

# Talking to your child about P.M.A.

## Children 3 to 5 Years Old

- Give very simple explanations of what's happening and repeat them often.
- Check on the child's understanding of what's happening. Remember that the child may be able to say back to you what they heard the first time or two, but this doesn't mean they understand it.
- Do not tolerate biting, hitting, kicking, or other aggressive behavior. Teach the child how to express feelings in healthy ways.
- Teach acceptable expressions of angry feelings such as talking, drawing, or pounding a pillow (things that don't hurt the child or other people).
- Encourage doll play and other play to rehearse or repeat worrisome or painful experiences, or ask the child to draw pictures about their teacher/friend. Use play and artwork to help the child understand what's happening.
- Create opportunities for physical activity.
- Be sure that the child understands which of the usual things they cannot do with their teacher/friend. Laugh together when possible
- Do not try to persuade the child using reason or logic.
- Give simple explanations for crying and sadness. For example, "I just feel a little sad and a little tired today. It makes me feel better to cry and get it all out of my system. Now I feel better."
- Pray with your children for their teacher/friend, for others with health challenges and always point them to the hope that we have in Jesus.

## Children 6 to 8 Years Old

- Keep the child up to date about the illness and treatment, and be sure to explain what the child sees and hears. You may need to keep repeating this information.
- Answer all questions honestly, including, “Will he die?” Get help from a pastor or others if needed.
- Listen for unasked questions, and pay attention when the child talks about fears and concerns.
- Encourage and help youngsters to identify and name feelings.
- Encourage expressing and talking about feelings, especially anger, and safe ways to do it.
- Teach the child about feeling and managing anxiety.
- Assure the child that it’s OK to be upset, sad, anxious, or angry and that their teacher still loves and cares for them.
- It’s OK for the child to see the teacher or other grown-ups cry or be angry as long as the child understands that they’re not to blame for these feelings. Try to help them understand that it’s normal to have strong feelings and it’s good to express them.
- At least one adult should give the child permission to ask them questions and express feelings that the child thinks might upset others.
- If parents have trouble listening to the child’s distress because of their own, get family, friends, church staff, or other professionals to help talk with and listen to the child.
- If a child is having trouble in school, explain that it’s normal for school performance to suffer a bit in these situations, and you are not upset with them.
- Tell the child that it’s hard for everyone at church, but that you are there for them.
- Be prepared to tell the child’s teachers, coaches, and other school staff about the situation if they begin to struggle.
- Keep a normal schedule as much as possible.
- Support the child’s having fun. Make sure they don’t feel guilty about it.
- Remind the child that it’s normal for them to need play time and time to be with their friends for games, sports, and other activities that they enjoy. It’s OK to still be a kid!
- Pray with your children for their teacher, for others with health challenges and always point them to the hope that we have in Jesus.

## Children 9 to 12 Years Old

- Tell the child as much detail as possible about the disease and what to expect and what the teacher may be feeling (for example, weaker, have trouble eating, loss of muscle control, etc.). Answer questions honestly.
- Let the child spend as much time with the teacher as they want and is appropriate. Suggest topics to talk about.
- Keep the child up-to-date on how the teacher looks.
- Help the child stay involved in after-school activities, sports, and keep him or her in contact with friends. Remind the child that it's OK to have fun.
- Be prepared to tell the child's teachers, coaches, and other school staff about the situation if they begin to struggle.
- Assure the child that it's OK to be upset, sad, anxious, or angry and that their teacher still loves and cares for them.
- Encourage expressing and talking about feelings, but allow the child to keep their feelings private if that's what they prefer.
- Encourage the child's interest in reading or writing about the disease and their responses.
- Pray with your children for their teacher, for others with health challenges and always point them to the hope we have in Jesus.

## Teenagers

- If they are interested, give teens details about the teacher's condition, symptoms, possible side effects of medicines, what they might expect in the future, and other information.
- Keep the teen up to date with what's happening with the teacher's treatment. Answer all questions honestly.
- Let the teen and the teacher spend as much time together as they like and is appropriate. Suggest topics to talk about.
- Explain that even though the teacher has less time and energy for them, they still love and value them.
- Be prepared to tell the teen's teachers, coaches, and other school staff about the family situation.
- Discuss any spiritual concerns related to illness, death, and dying.
- Try for as normal a life at home as possible.
- Be sure teens know that having fun and spending time with friends are important parts of their lives, and there's no need to feel guilty about it.
- Encourage teens to keep up their usual involvement in school and other activities.
- Ask a relative or trusted friend to take a special interest in the teen.
- Address feelings of anger and frustration (even if they are unspoken).
- Being willing to tolerate some reluctance to share thoughts and feelings.
- Teens may try to protect their teacher by trying to hide their sadness, anger, or fears. Check in with teens often and let them know that everyone has feelings that can be confusing and overwhelming. Tell the teen it's OK to ask questions and express feelings that they think might upset others.
- Encourage your teen to keep a journal or log.
- Pray with your children for their teacher, for others with health challenges and always point them to the hope that we have in Jesus.

## **Q&A For Kids and Youth**

(Progressive Muscular Atrophy (P.M.A.) is a less common form of Motor Neuron Diseases LIKE A.L.S. or Lou Gehrig's Disease. For our purposes, the below information on ALS is accurate.)

### **“How Is ALS Diagnosed?”**

Lou Gehrig's disease is different for every person who has it. In general, muscle weakness, especially in the arms and legs, is an early symptom for more than half of people with ALS. Other early signs are tripping or falling a lot, dropping things, having difficulty speaking, and cramping or twitching of the muscles. As the disease gets worse over time, eating, swallowing, and even breathing may become difficult.

It may take several months to know for sure that someone has Lou Gehrig's disease. The illness can cause symptoms similar to other diseases that affect nerves and muscles, including Parkinson's disease and stroke. A doctor will examine the patient and do special tests to see if it might be one of those other disorders.

One of the tests, an electromyogram (eh-lek-tro-MY-uh-gram), or EMG, can show that muscles are not working because of damaged nerves. Other tests include X-rays, magnetic resonance imaging (MRI), a spinal tap, and blood and urine evaluations.

Sometimes a muscle or nerve biopsy is needed. A biopsy is when a doctor takes a tiny sample of tissue from the body to study under a microscope. Examining this tissue can help the doctor figure out what's making someone sick.

### **“How Is ALS Treated?”**

Currently, there's no way to prevent or cure Lou Gehrig's disease. But treatments are available that can help. Medicines can control symptoms, such as muscle cramping and difficulty swallowing, and other drugs can slow the development of the disease.

Physical therapy can help people with ALS cope with muscle loss and breathing problems. Special equipment is also provided when it becomes necessary. For instance, a power wheelchair can let a paralyzed person with ALS get around. A machine called a ventilator can help someone breathe.

Also, a nurse or other health assistant may come to the person's home to provide care that the family cannot handle alone.

## **“Living with Lou Gehrig's Disease”**

Living with Lou Gehrig's disease is physically difficult, but it is reassuring to know that the mind usually is not affected. Most people with ALS can think as clearly as ever, are able to maintain relationships with friends and family, and should be treated respectfully and normally.

It's normal for loved ones to feel upset, overwhelmed, and sad if a loved one has ALS. Counseling, as well as support from other family members, the church and friends can make it easier to deal with the challenges they face.

Eventually, communication can be difficult because the disease affects breathing and the muscles needed for speech and arm movement. With patience, people can learn to communicate effectively with their loved one.

Researchers continue to study ALS as they try to understand why it happens, and how the disease damages the motor neurons in the brain and spinal cord. As they learn more about the disease, researchers can continue to develop new and better treatments.