

Understanding Baseline



INTRODUCTION

The New Normal

Some diagnoses have a projected trajectory, and you can anticipate how your child's issues and potential complications are going to progress. Others do not, and medical providers cannot say with certainty how the child's condition will progress; or, perhaps most important, predict lifespan. Regardless, living with a child with a life-limiting illness is an exercise in accepting uncertainty, and the ups and downs along the way.

Baseline is really just a technical term for "the new normal." It is the opposite of an acute moment or event; it is a description of where things are now, when they are stable. With children (or adults) living with illness, the baseline shifts. Often it shifts down over time like steps. While the ups and downs continue, the ups are, over time, not likely to be as high as they were, and the downs are usually lower. Each lower step represents a lower level of functioning and, with a declining baseline, the final step is end of life.

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Anticipating Baseline Changes

Understanding the concept of baseline can be helpful as a way to look at how your child's condition is progressing and noting patterns of progress and decline. Although it is not always possible to know how you will react to changes in your child's baseline, the changes themselves may inspire some questions for you to consider.

Your medical team may ask you to keep a record of your impressions of your child's condition over time. You may be asked to keep records in a particular way. Whether or not you are asked to do this, it may be helpful to journal about your child's journey, with notes about what you see as changes in baseline. This will help you help the team. It will also help you remember and appreciate how much and how well you are doing in caring for your child.

● **Priorities for your Child**

As your child's condition changes, and as health care needs may become more complex, the decisions can become more complicated and your priorities for your child may change. Your child may have thoughts about this, as well.

"My child's 'normal' looks different than it did a year ago. She can no longer go to school. What matters most to us now is to keep her comfortable at home. She wants to have as many friends visit as possible."

● **Goals of Care**

Baseline changes may also prompt you to think about possible new goals of care, and the choices you will make—including for medical interventions—to achieve those goals.

"My child is now aspirating often when she eats and is having an increasing number of aspiration pneumonias. We are thinking about how important it is to us, to be feeding her orally. We are looking at her life expectancy and our goals of care, and we are wondering if introducing a feeding tube would help us achieve those goals."

● **The Family Unit**

Finally, understanding baseline and how it may change can help you think about and prepare for changes in your family's life.

"Our other children are very aware that their sister sleeps much more than she used to. We are constantly trying to balance our daughter's needs with her siblings' needs to be children—to laugh out loud, to play in the house."

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Three Classic Patterns of Illness Trajectory

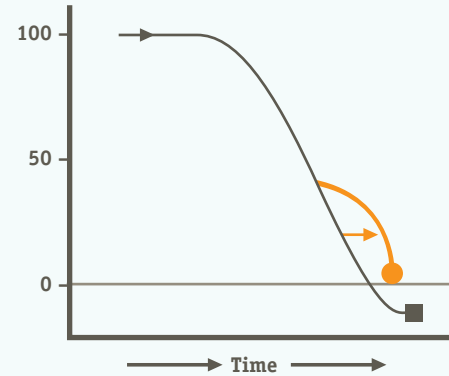
A shift in your child's overall health can creep up on you slowly or it can be masked by an acute event. Here are the three classic patterns of illness trajectory.

Steady Decline

A malignancy or degenerative disorder.

Children who had been in good health until the disease or condition begins to cause a steady and irreversible decline in quality of life.

The goal of palliative care in these instances is to maximize quality of life for as long as possible.

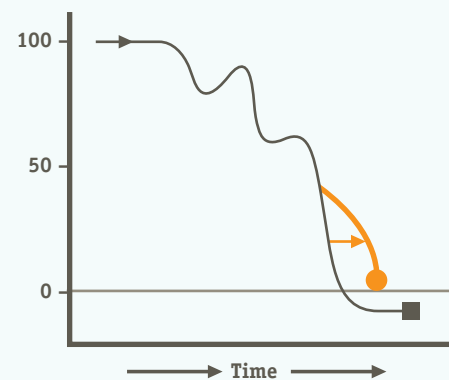


Fluctuating Decline

Malignancies that enter remission and then relapse such as cancer; cystic fibrosis; metabolic disorders that cause lasting injury with each episode.

The pace of decline after the onset of the condition varies; the child has episodes of worsening health followed by periods of relative recovery, followed by bad health & each recovery is not to the same level of normal as the child was before.

The goal of palliative care is to maximize quality of life and focus on the child and family's goals, such as going to school or being at home.

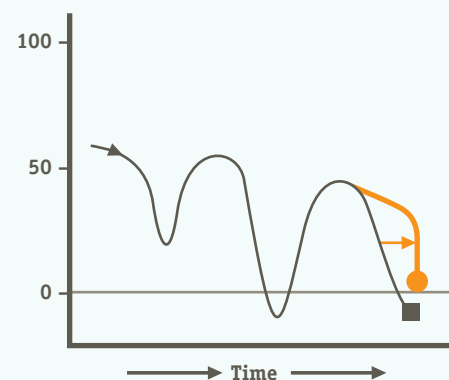


Unpredictable

Fragile health and vulnerable to recurring health crises, often triggered by outside events such as the common cold. Families live in a constant state of anticipating the next crisis or setback.

Some children with neurological conditions that are not progressively degenerative, such as a static encephalopathy, fall into this category. As the child ages the brain is not able to keep pace with physical growth and complexity increases.

It is harder to determine when the child's quality of life is not acceptable to the child or family. The goal of palliative care is to pay attention to shifts in quality of life over time.



Source: Feudtner C. Collaborative Communication in Pediatric Palliative Care: A Foundation for Problem-Solving and Decision-Making Pediatric Clinics of North America. 54 (2007) 583-607

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● Identifying Your Child's Health Trajectory

A shift in your child's overall health can creep up on you slowly, or it can be masked by an acute event. Parents sometimes don't notice changes in their child's physical or cognitive abilities until well after they have changed, which in many ways is a beautiful and merciful thing.

It can be helpful to periodically pause and take a step back to ask yourself what, if anything, has changed. It is extremely helpful to do this work with your child's medical team—or to answer the questions individually, and then compare notes.



Questions to Consider

Source: Julie Hauer, MD, Pediatric Medical Director • Seven Hills Foundation • Worcester, MA

- How does my child's health compare this month to six months ago and one year ago?
- After an illness, does my child return to the same baseline?
- What percent of each day, on average, is my child comfortable and happy?
- How does that compare to 12 months ago?
- What percent of each day, on average, is my child uncomfortable or unhappy, and how does that compare to 12 months ago?
- How often has my child been sick in the past 6 months and how does that compare to 12 months ago and 2 years ago?
- How does my child appear in photos or videos from a year ago?
- Is my child sleeping more?
- Is my child able to participate in the activities that they enjoy?
- Has my family and household recently made many adjustments to accommodate my child's changing needs?

Using Baseline to Help Make Critical Care Decisions

Each shift in baseline comes with its own challenges. There is often sadness as you adapt to the loss of what was. Each shift is also an opportunity for your family to consider what your new goals are, what quality of life means now, and how you will focus on achieving those goals.

Sometimes we do not have a great deal of time to reflect on what feels right and what might work. Acute events, for example, may bring on the need to make quick (and difficult) decisions. Here, understanding baseline is really one of your best tools for identifying options and guiding choices. Here are some questions to consider. Again, it is helpful to do this with your provider. While all of this can feel painful in the moment, your answers will help you consider what is best for your child's care and looking ahead.

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During or after an acute episode

- If my child survives this acute episode, what will it take for them to recover? Will that require a lot of medical intervention, such as intubation, and how do we feel about that?
- After my child's recovery is "complete" and s/he is at a new baseline, what will this new baseline be?
- What are our goals of care at this new point?
- How severe are future crises likely to be and what will it take to keep my child comfortable?

If you are evaluating a medical intervention

- Will this intervention impact other body systems? (spinal surgery, feeding tube, etc.)
- How will my child's overall health affect the recovery time from this procedure?
- What will our new baseline look like?
- What is the trajectory if we elect not to have this procedure?
- Will this test help us find an effective solution?

Communicating a New Baseline to Friends and Family

As baseline shifts, it can be helpful to share your new care goals with friends and family, so they understand what is important to you in this new place. Use words like

- Our hope for our child is _____
- It is our priority that he/she continues to be able to _____
- We could use your support in _____



CONCLUSION

A Helpful Reality Check

Baseline is a kind of reality check. Identifying and talking about the ups and downs makes them more real. This can be painful—even scary. On the other hand, knowing your child's baseline and adjusting as it changes can help you feel more control over your situation. Think of understanding baseline as a tool to help you anticipate and confidently make decisions, and do the best you can as a parent caring for a child with a serious illness.