



Building Your Alagille Syndrome (ALGS) Support System

A Guide for Talking to Others After Diagnosis

After an Alagille syndrome diagnosis, you may find it difficult to talk with others about what's going on. This is completely understandable. However, there may be times when it is both helpful and necessary to talk about Alagille syndrome and how it impacts your family.

This guide can help you to decide what you want and may need to share.

Who to Talk To

It can be hard to talk about something so personal and sensitive. While this is completely understandable, sharing your experiences and needs can help people in your life better understand how to best support you or your child.

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Make a List

Managing Alagille syndrome affects all aspects of life. What people in your life might need to know about Alagille syndrome? Think about common symptoms, mood changes, and ability to focus. Consider if these may—or may not—be important to discuss. Taking it a step further, consider the ways in which each person can help support you or your child.

- **Family.** Loved ones can pick up medication, help with meals, or tend to other siblings
- **Close friends.** Friends can lend an ear when you want to talk and lift you up when times are hard. It can be nice to turn to friends to schedule playdates and help out with meals for the family. In addition to close friends, it can be helpful to connect with other families living with Alagille syndrome. Visit the Alagille Syndrome Alliance at www.alagille.org for more information
- **Teachers, sports coaches, or other instructors.** For those in school, a little goes a long way. Teachers, coaches, and other instructors can make a big difference by both understanding how Alagille syndrome affects you or your child and by helping manage symptoms when they arise. Ask for specific accommodations that you think would be helpful
- **Employers.** If you work, flexible work schedules can help if you or your child have frequent doctor visits
- **Pediatrician or primary care doctor.** Your pediatrician or primary care doctor is at the center of your or your child's care, so they can offer advice and refer you to various specialists along the way
- **Specialists.** Specialists, such as hepatologists, cardiologists, nephrologists, gastroenterologists, and nutritionists, may have the best understanding of Alagille syndrome and can provide education on the disease and the impact it can have. They can also provide support and ideas to assist with schooling, therapy, and more

My Story, My Way



You or your child can help write this story, too.
Simply fill in the blanks below.



Do you or your child love to draw? Use the space below to
draw how Alagille syndrome makes you or your child feel.

My name is _____, and I have
(Name)

Alagille syndrome. If my Alagille syndrome were

an animal, it would be a/an _____
(Animal)

because it is _____. Alagille
(Adjective)

syndrome makes me feel _____.
(Adjective)

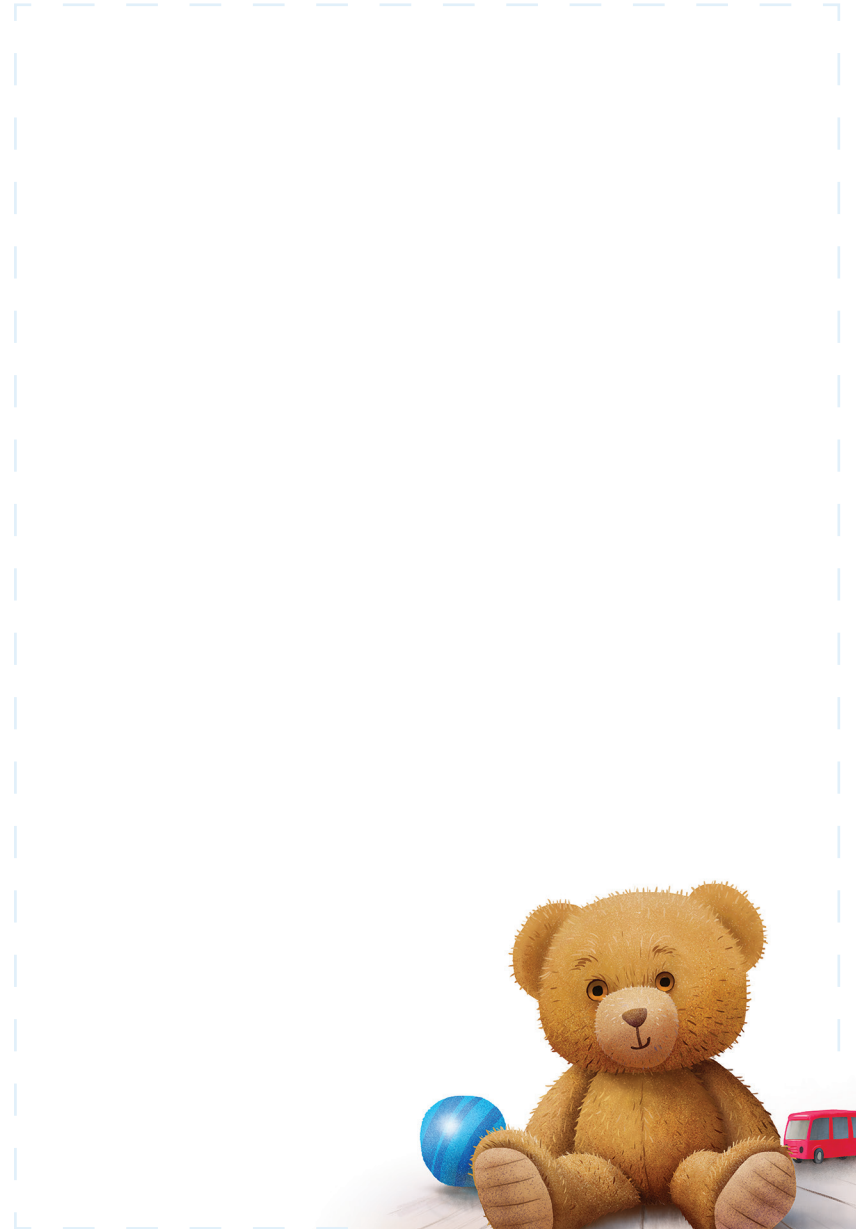
Alagille syndrome can make some things

hard, but I still like to _____
(Activity)

and _____. I wish my
(Activity)

_____ knew _____.
(Noun) (Person or group of people)

They can help me by _____.
(Verb)



Additional Considerations

You've identified who you're going to talk to, you've crafted your Alagille syndrome story, and now it's time to consider just a few more things.



Guide the conversation.

There may be some things you want to talk about and others that you don't—and that's OK. You don't have to share everything with everyone, and you shouldn't feel the need to.



Be open and honest.

Everyone is different. Some may be comfortable talking about Alagille syndrome, while others are not. You know yourself or your child best, so set boundaries as needed and be clear with others about your expectations.



Remember the good things.

You may want to talk about what you or your child have accomplished or what experiences you or your child were able to have because of, or despite, the condition.



Provide resources.

Some people will want to learn more about Alagille syndrome and help you navigate the road ahead. Consider sharing any helpful brochures, websites, or support groups they can check out on their own time.

Here are some resources to help you get started:

- ✓ The Alagille Syndrome Alliance (ALGSA): www.alagille.org
- ✓ National Organization for Rare Disorders: www.rarediseases.org/alagille-syndrome
- ✓ Chronic Liver Disease Foundation (CLDF): www.chronicliverdisease.org
- ✓ Johns Hopkins Medicine: www.hopkinsmedicine.org/health/conditions-and-diseases/alagille-syndrome
- ✓ Children's Hospital of Philadelphia (CHOP): www.chop.edu/conditions-diseases/alagille-syndrome

The Support You Need, When You Need It

Living with Alagille syndrome can feel challenging, but you should never feel like you're in it alone. By telling the right people the right information, you can build a strong support system around you and your family.

Use the space below to write down any additional questions or topics you want to share with your support network.

Strength and Support
for the Road Ahead

Visit **LifeWithALGS.com**
for more information.



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