

# ALS Activity Book

A fun activity book for children to learn about ALS.

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ALS, Amyotrophic Lateral Sclerosis, is most commonly known as Lou Gehrig's disease. In other countries ALS is called motor-neuron disease.

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To learn more about the The ALS Association, visit our website at http://www.alsa-stl.org.

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The ALS Association, St. Louis Regional Chapter, is dedicated to improving the quality of life for those affected by Amyotrophic Lateral Sclerosis, educating the community, and supporting research.

# Acknowledgment

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Dr. Chudler's information can be viewed at <a href="http://faculty.washington.edu/chudler/">http://faculty.washington.edu/chudler/</a>
<a href="mailto:neurok.html">neurok.html</a>

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# ALS Activity Book

Helping children to understand the puzzle of Amyotrophic Lateral Sclerosis.

This activity book was originally written for the Focus on the Family and Caring for the Kids Day in 2001. It has been revised with additional information and activities as our children's programs developed.

This book is a hands-on educational tool for practitioners, parents, and other adults caring for children who have a loved one with ALS. It contains educational and developmental guidelines to explain ALS to children. It also implements hands-on activities, games, and learning pages for children, presented in age-appropriate language and content that help them:

- · Understand ALS: the disease process
- Identify what is happening to their loved one
- Recognize and process confusing feelings and emotions they may experience, including grief
- Create positive ways to help themselves, their family, and their community

### TELLING CHILDREN ABOUT ALS

The diagnosis of ALS can be frightening and challenging for most adults. You may be feeling angry, confused, sad, or afraid. You may not even fully understand what ALS is or the impact this illness will have on you or your family. You may also not know how to tell others about your illness; what words to use or how indepth your explanation should be. Telling other adult family members and friends may be difficult enough, but finding the words to tell your children is often even harder.

### Why you should tell them

As parents and grandparents, a natural tendency is to protect or shield children from the worries and fears of a serious illness in the family. However, do not be fooled into thinking that your children do not know something is wrong, even if you have not told them. Even the youngest child has the uncanny knack of sensing or figuring out that something is seriously wrong. If you have not opened the dialogue about your illness with your child, he/she may not feel comfortable asking or talking with you about what is going on. Without this conversation, your child can live with the fears and worries of the unknown. A child's creative imagination can often conger up scenarios that are grossly inaccurate or terribly frightening. Children can even feel they are somehow to blame for what is wrong and live with unfounded guilt. Therefore, **honesty** is definitely the best policy when sharing your medical situation with children.

In addition to alleviating children's fears, honesty about ALS also promotes the notion that ALS is not something about which the child should be embarrassed or ashamed. As new changes develop in your health or abilities, allowing the child to understand and discuss these changes gives him/her a greater sense of trust in you. The only thing scarier for a child than having a parent who is seriously ill, is not having a **sense of trust and comfort** with you, the primary source providing this security.

### How you should tell them

Speaking to your child in an **age appropriate** manner is equally as important as being honest about your illness. Not only do children learn and absorb information differently than adults, but they process information differently based upon several developmental stages in their childhood. Intellectually and emotionally, a preschool age child cannot comprehend what an elementary school child can. The same is true for older age groups; their ability to understand and process information and concepts hinges on their developmental maturity. Therefore, the language you use to explain your illness and the amount of information you provide should be determined by the age of your child. If you have children of varying developmental ages, you may be discussing your diagnosis differently with each child. The key is to provide each of them with information that is age appropriate, while introducing a dialogue for future discussion and building an atmosphere of trust and openness. (see addendum #1 for discussion guidelines by developmental stages)

In talking with your child, use words that your child can comprehend and clarify your child's understanding as you discuss ALS and its impact on you and your family. It is not uncommon for children to misinterpret what you are saying, simply because they did not understand an explanation or comment you have made. Children may also feel guilty, thinking that in some way they have caused your illness. It is important to reassure them that while doctors do not know exactly what causes ALS, we *do* know it was not caused by anything you or your child has done or said.

Encourage your children to ask questions and respond as honestly as you can. However, consider the meaning of their inquiries when responding to them. For example, if you should fall and your young child asks, "Are you okay?," s/he is probably wanting to know if you are hurt by your mishap. An older child, however, is more likely to be associating your fall with your diagnosis and may be asking if your illness will continue to affect you in this way. Gauge the complexity of your answer to the age of your child and the context of the question. Remember that children often learn in smaller "bites" of information, so tailor your responses accordingly. For example, when asked by your child if you will "get better," you may need to differentiate between a reply about symptom management versus a disease cure. For a younger child, you may want to explain

that you can manage and accommodate your symptoms and be "better." However, for an older child or a child who has been more knowledge about your illness, you may need to address the fact that there is no cure to make you better.

### What you should tell them

Besides establishing an environment of security and trust, sharing information about your ALS diagnosis should also convey several other messages to your children. Through your honesty and openness, your children/grandchildren will have the basic tools for helping live well together as a family touched by ALS.

- Be willing to admit that ALS is a **confusing and upsetting disease**. Explain that it is hard to understand why ALS happens and what effects it will have on you and your family. Acknowledge your frustration as well as theirs.
- Emphasize that **no one is at fault** for your getting ALS. Explain that doctors and scientists do not know exactly what causes ALS. Especially point out that nothing you and anyone else did caused your ALS. ALS is not a punishment.
- Stress **acceptance and respect** for yourself (or the family member with ALS). Encourage your children to ask questions about this disease and its impact on your life. Also, support their efforts to offer help at what ever level they are able.
- Offer **optimism and hope**. Researchers are working every day to find a treatment and/or a cure. They may find positive results at any time.
- Also, be willing to "live in the moment." Allow yourself and your family to enjoy the joys of each day as they occur. This perspective offers continual hope for "good" days together as you live with ALS.

### **Children's Reactions**

You should also be aware that your children's reaction may be different than you expect. For instance, your child may seem disinterested, or ask questions that seem irrelevant. He/she may abruptly begin playing with toys during a conversation or act out in his/her play. Children may demonstrate a range of emotions, initially being angry or sad, but move quickly into silliness or happiness. All of these reactions are normal for children. It is important to understand that they are processing as is appropriate for children their developmental age. Allow your children time to process the information and work through these reactions. Expression of their emotions and feelings is healthy. Your children need to be allowed to accommodate these changes into their lives, developing the coping skills that will help them, while allowing for on-going openness and dialogue about the changes that are occurring.

### **Other considerations**

As your illness progresses, you will want to keep the lines of communication open and help your child understand and prepare for what is happening. Please consider the following issues:

- Do not assume that your child will react to each of your medical or physical changes. Reassess what your child is thinking and feeling. S/he may not be affected by changes as you think they might; alternatively, s/he may be greatly affected by something that you consider minor.
- Validate their feelings as normal. Every emotion they have can be "normal." Help them find positive ways to express these emotions.
- Recognize that, as your medical condition changes, so will your physical appearance. Acknowledge with
  your child the social reactions you get and help them to understand that others may react negatively or
  rudely due to being fearful or uninformed about an illness they do not understand.
- Talk with your child about issues other than ALS. Ask questions about school, friends, hobbies, television shows, or internet games. Remain an active part of their lives.
- Explain to your child that your irritability or personality changes may be due to the progression of your ALS. Watch for signs of anxiety or feelings of discouragement from your child; they may be feeling that they are to blame for your negative moods.

### **DEVELOPMENTAL STAGES GUIDELINES**

The following guidelines will help you talk to your child about ALS, using language and concepts that are understandable to his/her age.

### **INFANTS**

Infants are able to sense the emotions of their parents and other caregivers. Although not verbal yet, they may still express their discomfort or concern through their actions. Parents should make every effort to maintain a regular routine and provide nurturance and attention to a child in this age group, when dealing with their ALS diagnosis.

### **PRESCHOOLERS**

Use simple words and phrases in speaking honestly to a preschool-age child. Be sure to reassure them and provide continued attention and emotional support as well as a regular routine, when possible. This environment establishes a sense of security for them. Since preschool-age children have not yet developed their vocabulary, they tend to act out their feelings in play. Some children may act out aggressively on a short-term basis and this should be accepted, as long as they are not hurting themselves or others. Some children may seem to grasp the gravity of the situation, while others this age may seem totally unaffected. Allow preschoolers to experience their varied reactions while providing them with a safe haven to do so. Avoid punishment, but provide support and understanding.

Suggestions: Dolls, puppets, simple books, and stories may aid in talking with this age group. Explain in simple terms what some of your limitations may be due to your illness.

### **ELEMENTARY SCHOOL AGE**

This age group has developed more cognitive skills and will have a better understanding of the significance of your illness. However, coping skills are not very well defined yet, so denial is often used by this age group. Although more verbal that preschoolers, grade school children also tend to express their feelings through their actions. Therefore, you should try to help them find constructive ways to express their feelings and vent their frustrations. It is still important to set appropriate boundaries for this age group, but let them know you are aware of the additional stress they are experiencing. Again, avoid punishment, but communicate your support and understanding through your words and actions.

Suggestions: Write down the name of the disease and use age-appropriate web sites for additional exposure and education. Inform your child's teacher, school counselor, principal, and /or clergyman about your diagnosis and what your child knows; use them as team members in supporting your child. Provide an overview of how your doctors are helping you manage your symptoms; this provides a sense of control to this age child. Give the child concrete ways s/he can help you, i.e., by drawing a picture for you, feeding the dog, or getting the paper.

### MIDDLE SCHOOL

Adolescents are already in a volatile, emotional developmental stage without adding the stress of a serious illness of a parent or grandparent. This age group is busy trying to establish their own sense of self and pushing their boundaries, while separating from their parents. This situation makes the adolescent even more vulnerable, as they struggle between child-like emotions and feelings of being grown up. It is common for children this age to withdraw or act out; this behavior should be tolerated

with some parameters. First, you should leave the lines of communication open; acknowledge to the child that while you do not approve of the behavior, you want to support his/her feelings or worries. Offer to provide the child with additional options, such as a professional counselor, support group, or another trusted adult, if s/he feels that would be helpful. These actions show the child that you are giving permission for them to work through their emotions and concerns.

*Suggestions:* Make your child's school team aware of your child's understanding of your illness. Enlist their help in supporting him/her at school as appropriate. Decide how your family will handle telling your child's friends and/or their families. Provide an overview of how your doctors are helping you manage your symptoms.

### **TEENAGERS**

The teenager is able to think abstractly and understands the illness much like an adult. This age group may still have reactions similar to the middle school age child, depending on their maturity and development. Teenagers need to also know the lines of communication remain open and that they have permission to voice feelings and concerns. Anger is a normal reaction for this age group, but this child may react in any number of ways. Be sure this child has someone outside of the household with whom they can talk. While this person might be an adult family friend, a school counselor, or a professional counselor, s/he should be someone who your child trusts and who will keep conversations confidential. This age child may try to take on an adult role, so be careful not to expect him/her to act as chaperone for you. This situation creates too much responsibility and forces the child into dual roles with you, which is too emotionally burdensome and confusing. Encourage this child to help out if they want to, but do not expect them to take on the primary caregiver's role or other additional duties.

*Suggestions:* Answer questions as honestly and completely as possible. Encourage this child to do additional research on-line or in the library, being sure to recommend reliable resources.

### YOUNG ADULTS/COLLEGE AGE

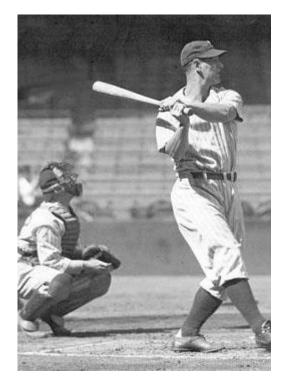
The young adult child faces many of the same issues as the older teenager. While this child will comprehend, react, and be able to assist in much the same ways as an adult, they still must process their worries and emotions of having a parent or grandparent with a life shortening illness. Additionally, this child may be living outside of the home, perhaps away at college or already supporting themselves in their own living accommodations. If this is the case, they many even be living in a different city. These parameters create further emotional burden, as this young adult realizes the implications of the illness and feels the responsibility of helping in some way. It is important to encourage this adult child to seek outside counseling for emotional support.

Suggestions: Most universities offer counseling services through their health services department for free or for a minimal charge. Encourage your college student to utilize this resource. If your young adult child is employed, many health insurance programs also have mental health benefits for counseling. Encourage your young adult to do additional research on ALS for their own education and understanding. Also, several websites focus on the needs of the college-age student or young adults with a seriously ill parent.

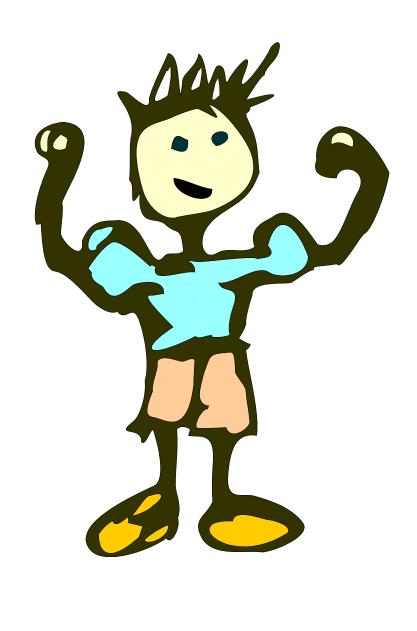
# Lou Gehrig

Henry Louis Gehrig played baseball for the

New York Yankees. Lou played 2,130 games over 13 seasons and left his mark in the game he loved to play. He played first base. His nickname was Iron Horse. Lou played every game for more than 13 years and hit 23 career grand slams, a major league record. He was inducted into the Baseball Hall of Fame.



Lou had a disease called ALS. Some people today call this disease "Lou Gehrig's disease." He had to retire from baseball because he couldn't run, hit, or play catch any longer. During Lou Gehrig Appreciation Day, held at Yankee Stadium, he said, "Fans, for the past two weeks you have been reading about the bad break I got. Yet today I consider myself the luckiest man on the face of the earth. I have an awful lot to live for."



There are a lot of muscles in our body. Muscles are what help our bodies move, walk, and talk. Muscles even help us breathe and eat, too.

# T O

Our muscles can't move alone.
Our brain must tell them what to do.
It sends messages through nerves
Called motor neurons.

# Brain Jokes!

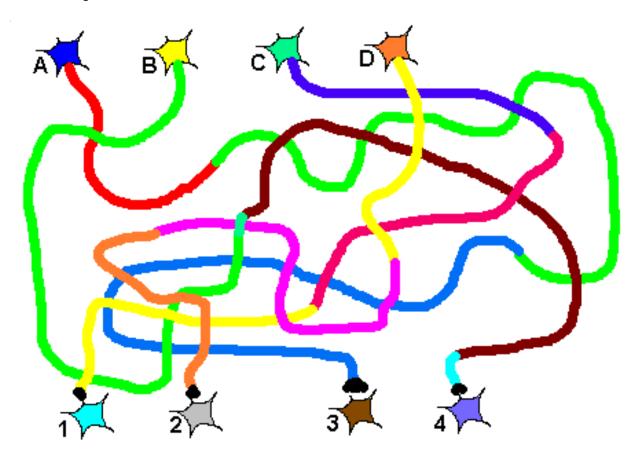
1. What does a brain do when it sees a friend across the street?
2. Why do neurons like e-mail?
3. What is a neuroscientist's favorite type of dog?
4. What did one eye say to the other eye?
5. Why didn't the brain want to take a bath?
6. When does it rain brains?

# Rhyme Time

The answers to the following questions all rhyme with the word brain. How many can you rhyme?

1. In a storm?	Brain Rain
2. Made a spot?	
3. When it hurts?	
4. Used as a walker?	
5. It flies!!!	
6. It is linked?	
7. Just regular?	
8. Hold back?	
9. When grumbling?	
10. When injured?	

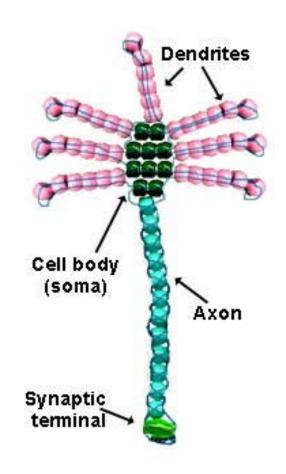
# Motor Neurons



There are lots of Motor Neurons in our bodies. You can't see or feel them because they are deep inside our bodies, but they do connect our brain to our muscles.

Follow the neuron trails (the "axons") at the top of the maze to the bottom of the maze. Try to match the motor neurons.

# Make a Neuron Out of Beads!



Get out those beads and make a neuron! This neuron with seven dendrites requires 65 beads: 42 beads for the dendrites, 10 beads for the cell body, 12 beads for the axon, and 1 bead for the synaptic terminal. String the beads using the pattern in the diagram above. The string can be yarn or rope, or for the best result use flexible wire.

# Messages

Sometimes motor neurons will not work properly. The messages from our brain that

tell our body to move do not get to our muscles.

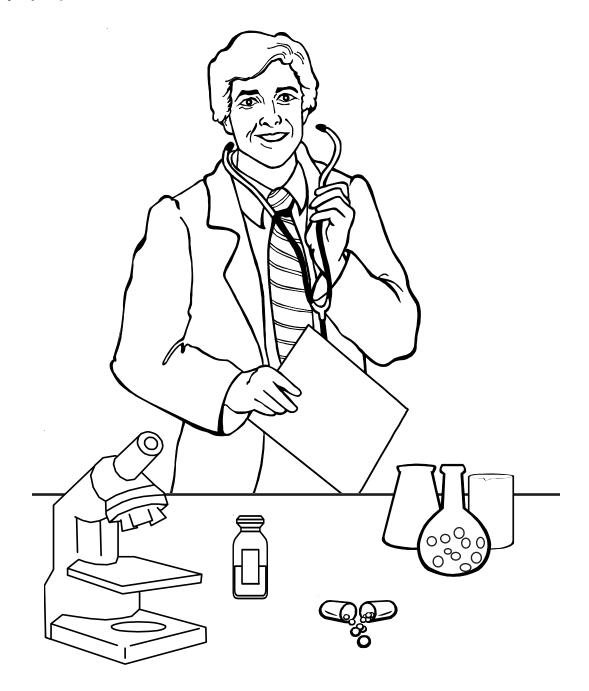
This is what happens when someone has ALS—Amyotrophic Lateral Sclerosis. Their muscles will not move. They



may have to use a wheelchair or other special equipment to help them go places or do activities. However, they can still think, feel, and love.

ALS is not contagious. You cannot catch ALS from someone else, so it is okay to hug and talk to someone who has it. Doctors and scientists do not know what causes ALS, so they have no medicine to cure it. Every person who has ALS will die from it.

# A Neuroscientist at work



Researchers are trying to find the cause of why motor neurons don't work properly. They are trying to find a cure for ALS. Color the picture of the neuroscientist.

# Word Search

EAABTSSAIICINIPD MTSRNEAWITTLENF SEGASSEMERRESEH ESUIERHKUIASSFG REHNGGASEHSTANRE ELYIAITEETSOICC SCASERNEVIULTXDR ESNUTHDMTOELURS AUKPDETNUELYINON RMEEXGEEFCNDORAG CNENBIRSLKHRAUAN HLSSCFERDDUOASE QIMSMOPIDETGBTF SEGNAHCENOAFIOEL HALSUGHFIVLNAHAE AEIYORAODMKERAAH

ALS BRAIN CHANGES FEELINGS GEHRIG HELPING HUGS LOVE MESSAGES MUSCLES NERVES NEURONS

RESEARCH RILUTEK SCIENTISTS TALK TRUST YANKEES

# Changes

If your mom or dad or someone you love has ALS, it probably means that your life will change. Because their muscles won't work, it might change the way you act, play, and even talk together. But it won't change how much they love you.

These changes can feel scary and confusing. You may feel lots of different emotions. It is okay to feel sad or angry or to cry when you miss doing things with them. It is also okay if you are not sad all the time. Your mom or dad or special someone loves you very much and wants you to be happy and have fun each day.



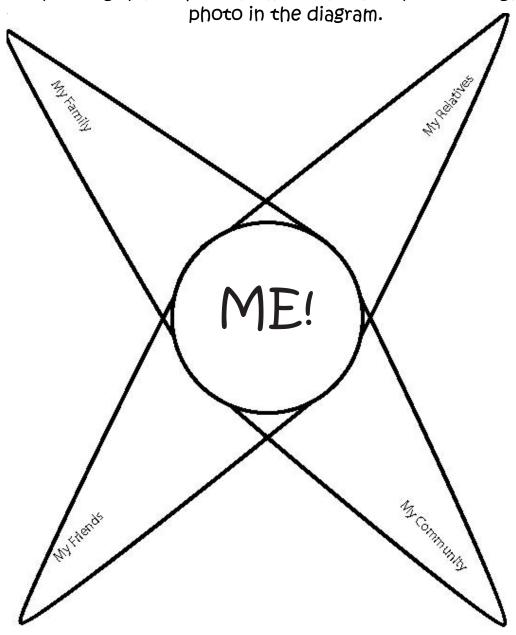
Change can be scary and confusing for grown-ups too. You may see your mom or dad or other grown-ups cry, seem worried, or seem angry. Remember, it is not your fault that they have ALS or that they are sad or mad.

Try to ask questions about what's happening and talk to someone you trust to let your feelings out. Sometimes, hugging and crying together can make everyone feel better.

# PEOPLE WHO CARE ABOUT YOU!!

You are surrounded by lots of people who care about YOU!!

Think of all the people who care about you and put their names in the corresponding space. You can also draw their picture or glue their



Look at this diagram whenever you need a reminder of all the support that surrounds YOU!!

# EMOTIONAL FACES

Emotions and feelings often show on our faces. Match the emotion on the left with the face that expresses it on the right.

HAPPY SAD ANGRY PROUD SCARED SILLY

# MIXED EMOTIONS

When some one you love has ALS, you may experience many different emotions. It is important to identify and talk about things that make you uncomfortable, as well as things that make you feel good.

Complete the following sentences. You can share your answers with an adult you trust and who cares about you.

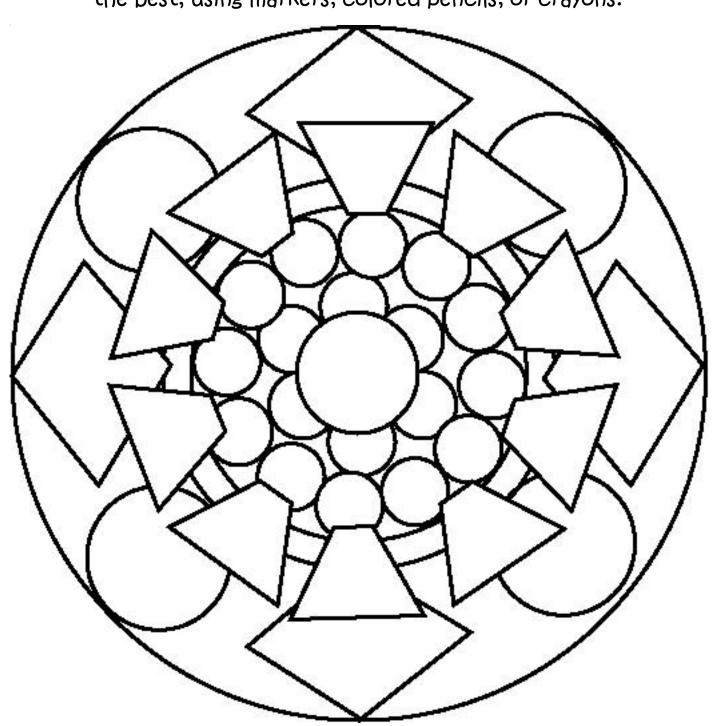
I feel happy when
Sometimes I feel sad because
] like to
I feel safe when
My favorite family activity is
Sometimes I worry about
One thing I like about myself is
If I could change one thing in my life, it would be
One person that I can talk to is
I feel comforted when

# Fun Ways to Help Let Your Feelings Out

- \*Play with your friends.
- **\***Listen or dance to music.
- \* Draw, color, or paint a picture.
- \*Keep a journal and write down how you feel.
- \*Stuff an old pillowcase with rags and use it as a punching bag.
- \* Hit baseballs in a batting cage.
- \*Go for a walk.
- \*Throw ice cubes in the bath tub.
- \*Ride your bike, roller skate, roller blade, or run fast.
- \*Write a letter to a trusted friend or grown-up.
- \* Make a collage with pictures cut from old magazines. Choose pictures that express your feelings or that remind you of favorite family activities.
- \* Shoot hoops with a basketball.
- \*Tell funny jokes and laugh with friends.
- \*Play a musical instrument.
- \*Write a poem about what you feel.
- \* Do a jigsaw puzzle.
- **₩Work** in the garden.
- \*Knit or sew.

# The Mandala

This drawing is known as a mandala, which means "circle." Sometimes our feelings can be shown in colors. Color this mandala to show how you feel inside. Our feelings/colors may overlap or mix together as we feel lots of different emotions inside of us. Choose the colors that help you express yourself the best, using markers, colored pencils, or crayons.

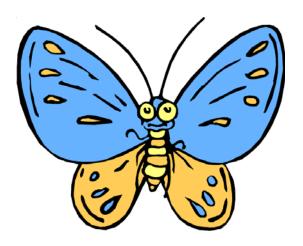


# Grief

People have ALS in their body only. It doesn't affect their spirit or soul inside them that makes them special and unique. Their spirit and soul is what makes us love them so much. We can't see their spirit or soul but we can feel it every time they laugh, smile and cry.

Eventually, everyone's body that has ALS gets tired and can't fight the disease anymore and dies. Their spirit or soul leaves their body and continues to live on somewhere else. Some people believe spirits or souls go to Heaven while others think

that they take a different form - kind of like a Caterpillar turning into a butterfly. We don't really know for sure, but we do know that the spirit of someone we love lives on deep in our hearts every time we remember them.



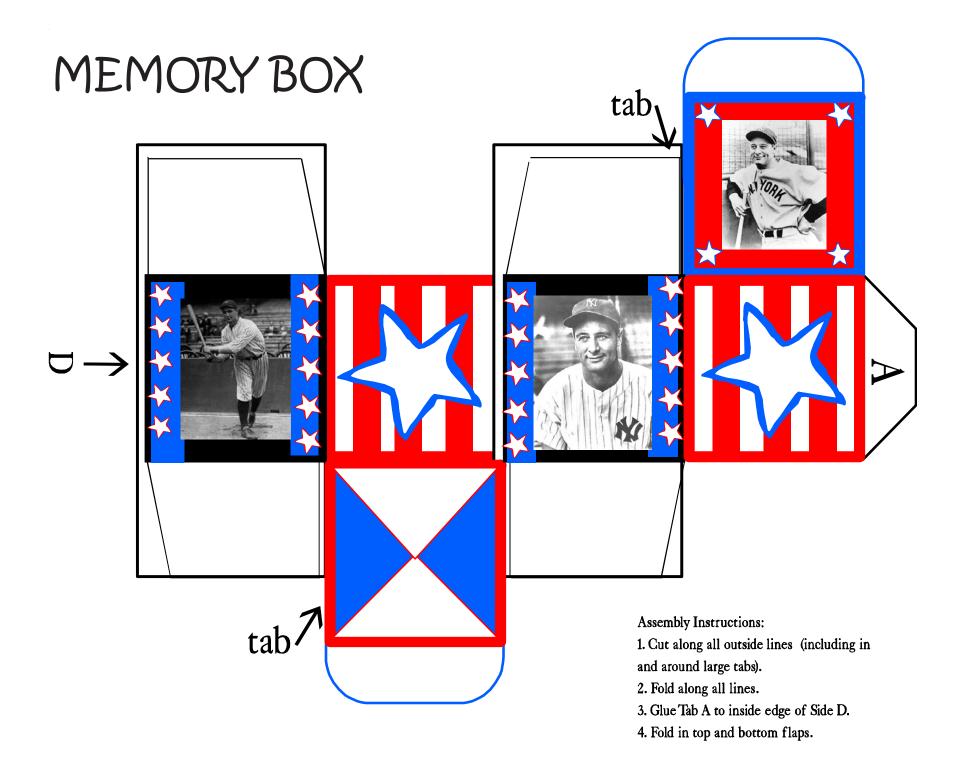
When someone dies, it leaves an empty space in our hearts and lives. This empty space is called a loss and that loss causes pain called grief. When someone we love dies, it is sad. It is okay to cry and ask for help from others that love you. Sometimes when we ask grown—ups for help, we help them too. Helping each other can make our loss and grief seem less scary and painful.

# Memories

One thing that ALS can not change is all the good memories that you and your mom or dad or special someone make together.

Cut out and put together the memory box on the next page. Then write down on these small pieces of paper different memories of activities or special moments you share with your mom or dad or special someone who has ALS. Put these papers in your memory box. This box will keep your memories safe and help you remember how much that person loves you and all the fun you have together. Add to your box whenever you remember another special memory. You can pull them out and re-read them when you are feeling sad about the changes in your life.

A favorite memory [ have is
A special activity we did together is
My family likes to
It makes me happy when



# Helping

Sometimes you might feel like no one understands or knows what ALS is. You might even feel like there is nothing that you can do to help your mom or dad or someone special with ALS. Or you may wish that you can make them better. Remember, it is not your fault that they have ALS.

But there are ways you can help your family and yourself. You can help others understand too. There are even ways you can help the scientists and doctors find a cure for ALS.

Here are some ways you can help:

- \* Write a report for school about ALS so others learn about it.
- \* Talk with your family about what's new with you, your friends, and your school. Your mom or dad or someone special with ALS wants to hear how you are growing and learning and having fun each day.
- \* Ask Questions so you can learn and understand and sort through your feelings. You can learn how others feel and deal with their feelings, too.
- \* Wear a Strike out ALS bracelet and ask others to wear them too. You can sell the bracelets for \$1. This money helps people living with ALS.
- \* Ask your family and friends or classmates to join your team to walk to Dreet ALS and raise money to find a cure for ALS.
- \* Do little things for your mom or dad or someone special who has ALS that they need help with like getting a drink for them, rubbing their hands, turning the TV channel, or reading the newspaper to them; even keeping your room clean & picking up your toys will help a make a difference everyday.
- \* Sell Lemonade or Kool-aid or cookies in your yard and donate the money to The ALS Association to give to the scientists to help find a cure.

Strike Out" Cut out the straps and the visor. Cut a slit at the black lines on both straps and on the visor. Attach "A" to "A" to "C" to "C". Fit slits together so that flaps with letters are on the inside and out of view. (If you are making visor for a child, you probably won't need the shorter extension strap.) It's not necessary, but if tape is available tape the inside flaps down for stability. SOOOL Sun Visor 8 K

K

B

### COUPON

This coupon is for \_\_\_\_

(write the name of your loved one with AI.S)

Good for one:

(Fill in the blank with something special from you to your loved one, such as making them a special treat, giving a foot massage, going for a walk, reading a story, or watching a favorite movie together.)

### COUPON

This coupon is for

(write the name of someone who takes Care of you)

Good for one:

(Fill in the blank with something special from you to your loved one, such as making them a special treat, giving a foot massage, going for a walk, reading a story, or watching a favorite movie together.)

------

### COUPON

This coupon is for ME!!!

Good for one:

(Fill in the blank with something that YOU would like, such as having your favorite story read to you, going to the park to play, eating a special dessert or treat, getting an extra hug, or taking a bike ride. Choose what this should be together with someone special in your life, such as your mom, your dad, or a grandparent.)

# Answer Sheet

### Brain Jokes!

- 1. Gives a brain wave.
- 2. They like to send messages.
- 3. A laboratory retriever.
- 4. There is something between us that smells.
- 5. It didn't want to get brainwashed.
- 6. During a brain storm.

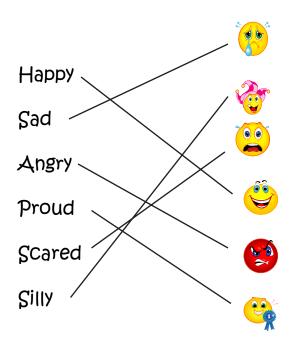
### Rhyme Time

- 1. Brain Rain
- 6. Brain Chain
- 2. Brain Stain
- 7. Plain Brain
- 3. Brain Pain
- 8. Restrain Brain
- 4. Brain Cane
- 9. Brain Complain
- 5. Brain Plane
- 10. Brain Sprain

### Motor Neurons

Neuron A goes to Neuron 3 Neuron B goes to Neuron 4 Neuron C goes to Neuron 1 Neuron D goes to Neuron 2

### Emotional Faces



# Word Search

EAABTSSAIICINIPD
MTSRNEAWITTLENFS
SEGASSEMERRESEHS
ESUIERHKUIASSFGS
REHNGGASEHSTANRE
ELYIAITEETSOICCV
SCASERNEVIOLTXDR
ESNUTHDMTOELYINON
RMEEXGEEFCNDORAG
CNENBIRSLKHRAUAN
HLSSCFERDDUOASEI
QIMSMOPIDETGBTFP
SEGNAHCENOAFIOEL
HALSUGHFIVLNAHAE
AEIYORAODMKERAAH

# Lou Gehrig's Certificate of ALS Knowledge

Awarded to:

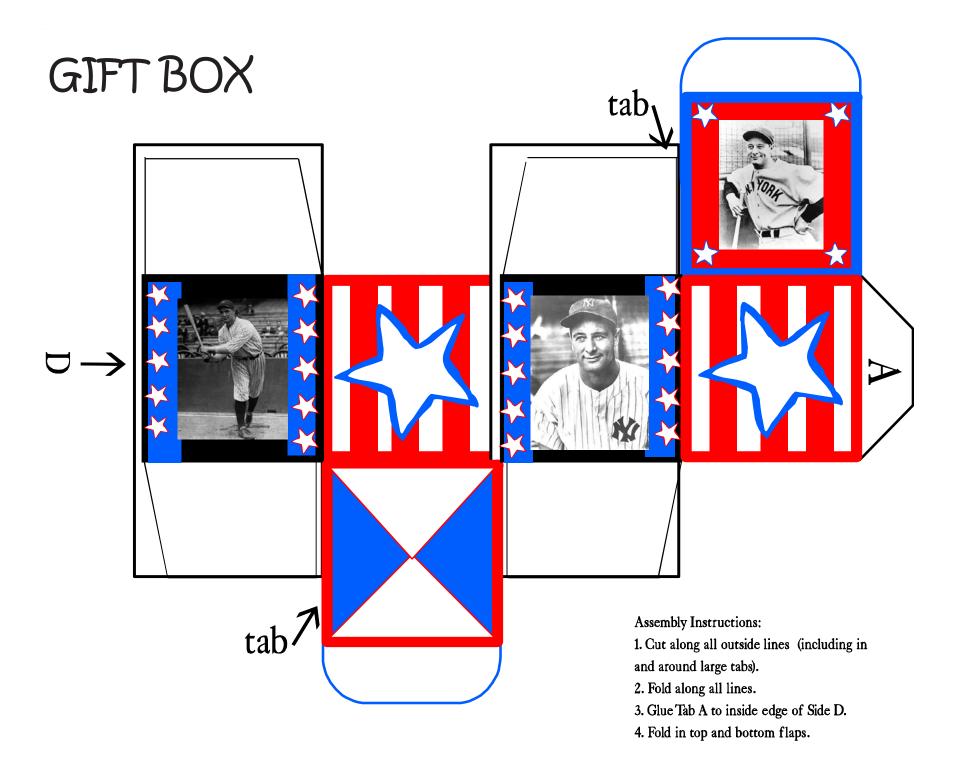
Date:



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Where Patients Matter Most



# ALS Activity Book



# Helping Children understand the puzzle of Amyotrophic Lateral Scienosis

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This activity book was originally written for the *Focus on the Family and Caring for the Kids Day* in 2001. It has been revised with additional information and activities as our children's program developed. The purpose of this book is to help children understand what is happening to their loved one with ALS. Another objective is to help children recognize and process the confusing feelings and emotions they experience while having a loved one with a life-threatening disease. It also includes developmental guidelines appropriate for talking to children about ALS.

The book contains different games, activities, and learning pages presented in age-appropriate language and content. Included are learning pages about Lou Gehrig, muscles, the brain, motor neurons, the body's message system, and neuroscientists, as well as activities to help children explore feelings and their emotional support system. Through hands-on activities, children may make a memory box, a sun visor, and motor neurons out of beads.



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