THE CAREGIVERS DILEMMA: ASSESSING QUALITY OF LIFE

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Knowing when is “time” is not an easy thing to do unless a pet is in the active stage of suffering. Most pet owners do not want to have their pet get to the point of extreme suffering. But when do you make that decision? These tools and tips will help guide owners through the decision process and provide them with guidelines to do what is best for the pet and the family.

Proceedings:
Melinda’s call to me started off with lots of tears. It was clear she needed support and additional education through this tough time. Chance, her 4 yr old male Staffordshire Terrier, greeted me at the door for our in-home hospice consultation, unconcerned that he has both severe mitral and tricuspid valve insufficiency, along with atrial fibrillation. Melinda understood the gravity of his condition. Her most pressing issue was knowing when to make that final decision. It’s the most important question we’re asked as doctors and although our clients want a specific timeline, more personalized patient and client information is needed to comprehensively evaluate quality of life (QOL) and reach an educated, informed, and supported choice that fits their pet’s medical condition and also the family’s wishes. “Quality of Life” applies not only to the pet; it applies just as much to the family!

The most commonly used objective measurements for quality of life by veterinarians are mobility, appetite, pain, and proper voiding. The presence of quality of life based on these items should not be answered with a “yes or no,” but rather “if… then”. I always start hospice consults with open-ended questions. The goal is to help families uncover their own thoughts, feelings, and boundaries for their pet surrounding end of life decisions. These questions help me gauge the family’s time, emotional, physical and (when appropriate, financial) budgets:

1. Have you ever been through the loss of a pet before? If so, what was your experience (good or bad, and why)? (Side bar: “Have you ever been through this before?” is usually the first thing I ask. Families experiencing quality of life evaluation for the first time generally need more hand-holding and direct language about the process ahead.

2. What do you hope the life expectancy of your pet will be? What do you think it will be?

3. What is the ideal situation you wish for your pet’s end of life experience?

4. Do you hold any stress or anxiety about any of these issues? (This helps identify the main concerns the family has.)
   - Pet suffering
   - Desire to perform nursing care for pet
   - Ability to perform nursing care for pet
   - Pet dying alone
   - Not knowing the right time to euthanize
   - Coping with loss
   - Concern for other household animals
   - Concern for other members of the family (i.e., children)

After some discussion, it was clear Melinda most valued the physical companionship Chance brought her. He followed her everywhere. She was aware that his condition could deteriorate
rapidly at any time (a condition I categorize as “imminent”). Knowing the significant anxiety that accompanies dyspnea and the happiness her presence brings him, Melinda placed great value on the quality of death for Chance. Her worst fear was coming home after work to find that he passed away on his own, not knowing if he was in pain or stress. Melinda’s stop-point came a couple weeks later when Chance no longer followed her to the next room; she knew it was time. She wanted to be with him and to lean on the support of family, so we met at Chance’s favorite spot on the beach at sunset the next day to peacefully say good-bye.

Ideally, every family’s budgets and boundaries align with the disease process, but it’s not always the case. The family that places greatest weight on the happiness of the pet and avoiding an emergency situation, needs to understand the significant risk they run by waiting too long with imminent conditions…. This determines what clinical signs should be weighted most heavily to evaluate quality of life. We have to move away from “call me when he stops eating”! Appetite truly does not concern me for the 85 lb Labrador that has severe osteoarthritis. This dog may never stop eating. The little Yorkie with congestive heart failure that suddenly refuses food, however, definitely concerns me. Each disease process has its own set of clinical signs that should be weighted most heavily.

If the pet is declining in health and there are no additional diagnostics or treatments the family is either willing or able to explore, then quality of life is either an imminent concern or will be soon. If the family’s emotional, time, physical or financial budgets are being drained there is a subjective time period in which euthanasia is an appropriate decision to make. This period could be hours, days, weeks, or even months. Before this specific period, I will refuse to euthanize since there is clearly a good quality of life. After this period, however, I will insist on euthanizing due to suffering of the pet. During this larger subjective time however, it is truly dependent on the family to make whatever decision is best for them under the guidance of a supportive medical team.

**Pain and Anxiety**

Pain in animals is another important topic that all pet owners should be well versed on. It’s the main topic I discuss during my in-home hospice consultations. Myself, and many other professionals, believe that carnivorous animals, such as cats and dogs, do not “hide” their pain, rather pain simply doesn’t bother them the same way it bothers humans. Animals do not have an emotional attachment to their pain like we do. Humans react to the diagnosis of cancer much differently than Fluffy does! This is vastly different than prey animals like rabbits or guinea pigs, who must hide their pain to prevent carnivorous attacks. The drawback is that once in pain, animals cannot sense an ending to their hurt. As humans, we can take a pill knowing that the headache will eventually subside but animals have no perception of their suffering ending. If you’re interested in learning more about pain and suffering in pets, grab Temple Grandin’s book “Animals in Translation” and read chapter 5.

When discussing the decision to euthanize, we should be just as concerned about anxiety in our pet as pain. Personally, I feel that anxiety is worse than pain in animals. Think about the last time your dog went to the vet. Was he nervous in the exam room? Did he give you that look that said “this is terrible!”? Now think back to when he last hurt himself. Perhaps straining a muscle after running too hard. My dog rarely looks as distraught when she’s in pain as she does when she’s anxious. It’s the same for animals that are dying. End stage arthritis patients begin panting, pacing, whining, and crying, especially at night time. Due to hormonal fluctuations and other factors, symptoms can usually appear worse at night. The body is telling the carnivorous dog that he is no longer at the top of the food chain; and if he lies down, he will become someone else’s dinner. Anti-anxiety medications can work for a time but for pets at this stage, the end is certainly near.
Waiting Too Long
The more times families experience the loss of a pet, the sooner they make the decision to euthanize. Owners experiencing the decline or terminal illness of a pet for the first time will generally wait until the very end to make that difficult decision. They are fearful of doing it too soon and giving up without a good fight. Afterwards, however, most of these owners regret waiting too long. The next time they witness the decline of a pet, they are much more likely to make the decision at the beginning of the decline instead of the end.

What about a natural death?
Many owners fear their pet “passing alone” while others do not. Occasionally I am asked to help families through the natural dying process with their pet. For different reasons, these families are against euthanasia. I explain everything I possibly can, from how a natural death may look, how long it may take, what their pet may experience, etc. Inevitably, almost all of these families regret doing this as they comment after, “I wish I would not have done that, I wish she didn’t have to suffer.” A natural death can be difficult to watch. To an extent, we can talk other humans through physical pain or discomfort. Humans can perceive an ending to their pain (via medication or even death) but there is little emotional comfort we can offer a pet that is suffering, they simply cannot perceive an ending to that pain. Families take this guilt difficultly and I do my very best to not only readily suggest euthanasia when appropriate, but prepare families for a “worst-case” scenario should they choose to wait.

Weigh Your Options Carefully
If the most important thing is waiting until the last possible minute to say goodbye to your baby, you will likely be facing an emergency, stress-filled, sufferable condition. It may not be peaceful and you may regret waiting too long. If a peaceful, calm, loving, family-oriented, in-home end of life experience is what you wish for your pet, then you will probably have to make the decision a little sooner than you want. Above all, our pets do not deserve to hurt. Making the decision to euthanize a pet can feel gut-wrenching, murderous, and immoral. Yes, those are strong words, but that is what our pet families experience. They feel they’re letting their pet down or that they are the cause of their friend’s death. They forget that euthanasia is a gift that can prevent further physical suffering for the pet and emotional suffering of the family.

Quality of Life Scale
When evaluating quality of life, personalized patient and client information is needed to reach an educated, informed, and supported choice that fits not only their pet’s medical condition but also the family’s wishes. Quality of life applies not only to the pet; it also applies to the family!

Pet’s Quality of Life
Score each subsection on a scale of 0-2:

- 0 = agree with statement (describes my pet)
- 1 = some changes seen
- 2 = disagree with statement (does not describe my pet)

1. Social Functions
   a. Desire to be with the family has not changed.
   b. Interacts normally with family or other pets (i.e., no increased aggression or other changes).

2. Natural Functions
   a. Appetite has stayed the same.
b. Drinking has stayed the same.
c. Normal urination habits.
d. Normal bowel movement habits.
e. Ability to ambulate (walk around) has stayed the same.

3. Mental Health
   a. Enjoys normal play activities.
   b. Still dislikes the same things. (i.e., still hates the mailman = 0, or doesn’t bark at the mailman anymore = 2)
   c. No outward signs of stress or anxiety.
   d. Does not seem confused or apathetic.
   e. Nighttime activity is normal, no changes seen.

4. Physical Health
   a. No changes in breathing or panting patterns.
   b. No outward signs of pain. (See Resources Below)
   c. No pacing around the house.
   d. My pet’s overall condition has not changed recently.

Results:

1. 0 - 8 = Quality of life is most likely adequate. No medical intervention required yet, but guidance from your veterinarian may help you identify signs to look for in the future.
2. 9 – 16 = Quality of life is questionable and medical intervention is suggested. Your pet would certainly benefit from veterinary oversight and guidance to evaluate the disease process he/she is experiencing.
3. 17 - 36 = Quality of life is a definite concern. Changes will likely become more progressive and more severe in the near future. Veterinary guidance will help you better understand the end stages of your pet’s disease process in order to make a more informed decision of whether to continue hospice care or elect peaceful euthanasia.


Family’s Concerns

Score each section on a scale of 0-2:

• 0 = I am not concerned at this time.
• 1 = There is some concern.
• 2 = I am concerned about this.

I am concerned about the following things:
1. Pet suffering
2. Desire to perform nursing care for your pet
3. Ability to perform nursing care for your pet
4. Pet dying alone
5. Not knowing the right time to euthanize
6. Coping with loss
7. Concern for other household animals
8. Concern for other members of the family (i.e., children)
Results:

1. **0 - 4** = Your concerns are minimal at this time. You have either accepted the inevitable loss of your pet and understand what lies ahead, or have not yet given it much thought. If you have not considered these things, now is the time to begin evaluating your own concerns and limitations.

2. **5 - 9** = Your concerns are mounting. Begin your search for information by educating yourself on your pet’s condition; it’s the best way to ensure you are prepared for the emotional changes ahead.

3. **10 - 16** = Although you may not place much value on your own quality of life, your concerns about the changes in your pet are valid. Now is the time to prepare yourself and to build a support system around you. Veterinary guidance will help you prepare for the medical changes in your pet while counselors and other health professionals can begin helping you with anticipatory grief.

### Basic Quality of Life Assessments

The most traditional method is when you ask a family to record the top 5 favorite things of the pet and when they stop doing 3 or more of them, it is ‘time’. My apprehension to this method is that it does not take into consideration the pet's ailment. One twist I like to add to the list is something that the pet hates. There are certain things that just ‘bug’ our pets – and when they stop caring for those things, it can be a sign that they are simply tired and do not have the energy to ‘care’.

Another easy way to track quality of life is to get two jars – one labeled ‘good day’ and the other ‘bad day’. Have the owner put a penny in the appropriate day jar based on the pet’s behavior, habits, daily functions, etc. Then after a few weeks – you can see if the pet is having more bad days than good and it is probably appropriate to recommend euthanasia.

A much better quality of life scale was created by Alice Villalobos, DVM and is called The HHHHHMM Scale. This takes into consideration hurt, hunger, hydration, hygiene, happiness, mobility, and more good days than bad. It can be downloaded by following this link: [http://www.pawspice.com/downloads/QualityofLifeScale.pdf](http://www.pawspice.com/downloads/QualityofLifeScale.pdf)

### Advanced Quality of Life Assessments

After helping thousands of families, I’ve realized that much of the quality of life assessment is ruled by the pet’s ailment. Questions used to evaluate each pet are very different. The daily questions I have owners ask are based on the ailment as well. Lap of Love has created an online interactive tool that owners can use to evaluate their pet’s quality of life. They create their pet’s profile and choose from a variety of ailments. Based on the ailment selection, the questions and parameters they evaluate are different. This tool is free for vets and the public and can be found at [www.pethospicejournal.com](http://www.pethospicejournal.com). Using this scale with the family’s quality of life has helped many owners feel empowered over their decisions.

Suggestions on using any quality of life scale:

1. Complete the scale at different times of the day, note circadian fluctuations in well-being. (We find most pets tend to do worse at night and better during the day.)
2. Request multiple members of the family complete the scale; compare observations.
3. Take periodic photos of your pet to help you remember their physical appearance.