few months, others may last longer. Children can experience something called <u>chemo brain</u> that can make is hard to focus, complete tasks or remember things. Some treatments have long-term effects on learning, so it is important to get help as soon as problems with schoolwork come up.

- Talk with the teachers and cancer care team about what is happening and get referrals for support, if needed.
- Ask your child if they are having a hard time with friends or other the social relationships. Trouble with other children can also affect school work. Your child's school or cancer treatment center may offer counseling support to help.
- Ask the cancer care team if your child's treatment is known to cause school
  problems as one of the late effects of treatment. Sometimes these school problems
  are called neurocognitive late effects.
- Talk to the cancer care team or school about resources to help understand the kind of problems your child is having. This testing might be called neuropsychology testing. If testing is recommended, it is often used to understand if a 504 plan or IEP would be helpful.
- Make sure you child knows that having trouble in school doesn't mean they aren't
  as smart as they were before. It might help to tell them that the cancer treatments
  might make their brain work differently than it did before. it might help them to know
  that the testing is to help understand their brain better so everyone can help in the
  best way possible.

Sometimes children who have had cancer treatment will have learning problems and need extra help. Most children who are at risk for learning problems from cancer treatment will benefit from testing, often called neuropsychology testing, to understand their individual learning needs. This kind of testing may be offered by the school psychologist or counselor at no cost to the parent or at the cancer treatment center where your child was treated. Neuropsychology testing usually covers assessments of reading, writing, math skills, memory, comprehension, attention, concentration, and fine motor skills. If your child has had radiation to the brain, you may want to ask for testing, whether you notice a problem or not.

If your child needs extra help learning, keep in mind that all children have a right to education in the least restrictive environment. This means that your child should be with other non-impaired children as much as possible. If parents have an issue with the school and the education their child is getting, they have the right to request a third party mediator to settle disagreements.

After getting all the results, the school can develop an Individual Education Plan (IEP) or

a 504 plan for your child.

#### What is a 504 or Individual Education Plan?

An Individual Education Plan (IEP) or a 504 Plan is a plan developed by both parents and teachers to meet the individual needs of a student. If your child meets all of the stringent legal requirements to qualify as a special education student, the plan is called an IEP; if not, it's called a 504 Plan. 504 plans are often used for children who do not qualify for an IEP. 504 plans and IEPs are provided by the school at no cost to the parent and the school and cancer care team can help identify which plan is right for your child.

- The plan describes your child's learning problem and sets specific goals for your child's education.
- It includes referrals to other services if needed, such as occupational therapy or speech therapy, and provides for regular evaluation of the plan.
- Sometimes students do better when their work is oral and not written. They may do better when they can use a computer, audiobooks, or are given more time to complete assignments. These kinds of things might be included in the plan.
- Your child's IEP or 504 Plan can be changed at any time to address any cognitive changes caused by the cancer and/or its treatment.
- Plans will need to be changed as the child's needs change. It's important to stay in touch with the school even after plans are set up to help support the child while in school. Planning, reviewing, and updating educational plans can go on for years after cancer treatment is over.

It can seem pretty unfair to have cancer and then to struggle to go back to school. But learning as much as you can about possible problems can help you and your child adjust faster. There are other resources that may help you.

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