

Take ACTION Check-In (Parent)								
In the last 24 hours, has your child had....	No	Yes	I don't know	If answer is yes/IDK, How distressed has your child been by...	Not at All	Some	Moderately	Very
Nausea/Vomiting/Stomach Pain								
Shortness of Breath								
Headache								
Fatigue								
Poor Sleep								
Thirst								
Loss of Appetite								
Chest Pain								
Post-Operative Pain								
Sadness								
Worry								
Blood Draws								
Dressing Changes								
Limitations in Activities (Play, School, Etc.)								
Noise from VAD								
VAD Alarms								
Uncertainty around Transplant Wait								
Other _____								
In the last 24 hours, have you/your family, experienced...				If answer is yes/IDK, How distressed have you/your family been by...				
Parent/Caregiver Worry								
Parent/Caregiver Sadness								
Balancing Parenting/Caregiver Demands								
Family Conflict								
Financial Stress								
Sibling Distress								

On the scale below, we ask you to rate your child’s health-related quality of life on a scale of 0 to 100. A score of “0” represents the worst health state that you can imagine. A score of “100” represents perfect health. A child with perfect health would be one who has no pain or physical discomfort, no emotional distress, and no problems with usual activities that would be expected for his or her age.

What else should we know?

Take ACTION Check-In (Patient)								
In the last 24 hours, have you had or felt....	No	Yes	I don't know	If answer is yes/IDK, How distressed have you been by...	Not at All	Some	Moderately	Very
Belly Pain/Vomiting								
Hard to Breathe								
Head Hurt								
Fatigue or Tiredness								
Troubles Sleeping								
Thirst								
Not Hungry								
Chest Pain								
Post-Surgery Pain								
Sadness								
Worry								
Blood Draws or Needle Pokes								
Dressing Changes								
Had to Stop or Not Do Activities (Play, Walk, School)								
Noise from VAD								
VAD Alarms								
Worry around Transplant Wait								
Other _____								

On the scale below, we ask you to rate how you feel right now. If you have no problems and feel really good, move your cursor towards the happy face. If you have some problems, move your cursor towards the middle. If you have many problems and feel really bad, move your cursor towards the sad face.

What else should we know?

KEY for TONIC Creation: Blue items to all parents, Red VAD only, green all pts listed.

Adapted from VADQL Pedimacs, DeWitt et al, Parent-Reported Symptoms and Effectiveness of Treatment in Children Hospitalized with Advanced Heart Disease, ISHLT 2019.