

The Caregiver's Dilemma - Assessing Quality of Life

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Learning Objective:

Knowing when is "time" is not an easy thing to do unless a pet is in the active stage of suffering – at that point, it is usually clear to all involved. But most pet owners do not want to have their pet get to the point of extreme suffering. But when do you make that decision? This presentation will give attendees tools and tips to help guide owners through the decision process and to provide them with guidelines to do what is best for the pet and the family.

Proceedings:

Melinda's phone call to me started off as most of our calls do, with lots of heartfelt tears. It was clear Melinda needed support and additional education through this tough time. Chance, her 4 year old male Staffordshire Terrier, greeted me at the door for our in-home hospice consultation, clearly unconcerned that he has both severe mitral and tricuspid valve insufficiency, along with atrial fibrillation. Melinda understood the gravity of his condition and was well-coached by the cardiologist. Her most pressing issue however, as with most of our clients, is knowing When to make that final decision. It's the most important question we are asked as doctors and although our clients want a specific timeline, more personalized patient and client information is needed to most comprehensively evaluate quality of life (QOL) and 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 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. I certainly do not disagree with any of these but the presence of quality of life based on these items should not be answered with a "yes or no," but rather "if... then".

There are numerous objective QOL scales available that do a wonderful job addressing these, and other, clinical signs of the pet but, in my opinion, leave out the other 50% of the equation; the family's time, emotional, physical and financial budgets. This is why I always start hospice consultations with open-ended questions. I need to get an idea of what the family values most in their pet's daily life, where their "stop point" is in relation to the pet's disease condition, and what their idea of a "good death" is for their pet.

The goal is not to evaluate the QOL for the family (although I feel owners want and deserve my opinion) but rather to help them 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. I find that families experiencing quality of life evaluation for the first time generally need more hand-holding and more direct language about the process ahead. They tend to wait for that hand-written letter from their pet saying "I'm ready now, Mom." This is not just my observation, it is what I hear from these pet owners time and again after the loss of their pet; "I can't believe I waited that long.")
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? (at home, pass away in her sleep, etc.)
4. Do you hold any stress or anxiety about any of these issues? (This section is meant to help 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)

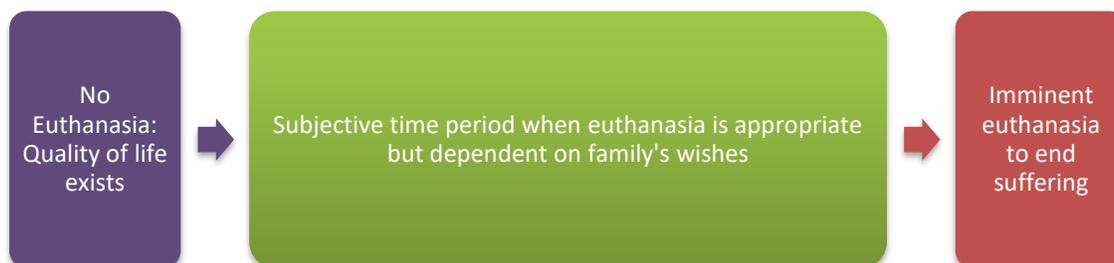
After some discussion, it was clear Melinda most valued the physical companionship Chance brought her. He

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followed her everywhere, even when it was clear his breathing was labored. She was aware that his condition could deteriorate rapidly at any time, leading to death in minutes to hours at best (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 during that death phase. 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 at that crucial moment, which is why 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 at hand. For Melinda it did, but this is not always the case. The family that places greatest weight on both the happiness of the pet in addition to avoiding an emergency situation at all costs 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 start moving away from the standard “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 and the family must not rely on this clinical sign to ever manifest itself. 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 some point 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. Some owners need time to come to terms with the decline of their pet while others want to prevent any unnecessary suffering at all. Everyone is different. After all, owners know their pet’s personality better than anyone, even the vet!



Chance was clearly a happy boy that loved his mom dearly, watching her every move and following her to the kitchen, just 15 feet from where I was sitting. Melinda, a 25 year old professional, found Chance in the Florida

Everglades as a puppy during a college field trip. He grew up with Melinda during her first years as an adult and now helps her feel secure while living alone. She has given Chance the very best quality of life thus far but with such a life-limiting condition, is facing the difficult and inevitable loss of her boy. Although tired and breathing more rapidly than normal, Chance is happy. He has no perception of what “heart failure” means and no emotional reaction to his physical condition. He is living in the moment (isn’t that what we love about our pets anyway!). 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. This key point is at the heart of quality of life evaluation; how do we measure happiness and prolong it as long as possible.

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! Fluffy doesn’t know she has a terminal illness, it bothers us more than it bothers her. This is vastly different than prey animals like rabbits or guinea pigs, who must hide their pain to prevent carnivorous attacks. 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 we are about pain. Personally, I feel that anxiety is worse than pain in animals. Think about the last time your dog went to the vet. How was his behavior? 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 scraping his paw or 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; he has been demoted and if he lies down, he will become someone else’s dinner. Anti-anxiety medications can sometimes work for a time but for pets that are at this stage, the end is certainly near.

Waiting Too Long

An interesting trend that I did not expect when starting my hospice practice is that 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. They reflect back on the past days, weeks, or months, and feel guilty for putting their pet through those numerous trips to the vet or uncomfortable medical procedures that did not improve their pet’s quality of life. 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?

Yes, there are those pets that peacefully fall asleep and pass naturally on their own, but just as in humans, this is rare. 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. Most of them comment afterwards “I wish I would not have done that, I wish she didn’t have to suffer.” A natural death can be difficult to watch, especially for non-medically oriented people. Most people can watch a human family member in pain much more easily than they can their pet. 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 to you is waiting until the last possible minute to say goodbye to your baby, you will

most likely be facing an emergency, stress-filled, sufferable condition for your pet. 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. Making that decision should not be about ceasing any suffering that has already occurred, but about preventing suffering from occurring in the first place. Above all, our pets do not deserve to hurt.

I've heard from countless pet owners that the death of their pet was worse than the death of their own parents. This might sound blasphemous to some, but to others it's the cold truth. 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 are letting their pet down or that they are the cause of their friend's death. They forget that euthanasia is a gift, something that, when used appropriately and timely, prevents further physical suffering for the pet and emotional suffering of the family. Making the actual decision is the hardest part of the experience and I'm asked on a daily basis, "Doc, how will I know when it's time?" Let me shed some light on this difficult discussion.

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. In short, *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)

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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.

Resources:

1. AAHA/AAFP Pain Management Guidelines for Dogs and Cats, www.aahanet.org/Library/PainMgmt.aspx

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

Let's face it – some people just need an easy way to evaluate a pet's quality of life. I'm not saying I agree with this method, but for some, this is all they can mentally handle during these delicate days.

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 this is adding something that the pet hates to that list. 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'. My own dog hated the Goodyear blimp that flew over our house. The week he passed – he didn't make a peep at it coming into his air space.

Another uncomplicated 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 HHHHMM 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>

Advanced Quality of Life Assessments

After helping thousands of families with determining when is 'time' – I have realized that much of that assessment is ruled by the pet's ailment. As mentioned above – the pet in heart failure is very different than a pet with arthritis. The questions that you evaluate are very different. Appetite in arthritis is not as important as it is in heart failure. Respiratory effort is vital in heart failure while not so much (except for panting due to pain) in arthritis.

Due to this – the questions I have owners ask everyday is based on the ailment. 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 at large and can be found at www.pethospicejournal.com

Using this scale in conjunction with the family's quality of life has helped many owners feel empowered over their decisions – whether to continue or euthanize their pets.

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.

Summary

How I wish the answer to the question 'when is time' was simple and clear cut – however, it is not. It is our duty to assist owners with end of life decisions and to help end and prevent suffering of animals. There are many ways to help families explore quality of life questions but the one way that is an injustice to our profession is if you simply say, 'Call me when it's time'. Owners need more than this and animals deserve more.