angelman
SYNDROME FOUNDATION

First 100 Days Journey

A Guide to Navigating Life After an Angelman Syndrome Diagnosis

With YOU for the Journey

An Angelman syndrome diagnosis is not the end, but instead the beginning of a journey down a new pathway. Receiving this diagnosis may be overwhelming, and you may be experiencing varied emotions that change from day to day. The Angelman Syndrome Foundation is here to help and provide you with resources, care and support in the days, months and years ahead.

This document was written by parents of individuals with Angelman syndrome who have walked this path before you, to help you navigate this new diagnosis. NOTE: You do not have to do everything on this list. Give yourself time to process the road that lies ahead and take what you feel is right for your family. This checklist is a support tool to help you start to think about important steps you can take to help your child thrive. If you have questions, please reach out and contact ASF anytime. We are here for you.

30 first DAYS

Family and Community

☐ Share your diagnosis.
☐ Surround yourself with supportive, positive people.
☐ Connect with your own feelings. The ASF provides free counseling to Angelman families. Find the information on our website.
☐ Visit Angelman.org for support and information. Make sure you sign up on the Contact Registry.
☐ Create a personalized 'All About Me" through our Canva or Microsoft Word templates to help introduce your child to others they are meeting for the first time. Canva Template | Microsoft Word Template
☐ Ask a family member or friend to accompany you to all appointments, to help with your child or take notes so you can focus and remember important information.
☐ Register and attend an AS 101 webinar. Learn about Angelman syndrome and resources that are available to you as you begin this journey.

Medical

☐ Use the Comprehensive Care Binder or other method to help you organize records, tests, reports, contacts, etc. Download the Comprehensive Care Binder on our website.
☐ Prioritize your child's challenges and focus on these right now (i.e. communication, fine motor, gross motor, sleep, eating / drinking / nutrition and growth).
☐ Consider making an appointment at an ASF AS Clinic. AS clinic physicians are then better able to confer with your doctors as needed.
☐ Research which clinicians, specialists, and therapists your child needs to see. Talk to other parents for recommendations.
☐ Educate yourself on current AS studies.

Record Keeping

☐ Create a logbook to track progress and regression.
☐ Create a video record of any unusual behavior to show your physician.

Services

☐ For children younger than 3 years, check your state's Early Intervention program to see what services are available to you.
☐ For children older than three years of age, specialized services will be provided by your local school system through an Individualized Education Plan (IEP). This varies by state.

Therapy

☐ What therapy is he / she currently receiving? Is this what is recommended for a child with Angelman syndrome?
☐ Prioritize your top three concerns today and focus on these (i.e. communication, fine motor, gross motor, sleep, eating / drinking / nutrition and growth).
☐ Make a consultation appointment with each therapist to discuss these concerns.
☐ Refer to the Physical Therapy / Occupational Therapy Best Practices for Angelman Syndrome.

School

☐ Make a consultation appointment with your child's Early Interventionists or Educators to discuss the learning and development plan now that you have a diagnosis.
☐ Turning three years old soon? Learn about the Individualized Education Plan (IEP) process in your state and school system.
☐ Visit our website to review our IEP Resources.

Awareness

☐ Refer doctors, interventionists and educators to Angelman.org to help them understand the diagnosis.
☐ Set up a fundraising page through Angelman.org in your child's honor. People who know you and love you want to help if you tell them how.

60 *first* DAYS

Family and Community

- ☐ Talk regularly with your spouse, other children, and family members to connect with their feelings.
- ☐ Suggest ways family and friends can help. They want to, but don't always know how to ask.
- ☐ Connect with other families who are experiencing the same journey as you. Connect with families directly or on our website with our ASF Family Champions.

Medical

- ☐ Schedule appointments with specialists for baseline evaluations and assessments (i.e. neurological exam, orthopedics, swallow study, EEG, EKG, etc.)
- ☐ Record and document any changes your child experiences. Update your binder/logbook.
- ☐ Organize new paperwork in your binder. Purge and add as needed.
- ☐ Review your calendar for upcoming appointments.

Therapy

- ☐ Schedule a team meeting to review and discuss beneficial therapies specific to Angelman syndrome now that everyone has learned more.
- ☐ Schedule a team meeting to discuss goals and encourage open lines of communication.

School

- ☐ Keep an open line of communication.
- ☐ Provide educators with research of best practices regarding how children with Angelman syndrome learn and thrive.

Insurance

- ☐ Review your insurance coverage regarding which, if any, therapies are covered to ensure you are maximizing your benefits.
- ☐ Document everything. You may need a second binder!

Research

- ☐ Double check with your State Health Department as your child might be entitled to services you were not aware of or had not considered.
- ☐ Waiver Programs as well as additional Federal and State sources of support.
- ☐ Special Needs Wills and Trusts.

Awareness

- ☐ Plan or attend a fundraiser for Angelman Syndrome Foundation.

90 *first* DAYS

Family and Community

☐ Research activities for individuals with special needs in your area.
☐ Research a special recreational association in your area with trained staff that provides programs and special events.
☐ Ask family and friends for help with appointments or therapies. They want to help.
☐ Find a caregiver or sitter for respite.

Medical

☐ Schedule any remaining tests and appointments or follow-ups.

Therapy

☐ Continue to evaluate therapy schedule and what is working best.
☐ Communicate any best practices you have learned.

School

☐ Track and document your child's progress.
☐ Communicate any best practices you have learned.

Research

☐ Research additional therapy options or specialists, such as therapeutic riding, aqua therapy, and more.
☐ Stay up to date with current AS research and studies by visiting Angelman.org.
☐ Register for an Angelman Syndrome Foundation conference or watch webinar recordings.

Awareness

☐ Continue to spread awareness by sharing your child's story.
☐ Ask your family and friends to help you plan or attend an Angelman Strong event or Angelman Syndrome Foundation event.

NEXT STEPS

- **Stay connected with ASF and visit Angelman.org regularly**
- **Remember, support comes in many forms, and your needs will change over time.**
- **We're here for you! We will meet you where you are and help you take the next steps at each stage.**

ADDITIONAL RESOURCES

Organize A Binder For You

Three ring binder with tabs including:

Reports
Include copies of all diagnostic reports, such as your Angelman syndrome genetic diagnosis or EEGs. Ask for an electronic copy of results.

Prescriptions
Include a copy of all prescriptions for any medications, specialized equipment and therapies.

Specialists
Include contact information for all specialists. Specialists may include: Physician/Pediatrician, Neurologist, Cardiologist, Gastroenterologist (GI), Pulmonologist, Orthopedist, ENT, Allergist, Ophthalmologist, Dentist, Orthotist, Physical Therapist, Occupational Therapist, Communication Specialist, and Nutritionist.

Therapies
Include contact information for all therapists (PT, OT, AAC, etc.). Include their reports and any handouts for exercises.

Equipment
Include receipts from equipment vendors, notes on how to use equipment and contact information. Know whom to call if equipment breaks.

Programs
Include information about the programs or organizations in which your child participates.

Early Intervention (EI)
Include documents and therapy reports for children under three years old receiving services from the state.

Individualized Family Support Plan (IFSP)
Include your child’s IFSP and any related documents for authorized support services such as respite, or personal care supplies.

Individualized Education Plan (IEP)
Include your child’s IEP and any documents related to school for children three and older.

Make An “All About Me” Book

Help others understand Angelman syndrome, your child, how AS affects your child specifically and how to work with her / him.

Include schedules, emergency contacts, likes and dislikes, sleep patterns, feeding information, personal care information and any additional information related to your child’s everyday care, comfort, and happiness. Include pictures of your child, your family, enjoying favorite activities, and more.

OTHER

Contact utility companies, and emergency departments (fire, police, etc.) to let them know you have a child who requires special needs in case of power outage or other emergency and inquire about possible Medical Baseline Allowance programs.

Contact your local DMV to apply for a Handicap Parking Placard. Your child is eligible.

HELPFUL LINKS

- Visit the Angelman Syndrome Foundation Website
- Learn More About ASF Clinics
- Connect with the ASF Family Champions
- Apply for the ASF Family Fund
- Review Our Communication Resources
- Review Our IEP Resources

FOLLOW US

FACEBOOK: @AngelmanSyndromeFoundation
INSTAGRAM: @angelman_asf
TIKTOK: @angelmansyfoundation
X: @angelman
YOUTUBE: @AngelmanSyndromeFdn
LINKEDIN: Linkedin.com/Company/Angelman-Syndrome-Foundation