

9 THINGS TO UNDERSTAND ABOUT BASELINE

- 1** Baseline is really just a term for what things look like when they are stable. As your child's condition progresses, the baseline changes with it: "the new normal."
- 2** Baseline often shifts down over time in a step-like fashion. Each lower step represents a lower level of functioning.
- 3** A shift in baseline may bring up sadness as you adapt to the loss of what was.
- 4** Understanding baseline can be one of your most useful tools for identifying options and guiding choices as your child's baseline changes. It can help you feel more control over the situation.
- 5** Baseline can be a helpful reference point for looking at how your child's condition is changing and noting patterns of progress and decline. Your reporting of changes in baseline can also help your medical team direct your child's care.
- 6** You may find it helpful to journal about your child's life, with notes about what you see as changes in baseline. Journaling will help you help the team, and it may provide a reminder to you to appreciate how much (and how well) you are doing in caring for your child.
- 7** A shift in your child's baseline can creep up slowly or be brought on by an acute event.
- 8** Changes in baseline may also prompt you to refocus priorities and think about possible new goals of care, and then the choices you may make—including for medical interventions—to achieve those goals.
- 9** 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.