



A letter to the professionals in our lives

Dear Professionals

Our baby has been diagnosed with Auditory Neuropathy Spectrum Disorder or ANSD. There are many professionals in our lives - from doctors to audiologists to early interventionists. You are an important part of our journey with our baby.

We love our baby and have dreams for our future together. Our dreams are different now but we need you to share our optimism for the future of our baby.

We know we will need to make difficult decisions and there will be challenges but we also know our baby will amaze and delight us.



What can you do to support and guide us along the way?

The diagnosis

If you are the person who needs to deliver the bad news to us, we need you to know how to do this. We have already come a long way with our baby. Many of us have already been through many ups and downs. You are about to pull the rug out from underneath us again.

We may be the 15th family you have seen today and the 50th baby you have diagnosed with ANSD. But this is the first time for **us**. What you do and tell us today will have a profound impact on us. We will remember this day for the rest of our lives. We need you to learn how to deliver bad news – with compassion and clarity. Give us hope.

Following diagnosis

We need experts in ANSD to support us. If you don't know much about ANSD, you need to refer us to professionals who do. We understand that you can't know everything but this is about our baby's life and future.

Your lack of knowledge about ANSD and uncertainty about a way forward makes us worry even more.

We understand that there is no single way forward for babies diagnosed with ANSD. But we do need a game plan. Appointment after appointment with still the same uncertainty and no end in sight drains our emotional reserves. Show us the things we can do NOW to make a difference in our baby's life. A bright future does not only depend on audiograms and technology.

We need some concise information about ANSD at the diagnostic appointment. It is hard to take in everything when we are feeling shocked and numb. Give us

some concise written information that we can take home and read and reread. We will need more detailed information soon so let us know where we can go to find reliable information that is parent-friendly. We don't know all the jargon yet but we want to learn all we can about ANSD and how we can navigate the road ahead of us.

Making decisions

We want to be as sure as we can that when we make a decision that will impact on our child's future, it is the best decision we are able to make at the time. For this to happen we need good information from many people.

Please don't assume that you know what is best or feel that you shouldn't tell us about things that are not available near our home/in our State/ in Australia. For us to make an informed decision, we need to know all our options.

Meeting and learning from other parents is one of the best ways for us to envisage a future for our baby and family. Please let us know where we can find parent support groups.

Listen to us

Don't make assumptions about what and how my child hears. The booth is so different to our home, the car, the shops. Please listen when I tell you what I've noticed about my child's response to sound.

We are experts too. We know our baby better than anyone. Listen to us.



Questions we may have when we come into your office...

Questions about ANSD

- What is Auditory Neuropathy?
- Are there other tests that need to be done? What are they?
- Is there any genetic testing that needs to be done?
- Are there any behavioural issues related to ANSD?
- Is ANSD progressive? Can it get better or worse over time?
- Do we need to consult with a neurologist to rule out any other neuropathies?
- Will ANSD affect my child's balance?
- Will this condition affect my child's cognition?

Questions about my child's hearing

- What does it sound like for my child?
- Will my child's hearing improve or get worse?
- Is the audiogram an accurate test? Will it give me all the information?
- Will my child need hearing aids?
- Will my child need a cochlear implant?
- Will my child need to use sign language?
- Are there any environmental factors that can influence or effect the quality of what my child hears?

Questions about my child's future

- How can I best support my child?
- What are our options?
- What therapy is needed?
- What is the treatment plan for my child?
- How can I best keep track of my child's progress?
- What does ANSD mean for my child's learning future?

Questions for my well-being

- Are there any support groups for families?
- Who can help me navigate the maze?
- Is there any financial assistance available?
- Who can I talk to when my emotional reserves are low?

This is a really scary time for our family and the last thing we need is to be the most educated person about our child's condition in the room. That's why we are asking for your help. We need to feel supported on this journey and to feel supported we must ask you to please educate yourself on this very complicated condition known as Auditory Neuropathy Spectrum Disorder.

Below are some links that we found useful when trying to understand our child's condition. We ask you please to take a moment and have a read so you can understand our child's world that little bit more.

Warm regards,

Parents of children with ANSD



Our reading list

- Management of individuals with Auditory Neuropathy Spectrum Disorder
<http://www.scribd.com/doc/7843429/Berlin-Lake-Como-Paper-in-Color>
- Developing a treatment program for children with Auditory Neuropathy
http://www.arlenestredlerbrown.org/docs/Auditory_Neuropathy.pdf
- Neuropathy Spectrum Disorder: Variation in diagnostic information and differential diagnosis
http://kresgelab.com/Resources/Auditory_Neuropathy_Morlet.pdf
- Journal Club: Controversies persist in audiologic treatment of ANSD
http://journals.lww.com/thehearingjournal/Fulltext/2012/05000/Journal_Club___Controversies_Persist_in_Audiologic.6.aspx
- Genetics and Auditory Neuropathy/Dys-synchrony
<http://www.asha.org/Publications/leader/2007/070213/070213d.htm>
- Cochlear implants in Auditory Neuropathy Spectrum Disorder
<http://www.asha.org/aud/articles/CochlearImplantsANSD.htm>
- Auditory Neuropathy Spectrum Disorder Simulation
http://www.youtube.com/watch?v=IY5Yliu_4t4&feature=youtube_gdata_player