



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. While we certainly understand that receiving this diagnosis may be overwhelming, and you may be experiencing varied emotions that may also change from day to day, we are here to help and provide you with resources, care and support in the days, months and years ahead. You are now a valued member of the Angelman community and the extended family of the Angelman Syndrome Foundation (ASF). **The mission of the Angelman Syndrome Foundation is to advance the awareness and treatment of Angelman syndrome through education and information, research, and support for individuals with Angelman syndrome, their families, and other concerned parties.** We focus our efforts on family support, expanding our clinic network, investing in research, and connecting the community in a variety of ways. Please visit our website at www.Angelman.org to start exploring all of our support services as well as ways to engage with ASF and the Angelman community.

The **First 100 Days Journey** is a guide, which was created by Angelman parents and caregivers who have walked this path before you, to help you navigate this new diagnosis. **Let us stress that you do not have to do everything on this list. Remember to give yourself grace as you are processing the road that lies ahead.** This is simply a support tool to help you start to think about important steps you can take to help your child thrive and the resources available to assist you along the way. If you have questions, please reach out and contact ASF anytime. We are here for you, working daily to provide the resources your family needs and hope for a promising future.

30 DAYS

Family and Community

- Share your diagnosis.
- Surround yourself with supportive, positive people.
- Connect with your own feelings.
- Visit Angelman.org for support and information. Make sure you sign up on the contact registry.
- Create a personalized 'All about me' through Angelman.org to simplify educating others about your child.
- 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.

Medical

- Create a binder or other method to help you organize records, tests, reports, contacts, etc.
- 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 by visiting angelmanclinicaltrials.com.

Services

- For children younger than three years of age, contact your State Department of Health to see what Early Intervention (EI) 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.

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 IEP Bank and schedule time with our Resource Director, Michelle Harvey, who specializes in IEP's.

Record Keeping

- Create a log book to track progress and regression.
- Create a video record of any unusual behavior to show your physician.

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 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. Angelman.org can connect you with families directly or online through 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/log book.
- 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. Provide them with the Angelman Syndrome Facts Sheet.

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.

FIRST 100 DAYS PATHWAY

90 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

- Track and document your child's progress.
- 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 angelmanclinicaltrials.com.
- Register for an Angelman Syndrome Foundation conference or webinar. Visit Angelman.org for more information.

Awareness

- Continue to spread awareness by sharing your child's story.
- Ask your family and friends to help you plan or attend an ASF walk, fundraiser, 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.



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.

ADDITIONAL RESOURCES

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.

WEB PAGES

- Angelman Syndrome A to Z
angelman.org/resources-education/angelman-syndrome-a-to-z
- ASF AS Clinics
angelman.org/angelman-syndrome-clinics
- ASF Champions
angelman.org/resources-education/asf-family-champions
- ASF Family Fund
angelman.org/resources-education/asf-family-fund
- ASF Family Resource Team
angelman.org/resources-education/asf-family-resource-team
- Communication Training Series
angelman.org/resources-education/communication-training-series
- State Resources
angelman.org/resources-education/state-resources
- IEP Bank
angelman.org/resources-education/iep-bank



800-432-6435 | www.angelman.org