

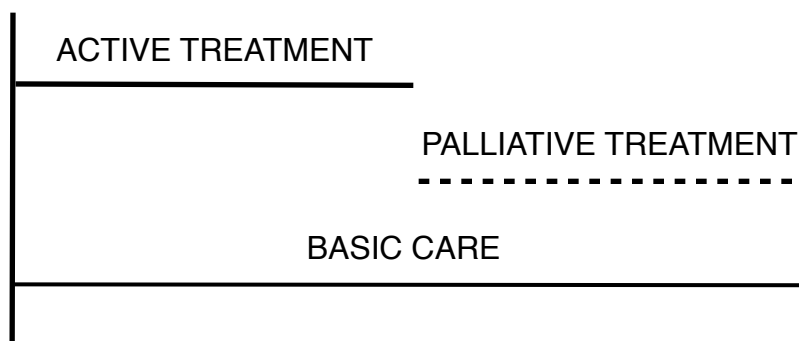
NAVIGATING LIFE'S LAST JOURNEY

Hand-out based on a talk given to Canmore Seniors' Association,
March 9, 2015 by Dr. Martin Tweeddale

Unlike travel by car or plane, life's last journey is always unpredictable and no two such journeys are the same. No one knows when their journey will begin, what difficulties they will meet on the way, or how long it will last - each trajectory is unique. For some, normal health ends abruptly in minutes or hours due to accident or catastrophic illness (e.g., heart attack, a bleed into the brain etc). Others suffer prolonged and deteriorating ill-health which might kill them, but, in the end, they too may die suddenly of an unrelated illness. For many, good health is interrupted by a serious disease which, over a shorter or longer time, in spite of the best that medicine can do, eventually results in death. Still others suffer from a progressive debilitating disease (e.g. heart failure, chronic lung disease, Lou Gehrig's disease etc) which they ultimately do not survive. Some people remain conscious and able to communicate until the very end, whereas many lose awareness much earlier in the dying process - the combinations and permutations are endless!

Given such levels of uncertainty, how can any useful plan be made for that last journey? Obviously all such planning has to be general, not specific, but it is still better to have made what preparations one can than to enter the journey unprepared. But before we look at some of the preparations which can be made to mitigate the potential difficulties of the journey, we need first to have some understanding of the process of care and the factors which might help or hinder that process.

1) The process - the continuum of care: We often speak of "medical care" rather loosely when we actually mean "medical treatment". The distinction is an important one, since treatments can (and often should) be withheld or withdrawn, but "care" should always be provided. I have tried to show this in the diagram below.



The vertical line on the left marks the onset of a serious illness and as we move to the right, time is passing. The two lower horizontal lines end at the death of the patient. When we become seriously ill, we cannot continue to provide for ourselves our basic bodily needs (food, clothing, cleanliness etc) - so we need someone else to take care of those needs for us. This is "basic care" and it should never be neglected at any stage of an illness (as shown by the lowest line in the diagram).

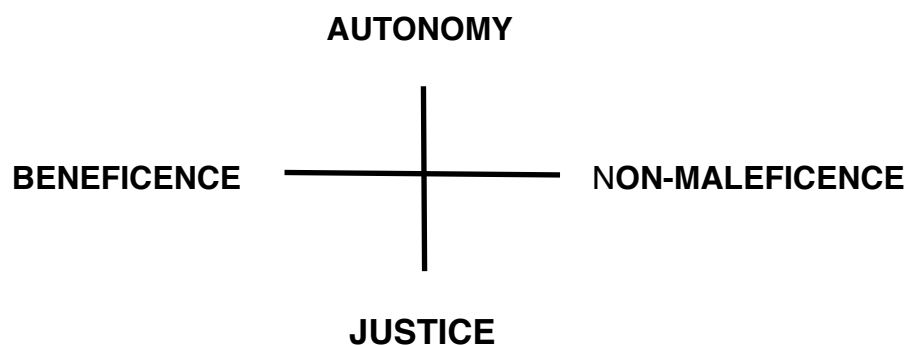
Treatment, however, is a different matter. Initially, "treatment" will obviously be directed to reversing the disease process and returning the patient to the best possible level of health. This is shown by the upper solid line labelled "active treatment". But what if the treatment is unsuccessful, and the disease process cannot be reversed or controlled? When that happens the patient has entered the dying process and the focus of treatment needs to change from seeking a cure to maximizing comfort

and well-being. The medical term for this is palliation (sometimes called “comfort care”), and, once initiated, it should be continued until the death of the patient as shown by the dotted line in the diagram. The transition to palliative care should begin either when it is determined that the patient is dying, or when a patient with a life-threatening illness decides that they do not wish to receive any further active treatment. While the latter situation is clear enough, it is often very difficult to determine the start of the dying process - perhaps that is why there is no formal definition of “dying” - but we can think of it as beginning when a life-threatening disease can be neither cured nor controlled by active treatment. A real-life example may help. The physicist Stephen Hawking has suffered from a life-threatening disease for many years. He is dependent on others for all his basic care needs, and his disease is incurable and progressive. However, with active treatment (wheelchair, artificial voice, tracheostomy etc) the effects of the disease have been controlled and, at the time of writing, he is clearly not dying - though that will inevitably come.

2) Helps/hindrances: Many things can affect our approach to and progress along life’s last journey. I have chosen four, and titled them “helps/hindrances” (not helps and hindrances) because each of these things can work either positively or negatively for us on our last journey. The four items are: biomedical ethics, world-view(s), character(s) and medical processes. The middle two have been written as potentially plural because it is not just our world-view and character that matters - the world-views and characters of our doctors and (potentially) our surrogate decision-makers can and do interact repeatedly with ours during that last journey.

a) Biomedical ethics: Apart from a few rogue examples, all health care professionals seek to act ethically. The problem is that there is no single ethical system that they all can follow, and all approaches to ethics have their limitations. For example, when I was in training, most doctors were paternalistic - the doctor was the professional who knew best, and the patient was expected to just accept their decisions. While a certain amount of paternalism is OK (it is, after all, how we bring up our children), strong paternalism in health care is now generally viewed as inappropriate. Again, some doctors have such a strong sense of duty that they feel obligated to do “everything” for their patients - which is fine, except that in modern medicine there is always something more that can be done, even if it will not usefully affect the outcome. Still others are consequentialists, concerned primarily about achieving the best outcome. The problem here is to define what the best outcome might be - is it the best outcome for the patient, the doctor, the family, or even a third party (in the case of solid organ transplantation)? And since multiple people are involved, how does one balance their respective inputs?

To avoid the pitfalls of single ethical systems, an approach to medical ethics called “principlism” (because it involves multiple ethical principles) has been developed recently and is now widely taught. It is illustrated below:



In this ethical system clinical decisions should be made by satisfying all four of the principles simultaneously. “Autonomy” is literally “self-rule”. That does not mean that the patient is now in the driving seat (that would effectively be just the reverse of paternalism). Rather, autonomy refers to

treating the patient as an individual with rights, values, hopes and fears, thereby encouraging their active involvement both in decision-making and in the treatment process itself. Should the patient not be able to participate, a substitute decision-maker is identified to act on behalf of the patient (more on that later). “Justice” refers to doing what is right and proper for the patient as an individual, but, also doing what is legally and morally right by society at large. “Beneficence” refers to the duty to do only what is in the best interest of the patient, while “non-maleficence” means the duty to do no harm - and remember, benefits and harms involve more than just medical matters. To show how all four of the principles interact together consider the example of blood transfusion. Although widely used, for a Jehovah’s Witness to receive blood would cut them off from their faith community and violate their world-view - both of which are “harms” and would therefore negate the principle of non-maleficence. Furthermore, to give blood to such a patient without their express permission would not only fail to protect their best interests, thereby causing harm, but would also violate their autonomy, and (being illegal) would also be unjust. Note that in this example none of the harms and benefits are direct medical matters but involve much wider aspects of life.

b) World-views: The example above illustrates how world-views can affect even day-to-day medical decisions, let alone our approach to life’s final journey. Arguably the two most common world-views in our society are those of the Christian and the secular humanist. The two quotations below contrast these two perspectives on life and death. Sir Bertrand Russell (a philosopher admired by Richard Dawkins) wrote the following in a work entitled “A free man’s worship” (1903): *“Brief and powerless is man’s life; on him and all his race the slow, sure doom falls pitiless and dark. Blind to good and evil, reckless of destruction, omnipotent matter rolls on its relentless way. For man, condemned today to lose his dearest, tomorrow himself to pass into the realm of darkness, it remains only to cherish, ere yet the blow fall, the lofty thoughts that ennoble his little day.”*

Contrast that quotation with these words from the Bible (Psalm 23): *“Though I walk through the valley of the shadow of death, I will fear no evil, for you (God) are with me.”* It hardly needs to be said that those who hold such views will have dramatically different approaches to dying and death. From my 32 years as an intensive care doctor, I am very much aware that world-views do indeed matter during life’s last journey. I also recognize that in our pluralist society there exist not only many world-views, but many variants within each of those world-views. That being so, it is important that each of us can articulate our world-view - not simply the category to which we assign ourselves (Christian, Muslim, atheist etc), but the ideas and ideals that we actually live by. Only then will we be able to assess the influence that our world-view actually has on our approach to the last journey.

But our own world-view is not the only one that influences the journey. The perspectives of healthcare workers, family members and surrogate decision-makers can all come into play at various times, but should not override our own (since that would violate our autonomy). But, as previously noted, our own world-view cannot even be considered unless we first define it and then make it known to family and friends - and our doctors.

c) Character: Anyone who has been a doctor for any length of time will have seen patients who managed to stay alive against the odds to fulfill a particular goal (like seeing their newborn child), while others have just faded away when there was no obvious medical reason for them to do so. Like our world-view, our character not only affects the way we live, but will also influence the way we deal with serious illness and approaching death. We may not be able to change our character, but we should at least recognize its potential influence on our last journey. And again, as with world-views, our own character interplays with the characters of others who are involved in our journey. A doctor who is competitive by nature, and who sees disease as a challenge and death as a personal failure, is likely to approach life-threatening illness very differently from a doctor who is pessimistic about “heroics” and does not like to put patients through difficult treatments with a limited prospect of success.

d) Medical processes: Our healthcare system is focussed on acute care, specifically the delivery of safe and efficient curative treatments. Much of the activity within this system is governed

by prescribed pathways and published guidelines which tend to be followed almost automatically. That works well most of the time, but for the elderly (and for anyone with a chronic disease) it may not always work to their advantage. Excellent protocols for, say, prevention of heart attacks and strokes in younger people may not apply, or at least may need to be modified, in the elderly - particularly in those with chronic or life-threatening disease. Similarly, interventions that would be automatically provided to a younger person in an acute situation may not be appropriate for those approaching, or on, their last journey. Sometimes, medical protocols may be initiated without proper thought, and, once initiated, that protocol is then often followed to the letter although that may not be in the best interests of the patient. I call this the “medical juggernaut” - it just keeps rolling on. This pattern of thought and activity can occur anywhere, even in the best intensive care units. One of the inputs that I most valued from our nurses on ward rounds was the question “what are we achieving here?” It often led to a more realistic assessment of treatment goals and to a re-evaluation with the family of what was really best for the patient.

3) Preparing for the journey: None of us know when and how our lives will end, nor can we predict the path our last journey will take. However, despite all the uncertainties, it is both possible and advisable to make preparations ahead of time for that journey. Failure to consider end-of-life matters ahead of time can lead to significant complications and difficulties at what is, by definition, a very difficult time for both the dying patient and their family. On the other hand, proper preparation not only provides more solid ground for decision-making at the end of life, but can also help to resolve differences of opinion which may emerge among family members at this distressing time. Several components of preparing for the last journey will be dealt with below.

4) Preparing for sudden events: By definition, sudden death, or an illness or accident that leads to permanent disability, can happen to anyone at any time. Any preparation for such events must therefore be made ahead of time, which generally means while there are no serious health issues on the horizon. It is always wise to ensure that those who will be most affected by a sudden event are protected as much as possible (remembering that death is not the only bad outcome from a sudden event - some people are left permanently unable to work, severely brain-damaged, or even in prolonged coma). So what to do? Here are some suggestions:

a) On the practical side, regularly review and update arrangements such as wills, critical illness coverage and life/mortgage insurance.

b) On the philosophical side, explore with family (and/or close friends) the vision and values that might influence your approach to matters such as death, prolonged coma, permanent disability (both mental and physical), cardiopulmonary resuscitation (CPR) and solid organ or tissue donation. It is wise to repeat this process whenever your life situation changes (for example, with marriage, children, retirement etc).

c) On the legal side, consider crystallizing the above discussions in a Personal Directive as described in Section 6. Anyone in Alberta over the age of 18 can make such a directive.

d) On the personal side, don't let discussion of these matters decrease your enjoyment of life. Sudden events are not common, so making the preparations described above should not lead anyone to join the ranks of the “worried well”.

5) Preparing for loss of capacity: At the core of medical treatment in our society is the concept of consent. All treatment, whether active or palliative, requires the express consent of the patient. However, for consent to be valid it must be given without any kind of coercion, and must be “informed”. Clearly, simply providing information is, in itself, insufficient. The patient must be able to understand the information given, and must be able to retain it and then use it to assess the possible consequences of the decision(s) they make (including that of refusing to make a decision). Most patients easily meet these standards and so are said to have the “capacity” to make decisions for

themselves. On the other hand, “capacity “ is not present if the patient is comatose, or suffering from delirium, dementia or other significant brain damage, or is impaired by drugs (including therapeutic agents) or alcohol. Loss of capacity may be temporary or permanent, and the former is quite common in the setting of accidents and acute illness. When a patient without capacity presents in an emergency situation and no family can be found, the doctors simply act to save life or limb on the basis of the information they have. In a non-emergency situation, the closest family member is identified and can consent on behalf of the patient until they regain capacity (a lot of Intensive care patients are managed this way).

In Alberta, family members acting in this way are called “specific decision-makers”, and ideally, the decisions they make should be “substituted judgments”. That is, they should make each decision on the basis of what they believe the patient would have decided for themselves if they had not lost capacity. However, if the specific decision-maker does not know what the patient would have wanted (either because they have not been in recent close contact, or because such matters have not been talked over), then the specific decision-maker must work together with the doctors to make a “best interests” judgement on behalf of the patient - that is, they work out what most people with capacity would choose to do in such circumstances, and, taking into account any specific information they have about the patient, make a decision on that basis. If no specific decision-maker can be identified, then the Office of the Public Guardian will become involved. It is obvious that decision-making becomes increasingly remote from the patient’s own wishes at each level of this process. Furthermore, the specific decision-maker process is only allowed for temporary loss of capacity. If that state should become long-term or permanent then application must be made to the Court to appoint a guardian (which takes at least 2 months) unless the patient has previously appointed an agent to act for them - but becoming an agent/guardian only applies to health-related matters, not to financial affairs - for those a trustee needs to be appointed. The other concerning aspect of all this is that the government website states that specific decision-makers cannot act for the patient on end-of-life matters or tissue/organ transplantation (although I understand that this rule is not always followed). The only way to avoid such complications occurring at the end of life or when long-term loss of capacity has arisen is to have a personal directive in place.

6) Preparing a personal directive: Personal directives can ONLY be prepared while one still has capacity. Although it is helpful to have legal involvement in this process, as with making a will, this is not essential. Even with a lawyer involved, the directive should state plainly and unambiguously your perspectives towards death, dying, CPR and the use of life-support systems, as well as your approach to organ and tissue donation. Each of us has certain situations and outcomes that we would not wish to occur (e.g., the persistent vegetative state, or receiving CPR when we are suffering from an irreversible disease process) and the directive should clearly identify our preferred approach to such matters. The directive will also identify one or more people who will act as “agent(s)” in the event that capacity is lost, either temporarily or permanently. While an agent is normally a close family member, it does not have to be, and can be anyone you choose. The choice of agent is extremely important - your agent(s) must not only be aware of your perspectives on life and your hopes and wishes with regard to death and dying, but they must be prepared act on your behalf by following the personal directive, even if they would make different choices for themselves. It should be straightforward for the medical staff to contact your agent(s) when needed, and it is best if agents do not live on the other side of the world so that they can quickly come to your bedside when needed.

Remember to update your personal directive whenever there is a change in your circumstances, state of health or the way you think about end-of-life issues. Since a personal directive deals only with health issues, to ensure that there is minimal disruption to your financial affairs due to a capacity-losing illness, it is wise to consider appointing a trustee to deal with financial matters in addition to your agent(s) for health matters. It is also worthwhile to register your directive with the Office of the Public Guardian. This is not mandatory, but does allow the medical team to

easily find out if you have drawn up a personal directive. The Office of the Public Guardian does not receive or keep a copy of your directive - it simply records that a personal directive exists for you. Whether or not you choose to register your directive, it should not be kept out of sight. The agent(s) should have a copy, as should your lawyer, and if any health issues should arise it is wise to discuss the contents of the directive with your doctor(s) and to give them a copy too. In a situation where capacity is lost and the agent is called into action, they should bring a copy of the directive with them to give to the medical team. It is also wise to ensure that other family members (who are very likely to be involved with your agent in any serious discussions arising from a capacity-losing illness) are also aware of the reasoning behind the contents of the directive. This reduces the likelihood of conflicts and misunderstandings later on. However, in the end, it is the agent who must take sole responsibility for making decisions on your behalf, based on the directive.

7) Adapting to chronic illness: The onset of a chronic, potentially life-limiting, illness is a game-changer. We normally anticipate that treatment of our acute illnesses will lead to cure and recovery. However, by definition, chronic diseases cannot be cured and are often progressive. That said, with modern medicine, many chronic diseases can be well-controlled for a long time, and it is quite common for people with a chronic disease to die with it, not of it. So, while not a cause for despair, it still must be recognized that the onset of a chronic disease will not only change our overall state of health (and our travel insurance premiums), but is also likely to increase our susceptibility to other medical problems and reduce our ability to recover from them. Furthermore, its rate of progression cannot be accurately predicted (to go back to Stephen Hawking, the average survival time for patients with ALS - Lou Gehrig's disease - is 2 years. He has survived nearly 4 decades!). Although the principles for coping with a chronic disease are not different from the principles governing any medical care, the situation and its implications require a somewhat different approach simply because the disease isn't going to go away. The differences are nicely set out in an editorial in the British Medical Journal by Holman and Lorig of Stanford University: *"When acute disease was the primary cause of illness, patients were generally inexperienced and passive recipients of medical care. However, with a chronic disease the patient must become a partner in the process, contributing at almost every decision or action level. This is not just because patients deserve to be partners in their own health care (which, of course, they do) but also because health care can be delivered more effectively and efficiently if patients are full partners in the process. - - - - With chronic disease, the patient's life is irreversibly changed. Neither the disease nor its consequences are static. They interact to create illness patterns requiring continuous and complex management. Furthermore, variations in patterns of illness and treatments with uncertain outcomes create uncertainty about prognosis. The key to effective management is understanding the different trends in the illness patterns and their pace. The goal is not cure but maintenance of pleasurable and independent living."* That last sentence is of key importance. The authors then go on to say that the patient is more aware of trends in the disease's process than their doctors so that the patient can *"provide information and preferences that are complementary to the doctor's professional knowledge. In general, the patient provides the individual information and the doctor the general information, and both are necessary for effective management"*. So, with all that in mind, how can we set about achieving it?

a) Learn how the system works: In particular, become familiar with your rights in our healthcare system - you may at some point need to insist on them. For example, as a patient you are entitled to access "reasonable" health care (although what is "reasonable" is often politically determined). Other rights include the right to receive full information presented in an understandable manner (I once heard a treatment described as "having a 20% chance of producing a meaningful improvement" - a statement which I do not consider to be helpful or understandable), the right to request a second opinion should it become necessary and the right to have nothing done to you without your full and informed consent (except in an emergency, for a doctor to proceed without consent constitutes an assault). Patients also have the right to refuse any or all treatment for whatever reason (we once had

a patient who refused blood transfusion - and the reason given was that blood was red!). It should be noted that the right to demand a specific treatment does not exist.

b) Get as much information as you need: It is important that you understand both your disease and the management plan. Your doctor is a good person to begin with, but remember that family doctors need to know a good deal about a wide range of diseases, but are not usually familiar with the minutiae involved in managing specific chronic diseases. Getting referred to a specialist in your particular disease is very helpful, even if you only see them once or twice a year. Many specialized clinics have nurse specialists, dietitians and other professionals who are knowledgeable and skilled in giving advice - and because they specialize in one condition, their practical knowledge and understanding are invaluable. Many chronic diseases have national societies devoted to providing information about, and supporting patients with, their specific disease. It is well worth connecting with them. Local patient support groups not only provide useful help and advice, but are a great source of mutual support for fellow-sufferers. And after all that, there is the internet - but use it with caution since there is a lot out there that is biased, commercially-driven and misleading. Be particularly careful with websites promoting a special cure that no-one else is using and which promises remarkable results - always remember, if the treatment was really that good, it would be widely available.

c) Maximize the benefit of visits to your doctor(s): All doctors work under considerable time pressures, but the overwhelming majority are very concerned about doing the best they can for their patients. You can help them out by preparing beforehand. Are there any changes or problems that you want to report to the doctor? Are you experiencing any new or worsening side effects from your treatment(s)? Do you have questions about managing your disease? Write them down before your visit and make sure that you get an answer to them. It also help to remember that even routine visits to the doctor can be emotionally charged encounters, and patients often very quickly forget what has been told them. With your doctor's permission, write down what you hear so that you can refer back to it and use it later on. Another way of dealing with that is to take someone with you into the interview room. Having someone with you is particularly important if the visit is to discuss future plans or to receive the result of special tests, especially if you fear what the results might show. Not only will the other person be able to support you if the news is bad, but a second pair of ears will help to ensure that the message is correctly received, and that there is no misunderstanding of what the doctor is saying. Should you still have capacity, but think it would be helpful to have support when making medical decisions, it is possible in Alberta to identify either a "supported decision-maker" (who can accompany you and advise you, but does not participate in the consent process) or a "co-decision-maker" (who will make decisions with you - not for you - and must co-sign any consent forms). Neither of these options is necessary if you have already appointed an agent in a personal directive.

d) Start thinking about the future: It is quite likely that your doctor will initiate discussions about disease progression and its implications, about the complications of treatment and about end-of-life issues. If your doctor does not do so, then you should consider starting these conversations. Early on in the disease process there may be only minimal interference with your daily life, but, should the disease progress, life may become more restricted - things that you could do previously may eventually become impracticable. So the onset of chronic illness is definitely a time to review and prioritize one's bucket list. It is also time to review your financial affairs, your will and your personal directive. It is definitely time to prepare one if that has not already been done. You may find that the onset of chronic illness results in some changes in your thinking about death and dying. For example, many patients who until that point would have definitely wanted CPR in the event of a cardiac arrest may begin to wonder about the wisdom of being brought back only to face progression of their illness. Others who previously may have decided for full life-support in the event of a major illness may now wish to put some limits on such interventions. And, once reviewed, these matters should be discussed with family, close friends and the medical team(s). It advisable for such reviews

and discussions to take place as needed during a chronic illness to ensure that your most up-to-date thoughts and wishes are widely known should you ever lose capacity. Interestingly, such discussions, once initiated, often prove not to be as morbid or intimidating as one might expect, and they have enormous value in helping to remove some of the misunderstandings and uncertainties that often occur at the end of life when these issues have not been faced or talked about.

e) Live life as fully as possible: As quoted above, “the goal is not cure but maintenance of pleasurable and independent living.” Whatever one’s underlying character, in dealing with a chronic illness it is better to see the glass as half full, rather than half empty. Activities may well become more limited, but it is better always to seek to maximize opportunities, rather than to withdraw from life and to focus only on what has been lost. It is surprising how fulfilling life can be even with significant disability, particularly if one is willing to accept and use all the supports (physical, mental and social) that are now available. For example, if the use of a cane, a walker, a mobility cart or even a wheelchair will enable you to get out and about, that is far better than remaining housebound. Some good advice I have heard some doctors give their patients when a chronic disease has been diagnosed is to “live your life” - that is to say, one should aim to adapt to one’s disease only as far as is necessary, and avoid as far as possible being defined or controlled by it.

f) Regularly review how things are going: For a general overview, consider your progress in relation to the ethical screen (described in section 2 above), with special emphasis on the beneficence and non-maleficence components. With your doctor, review the progress of your disease and its treatment. You should be aware what each medication/treatment is for, and what is expected from it, not only in terms of benefits but also possible adverse effects. Each component of your treatment plan should be reviewed to ensure that it is producing benefit and that any side-effects are acceptable and manageable. If not, consideration should be given to changing or stopping it. It is also worth ensuring that all your medications are really necessary. It is easy, particularly in the context of chronic illness, for multiple medications to be prescribed, with some medications being given to prevent or treat the side effects of others. While an ideal treatment would be universally effective without producing any ill-effects, in reality no medical treatment is always effective, and all have some adverse effects. So, for each component of treatment, the burning questions are: a) is it working (by reversing or controlling the disease process)? and b) is it doing so without producing unacceptable side-effects? The balance between these two factors is measured by the cost-benefit ratio - generally the smaller this number the better (that is, the benefit should be much larger than the adverse effects). It is always important for this ratio to be taken into account, but particularly so with chronic diseases, or at the end of life. So there will be more on this in the next section.

8) The last phase of the journey - dying: Sometimes death comes suddenly, or a severe illness is attended by early loss of capacity. In those situations one’s relatives and carers can only be guided in their decision-making by the clinical circumstances and by their own intuition unless proper preparations have been made beforehand, particularly through a personal directive. For most people though, death is neither sudden nor accompanied by loss of capacity, except at the very end. For most of us, then, the issues will be how to navigate our last journey more smoothly, and how to maximize the benefit of the life we have left.

a) Getting started: As described above, the journey begins when a mutual decision is made by both doctor and patient that active treatment is no longer beneficial, because it can neither reverse or control the disease process. (In some cases that decision is provoked by the patient deciding that the cost-benefit ratio of further treatment is too high. One patient I remember had received several courses of chemotherapy for cancer in the past with bad and persistent side-effects. So, when the cancer recurred, she refused all further chemotherapy even though her doctors strongly recommended it. Although her disease was not immediately life-threatening, that decision set her on the pathway that eventually led to her death.) Unfortunately, one of the major problems at the start of

the last journey is an unwillingness to accept the reality of the situation. This can be an issue for any or all parties involved - the doctors, the patient and the family. No patient wants to hear bad news, and no doctor enjoys giving it, but if the situation is irremediable, or is heading that way, it is important for the facts to be brought forward and discussed openly. Without that information, no proper planning can be put in place. For those with a chronic or severe illness, it is wise early on to make it clear to your doctors that you wish to be kept fully informed, even when the news is not good.

b) Get the information you need to guide decision-making: To properly navigate the last journey, you and your family need to understand why the situation is now irremediable and the likely ways in which the disease process will unfold. Remember that doctors can only give general information in answer to your questions, based on their experience and the medical literature. Such information is often presented proportionally (“most people”) or as a percentage, but it is completely impossible for doctors to predict whether you will prove to be an “average” case or not. Even if a particular event occurs in the majority of patients, it may not happen to you, and, equally, although something may occur only rarely, that does not mean that it will not happen to you. It is particularly important to remember that estimates of survival time are notoriously unreliable (and cannot be anything else).

c) Re-examine your thinking about end-of-life issues: It is important to define what is really important to you at this stage of life and what your hopes and wishes are in relation to relevant medical and non-medical matters. Medically this includes issues such as cardiopulmonary resuscitation (CPR), the use and withdrawal of life-support (for example, artificial ventilation or kidney dialysis) and transplantation. Non-medical aspects might include your financial arrangements, your will, where you would ideally wish to be when life ends (recognizing that it may prove impossible to fulfill those wishes), and your preferred funeral arrangements. How these matters are dealt with will vary according to your circumstances, worldview and personality. With regard to transplantation, although organ donation has generally been confined to younger people, the focus is currently turning more towards the function of the organ, rather than just the chronological age of the donor. However, even if organ donation is precluded by your age, a wide range of tissue donation options (bone, skin, corneas etc) remain, even for older patients. As a final thought on this section, it is worth recognizing that end-of-life issues look very different while one is younger and in good health (and the issues seem remote and hypothetical), than when the end is actually in view and perhaps some serious symptoms are already being experienced.

d) Involve those around you: This has been a recurring theme, but the last journey is definitely not the time to keep things to yourself. This journey cannot be successfully navigated without the help and support of others, and they, in turn, cannot play their part to the full unless they are, and remain, actively involved in discussions, planning and decisions. The immediate family, close friends, and especially the agent named in one’s personal directive should all be kept in the loop at all stages. The journey becomes much more difficult when understanding, expectations and goals differ between the involved parties. Doctors and other carers also need to be aware of at least the major elements of your plans, otherwise they will not be able to act in accordance with your wishes - so make sure that your personal directive is not hidden in some lawyer’s safe, but that copies are given to your next of kin/agent and are filed (and flagged) in your patient record(s). If changes are made as time goes on, make sure all relevant parties know about them. My experience in the ICU interview room confirms that wide and free discussions beforehand can avoid uncertainty, confrontation and controversy and lead to a much better outcome for everybody.

e) Regularly review all treatments: As noted above, at the end of life treatment should be directed solely to the well-being and comfort of the patient. Only those treatments that directly contribute to effective symptom relief should be continued or introduced, and a careful cost-benefit analysis should be made for each continuing or new treatment. During active treatment even major and unpleasant side effects may be acceptable because the intended benefit is a cure (think chemotherapy), but at the end of life, any side effects that reduce your state of well-being are

counter-productive. Obviously, preventative treatments (statins for example) become irrelevant at the end of life, although it may be advisable to continue some pre-existing medications (for example, anti-depressants). Even if they are no longer considered necessary at the end of life, some pre-existing medications cannot be stopped abruptly without causing unpleasant symptoms and so may need to be continued. However, the general principles should be to minimize medication, to define the specific benefit expected from each medication, to have a very low tolerance for adverse effects and to quickly discontinue or change any treatment that is not producing measurable benefit or is causing unwanted effects.

f) Make early contact with the palliative care team: The optimal time for the referral will be decided in consultation with your doctor(s), but, in general it is better to know, and be known by, the palliative care team before an urgent need arises. Palliative care medicine arose out of the hospice movement and is now a recognized medical specialty in Canada. It is practiced, not just in hospices, but in hospitals and in the community as well. Its role is “to enable those suffering from terminal illness to live as fully as possible up to the end of life, and to assist them and their families to realize, as far as possible, their end-of-life goals and wishes.” On the purely medical side, palliative care is focussed on the relief and control of symptoms such as pain, nausea, shortness of breath etc. But it is much broader than that and includes psychological, social/family, emotional and spiritual support as well - in fact anything that makes the last journey easier. The help of the palliative care team is often invaluable.

(NOTE: The statement in quotation marks in the last paragraph is taken from the founding objects of a local charity that will hopefully be incorporated later in 2015 and whose eventual goal is to build and operate a palliative care centre in Canmore to serve the whole Bow Valley. At present palliative care resources in the Valley are largely limited to community care, supported by two dedicated beds in each of the local hospitals - anyone who needs hospice care must travel to Calgary.)

Useful resource: The Alberta Human Services website (humanservices.alberta.ca) provides good information and useful links. On the website under “Programs and Services” there is a section on “Personal Matters” which deals with personal directives and other supports for medical decision-making, while under “Financial Matters” there is information on trustees.