



Personalized QUALITY OF LIFE TOOL

For Rare & Chronic Conditions

 **EOSINOPHILIC & RARE DISEASE**
COOPERATIVE

www.eosinophilraredisease.org

QUALITY OF LIFE TRACKING TOOL INSTRUCTIONS

Step 1 - Create your objective scale about how you feel. The items you list should have connection to quality of life. For example, if you have nasal congestion but it has no impact on your quality of life, function or ability to live your life then it would not go on the list. Clarifying the difference between symptoms that might be tied to your disease but do not impact you, versus symptoms that impact your quality of life, regardless of if they show up on a lab or test, will change the focus of conversations with your health care providers.

Step 2 – List your symptoms in the column on the left, specificity will be helpful. Be sure to include the symptoms that are problematic, even if they do not appear on a blood test. Here is an example:

| SYMPTOM | 10 – BEST POSSIBLE | 7 | 5 | 3 |
|---------------------|--------------------|---|---|---|
| Shortness of breath | | | | |
| Coughing | | | | |
| Fatigue | | | | |
| Loneliness | | | | |

Step 3 - Now identify, with specificity how these show up based on how you are feeling with 10 being the best you can be with your disease (not pre-disease) and 3 being nearly the worst. Here is an example:

| SYMPTOM | 10 – BEST POSSIBLE | 7 | 5 | 3 |
|---------------------------|---|--|---|-------------------------------------|
| Shortness of breath (SOB) | No problem breathing | Slight after 30 min walk, 2 flight of stairs | After 15 min of walking, 1 flight of stairs | Cannot walk more than 5 min w/o SOB |
| Coughing | None | Very rarely | Occasional | Frequent |
| Fatigue | 1 nap a day, energy for 5 hours of activity | 2 naps, 4-5 hours of activity | 2-3 naps, 3-4 hours of activity | Continual, 2 hours of activity |
| Loneliness | Connected with someone | Most days I feel ok | About ½ of the time | More days than not |

Step 4. Map out your number on the graph to track it over time. Ideally, you will rate how you are feeling and where your score is overall each month. During the times that are tough, it can be helpful to rate more frequently to identify small gains or increased challenges.

Step 5. Identifying what quality of life means to you will be important for the times you feel good, or are not feeling good. This will help you identify when your health is falling below what is acceptable. It also helps us keep our expectations realistic as we navigate unpredictable and challenging systemic diseases. Here is an example:

| WHAT SPECIFICALLY ADDS JOY OR BRINGS ME QUALITY OF LIFE | VALUE OF THIS ACTIVITY OR ITEM | MINIMUM FREQUENCY REQUIRED FOR MY QOL |
|---|--|--|
| Being able to drive myself. | Independence | Nearly all of the time. |
| Being able to cook dinner. | Independence and caring for my family. | At least a couple times per week. |
| At least 4 hours of a day of good, active time. Does not need to be in a row. | I feel alive even with this disease, versus feeling like I am just existing. | At least 75% of the time. This is a 6 on my scale. |

QUALITY OF LIFE TRACKING TOOL

| SYMPTOM | 10 – BEST POSSIBLE | 7 | 5 | 3 |
|---------|--------------------|---|---|---|
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What number is an acceptable quality of life for you?

When it falls below, how long is it acceptable to be at this number before you need to contact your doctor? What does that conversation need to look like?

Map out your number at least monthly:

| | | | | | | | | | | | | | | |
|-------|--|--|--|--|--|--|--|--|--|--|--|--|--|--|
| 10 | | | | | | | | | | | | | | |
| 9 | | | | | | | | | | | | | | |
| 8 | | | | | | | | | | | | | | |
| 7 | | | | | | | | | | | | | | |
| 6 | | | | | | | | | | | | | | |
| 5 | | | | | | | | | | | | | | |
| 4 | | | | | | | | | | | | | | |
| 3 | | | | | | | | | | | | | | |
| 2 | | | | | | | | | | | | | | |
| 1 | | | | | | | | | | | | | | |
| Date: | | | | | | | | | | | | | | |

It is important to share this graph with your doctor and discuss what feels acceptable to you. This will enable you to be on the same page with your doctor about how your health is impacting your quality of life -and when new treatments, alternative or additional treatments might be explored.

MY LIVING WILL:

What brings me joy and/or makes me feel like I am living vs exiting? What number is acceptable?

[illegible]

Resources & References

View the Livestream Educational Program with a Walk Through of the Tool

[Rare Candor Podcast on Spotify](#)

[Rare Candor Podcast on Apple](#)

["Best Practice" for Patient-Centered Communication: A Narrative Review](#)

[Quality-of-Life Inquiries Aid Doctor-Patient Relationships](#)

[Managing the Psychological Impact of Medical Trauma](#)

[The Shifting Perspectives Model of Chronic Illness](#)

The Standard Quality of Life Health Care Tool:

[Quality of Life in Chronic Disease Patients](#)



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