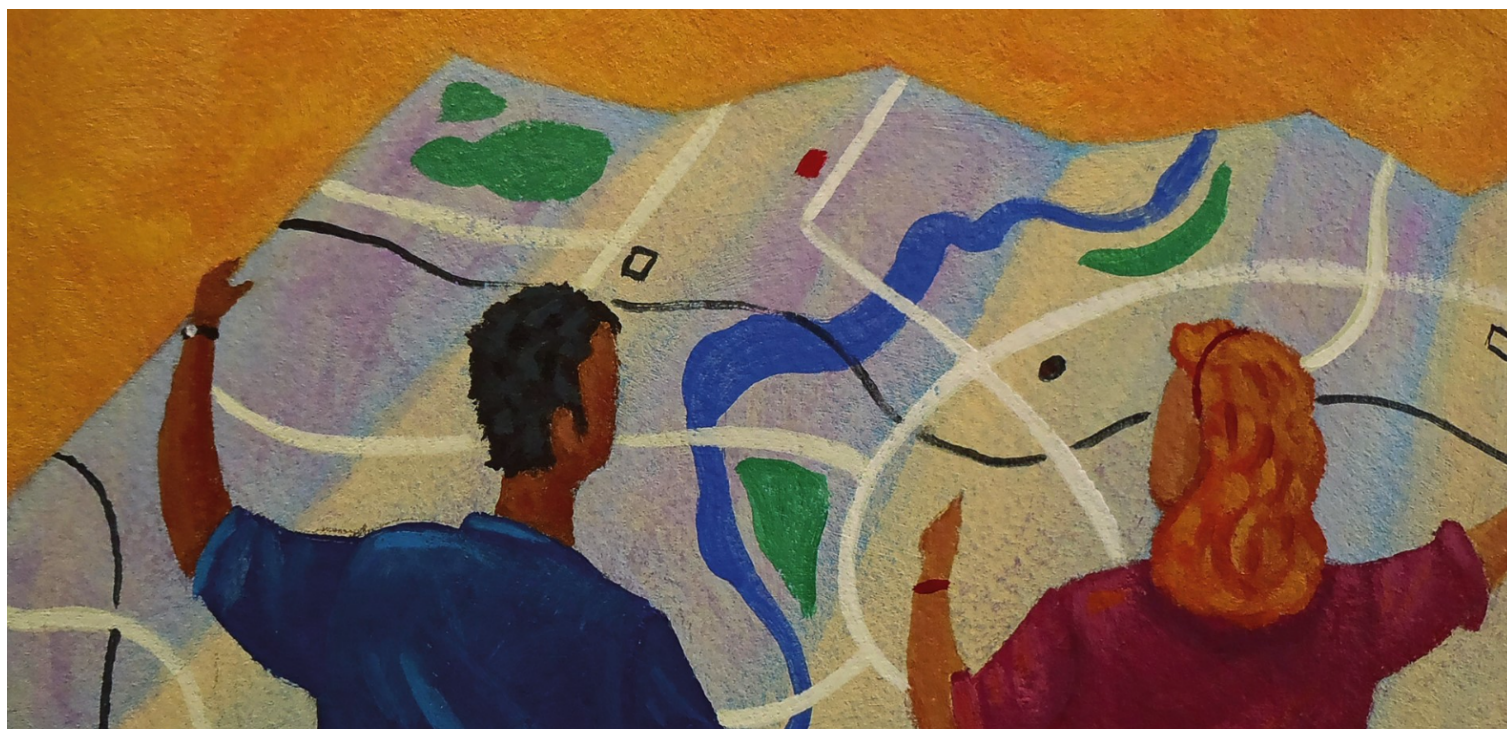


BREATHING DIFFICULTIES: USING A BIPAP MACHINE

*From the Massachusetts General Hospital
ALS Parenting At a Challenging Time (ALS PACT Program)*



Parenting with ALS: Guidance for Supporting your Children

From the Massachusetts General Hospital ALS Parenting at a Challenging Time (PACT) Program

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The entire series is available in both English and Spanish and can be downloaded at no cost from <https://www.massgeneral.org/als-pact>

**Parenting with ALS: Guidance for Supporting your Children* is intended for educational purposes. It is not medical treatment or advice. If you have questions about your or a loved one's medical condition, please contact a medical provider.*

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Breathing Difficulties - Using a BiPAP Machine

ALS-related breathing difficulties, including shortness of breath doing activities while upright, shortness of breath while lying down, difficulty with airway protection, and respiratory insufficiency, are obvious and a common source of concern to children

This handout:

- describes types of breathing difficulties a person with ALS may experience
- describes ways that children may notice or experience a parent's breathing difficulties
- makes suggestions for how parents can explain the BiPAP machine to children of different ages
- considers how parents can support children as they navigate conversations about the parent's assistive equipment

Physical changes and changes in daily functioning

Breathing difficulties can be a complication of ALS very quickly or only after a long period of time, depending on the person and the rate and pattern of progression of ALS. It is rare that it begins with breathing difficulties. In most cases the symptoms begin elsewhere in the body and spread to include the muscles that help with breathing.

Breathing difficulties might include:

- Feeling short of breath doing activities that used to be easy, walking, with daily activities like eating, bathing or getting dressed, eventually even when sitting down.
- Feeling short of breath while lying down- it may feel more comfortable to sleep with pillows, or sleep sitting up.

“Airway protection” is the process of keeping food and saliva out of the airways. This important part of breathing can be affected early in people with bulbar onset ALS (See handout entitled, “Bulbar symptoms: Speech, swallow, salivation, and eating” for more information about this subtype of ALS, found here: <https://www.massgeneral.org/als-pact>).

Breathing difficulties from problems with “airway protection” can include:

- Coughing when eating or swallowing saliva
- Difficulty clearing secretions or saliva from the mouth or throat

The BiPAP uses compressed (pressurized) air to open and support the airway.

Equipment and Intervention

BiPAP machine/positive airway pressure therapy

At some point, the muscles used for breathing do not function well enough to take in air (including oxygen) and then expel air (including carbon dioxide) from the lungs and maintain the best balance of oxygen and carbon dioxide in the blood. This is called “respiratory insufficiency.” A BiPAP machine may be used to help ensure that a person receives adequate levels of oxygen.

The BiPAP uses compressed (pressurized) air to open and support the airway during sleep. The air comes through a hose and mask attached to a person’s face. Someone may start to use a BiPAP machine just at night, then also use it off and on throughout the day, then most or all of the time.

The Experience of Children and Families

Breathing difficulties can lead to changes that are very noticeable to children of all ages. A Parent with ALS may become less physically active and need to find different ways to play or interact with children. Stairs may become difficult and sleeping arrangements might be moved around. Children will notice the new equipment to help with breathing- some will be openly curious about it while others may be more wary or anxious.

Strategies for Parents with Age-Specific Guidance

Some of the challenges that you may face in helping your children adjust to these changes include explaining the purpose of new equipment to children of different ages and helping children think about how to talk about these changes with peers. (Also see the handout, “Including children in caring for a parent” which discusses making decisions about types of help children might be asked to provide: <https://www.massgeneral.org/als-pact>).

Knowing in advance about changes like new equipment is easier for children than being surprised, so if it's possible, try to talk with your children before the BiPAP arrives. Explain why the equipment is needed, how it will help, how it will change the parent's and family's routine, and whether the child will be asked to help out in new ways.

Toddlers/early preschoolers (2-4):

This is a machine to help Dad breathe better. It's called a BiPAP.

It makes some loud noises, but that means it is working right. You can look at this machine with your eyes but it is not for touching with your hands or body. What does it sound like to you?

Preschoolers/early school-age (4-6):

You know that Dad has been [whatever words you are using to talk about ALS] and because of this he is having some trouble with breathing. He is going to be using this machine, called a BiPAP, to help him breathe better at night and sometimes during the day. It makes a sound when we turn it on- do you hear it? Dad will wear a mask when he is using the BiPAP, and it will be harder for him to talk with us with the mask on. This is what he looks like with the mask. You can look at this machine but it is not for touching. Is there anything you're wondering about?

School aged children(6-12):

You know that Dad has been sick [whatever words you are using to talk about ALS] and you might have noticed that he has had some trouble with breathing, and it's been harder for him to move around very fast. His doctors suggested that he use this machine, called a BiPAP, to help him breathe better at night and sometimes during the day. We're hoping it will help him feel better, not so tired, even when he isn't using it. Do you want to see how works? Dad will wear a mask when he is using the BiPAP, so it will be harder for him to talk with us. It's a little noisy but I think we'll get used to it. Please don't touch them, we want to make sure it all stays together and stays really clean.

Also, Dad's doctors want the buttons/dials to stay set where they are unless a grownup changes them, so please just look at this but don't touch it. What are you wondering or curious about? Do you think your friends will be curious or ask questions about this? What will that be like for you? How do you think you'd explain it to them? (You might coach your child to say simply that it's called a BiPAP machine, and helps Dad to breathe better).

Teens and young adults(13+):

You know that because of ALS, Dad has been having more trouble breathing lately, especially when he's moving around a lot. His doctors suggested that he use this machine, called a BiPAP, to help him breathe better at night and sometimes during the day. We're hoping it will help him feel better, not so tired, even when he isn't using it. Do you want to see a demonstration? Dad will wear this mask when he is using the BiPAP. It has to be washed every day so you might see the pieces on the counter drying off . (Depending on your family's needs: That might be something you could help with sometimes and we can show you what to do.)

What questions do you have about any of this? Is this something you are likely to ever talk about with your friends? Do you think they'll notice it or ask questions? Will it be hard to come up with something to say? I'm happy to brainstorm ideas if you'd ever want to do that.

Helping Children Talk with Friends About Equipment

Some children, often "tweens" and early teens (11-14 yrs) are sensitive about a parent's being obviously different from other adults and may worry about feeling embarrassed if peers see or learn about the breathing equipment. You've likely had other conversations about differences—this might be a good time to remind children that people are the same in lots of ways and also different in lots of ways—sometimes differences are visible and sometimes they are invisible, and sometimes they look bigger than they really are. Some differences matter more than others and that's something we all have to figure out for ourselves. It usually helps to talk about differences in a matter-of-fact way and assume that friends are mostly curious but feel uncomfortable asking about something that is unfamiliar and maybe a little scary.

You might also ask children how they think they could explain the equipment to friends who are likely to see it. If they have trouble deciding on an explanation, you might suggest they describe in a very simple way what the equipment is called, what it does (helps Dad breathe better), and whether the child wants to talk about it more or not (it's ok to ask me questions, or, I don't really like to talk about it but it's ok to ask my Mom questions, or, it's something I don't like to talk about much).