Appendix 1: Tools for documenting discussions/decisions

Step 1: Living with life-limiting illness

What do you (child)/does your child enjoy?
What do you (child)/does your child find most difficult about their illness/treatment?
As you think of the future What is most important?
what is most important:
What are your hopes?
What are your fears? What are the things that keep you awake at night?
What are your goals?
Any other important information from this discussion? For example, what role in decision making would the child or parent prefer to take?
Name of health professional documenting discussion:
Date: