

When meeting with Akka's primary care provider (family doctor), these were the characteristics and questions that I/we used to help us assess if we were in good hands and he was the right doctor. I compiled these based on discussions with friends – nurses and volunteers - in hospice palliative care, as well as internet resources. They are not formatted.

In general we wanted to get a sense of his:

- Kindness, patience
- Complete explanations of what to expect
- Patient is in control
- Open dialogue
- Zero pain / Total pain management
- Physical and emotional
- explaining of options
- home vs hospice, total assistance with available resources
- response to our expectations for caring and undivided attention, i.e. proper listening, interest in Akka, no tapping fingers
- A feeling more than anything
- A friend more than a dr.
- Always including family stuff....

### **Specific Questions**

- What are the hospice options here?
- Akka values fresh air, light and views - does he know of a hospice in the area like that?
- Accessibility - 24/7 who/how / availability/alternatives in his absence
- How is the family involved?
- Personal Care Wishes document? How does he use it? Help you phrase your requests in a way that makes sense to medical professionals and can answer any questions you may have.
- Point out any illogical or inconsistent features of your requests. Sometimes refusing one kind of treatment makes it illogical to expect to receive another kind of treatment. Your physician can smooth out some of these "rough edges" and help make a consistent and coherent directive.
- Tell you if there are aspects of your requests that he or she cannot honour because of personal, moral, or professional constraints.
- How do we work with CCAC? How does that work?
- Are you familiar with the work of Mont Sinai Hospital's Stephen Jenkinson (Griefwalker video)?
- Acknowledging his expertise in ER, what is his motivation as a palliative care doctor?
- Does he see competing goals (e.g.in ER death is viewed as a failure; in palliative

care, "good" death is the goal), or would he disagree, believing both aim to reduce suffering?

- Approach to pain management, including palliative sedation/medical assistance in dying (MAID);
- What if a ventilator were needed as a bridge to recovery? Would it be all right to use it for a trial period if doctors thought it might help you regain consciousness?
- develops a care plan tailored to a patient's individual need for pain management and symptom relief, and provides all the necessary palliative drugs and therapies, medical supplies, and equipment. Typically, hospice care is provided at home and a family member acts as the primary caregiver, supervised by professional medical staff
- hospice care also focuses on the emotional needs and spiritual well-being of the terminally ill and their loved ones
- are there IVs in palliative?
- give akka a solid understanding of what will typically happen
- How often will he check in? 24 hours is a lifetime. Hospital to hospice too difficult.
- what resources you need now and what resources you may need in the future.
- Home care programs may also provide access to equipment such as wheelchairs, walkers, bath seats, shower rails, and hospital beds to help family caregivers provide safe care.
- It is possible in many provinces to notify the medical examiner's office of an anticipated home death due to a terminal illness before the death occurs. Check with your health care team to find out what steps need to be taken in your area. Generally, your doctor needs to write a letter of anticipated death and give copies to the medical examiner's office and funeral home. Then, when the death occurs, no investigation is required.

What I wanted to keep in mind:

- Want to have things in place to avoid crisis
- Despite your best efforts to plan for all eventualities in a health care declaration, actual events may not "fit" your directives. It is therefore important that you discuss your desires with family and friends.
- Your family can often help clarify your directives on the basis of recollections of specific discussions under specific circumstances.
- If you have discussed your wishes with a number of people, it is more likely that those wishes will be honored.
- Discussions with family members can help avoid unpleasant scenes and confrontations when you are incapacitated. While family members may have little legal authority to make decisions for incapacitated patients, they often feel they have moral authority. They may be confused by statements not previously shared with them, and may even try to contest your wishes legally if they feel your choices are not in your "best interest."

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- Meds are constantly being rejigged