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In this issue

Last year, when the Italian Parliament was considering whether the Italian people would be well-served by a law authorizing the use of advance care plans, the Senate held a two day conference on the matter. Amongst the mostly Italian speakers were three speakers whose presentations formed a coherent whole:

- Professor Daniel Sulmasy of St Vincent's in Manhattan argued that advance care plans (or 'advance directives') should be seen as an extension of the tradition of forgoing extraordinary means of care.
- Dr Bernadette Tobin of St Vincent's in Sydney argued that one form of advance care plan (the appointment – in advance – of someone to represent a patient if circumstances should arise in which medical decisions have to be made but the patient can no longer think or communicate) should be seen as better than another form of advance care plan (a piece of paper, or 'living will' on which a patient sets out in advance which treatments she would accept and which she would refuse).
- Professor Nancy Dubler of Montefiore Medical Centre in the Bronx argued that hospitals and nursing homes will need to develop new habits and practices if they are properly to respond to the people who have been appointed by patients as their representatives.

In this issue, we present Dr Sulmasy's paper in full. The other two papers will appear in forthcoming issues of *Bioethics Outlook*. Daniel Sulmasy is a Franciscan Friar and a medical doctor with a PhD in philosophy. He holds the John Conley Chair in Medical Ethics at St Vincent's Hospital in Manhattan (where he also practices as an internal medicine physician) and is also on the staff of New York Medical College.

'Advance Directives' as an extension of the tradition of forgoing extraordinary means of care

Daniel P. Sulmasy, OFM, MD, PhD

Advance directives are an extension of the moral tradition of forgoing extraordinary means of care. They have nothing to do with debates about euthanasia. Extraordinary means are optional means. Treatments become extraordinary if they are futile or if the burdens outweigh the benefits. By tradition, the person who judges an intervention extraordinary is the patient, not the doctor. If the patient is unable to speak, the family has traditionally decided. The term *mezzi straordinari* is preferable to *accanimento terapeutico*. The latter is a non-traditional term, translated from the French *acharnement thérapeutique*, introduced into Italian in 1985. *Accanimento* linguistically distorts the tradition and narrows choices that traditionally have been open to patients and families. Advance directives are useful instruments for re-asserting traditional moral approaches to the forgoing of extraordinary means. With so much new technology, there are innumerable decisions to be made for patients who cannot speak for themselves. Advance directives, especially health care proxies, are an aid to families and friends who, in conjunction with physicians, must make these difficult decisions for their loved ones. This intervention will end with a description of two cases illustrating the clinical usefulness of advance directives— one involving a ventilator for a brain damaged homeless person and the other the use of a feeding tube in a patient at the very terminal stages of Alzheimer disease.

The three central points I will make are these: First, advance directives are not a revolutionary idea. They are an extension of a centuries-old tradition of forgoing extraordinary means of care. Second, it is also vital to separate any debate about advance directives from the debate about euthanasia. Divisions over this latter question should not be allowed to prevent a legislative consensus about advance directives. Third, advance directives, although not a panacea, can be very helpful in making health care decisions regarding the end of life.

Advance directives should be viewed as useful tools in a larger project to help patients, families, and physicians make good decisions at the end of life. They fit squarely within the tradition of forgoing extraordinary means of care. This tradition springs from four principles.

The first principle is the dignity of the person. Each human being, by virtue of the mere fact of being human, has an intrinsic value we call dignity. This is the fundamental principle of all interpersonal morality. Medicine reaches out to the sick first and foremost because each has an intrinsic dignity that must always be respected.

The second principle is the *prima facie* duty to preserve life. This springs from several sources. The most obvious is self-interest. Yet we also have duties of gratitude for the gift of life—at least to our parents and their forebears if not to a God. Last, our duty to preserve life must also take account of our roles and responsibilities towards others.

The third principle is the fact of finitude. We human beings are finite—morally, intellectually, and physically. We get sick and die. Medicine is an imperfect art as well, and ultimately all patients die. And our individual and collective resources are finite—physically, psychologically, socially, economically, and morally. The fact of finitude constitutes the limits on the *prima facie* duty to preserve life.

The fourth principle is the diversity of the human. We are each unique. For example, we react to medication differently. We are also all different psychologically, socially, economically, and morally. Every physician knows that Aristotle was right when he said that physicians do not treat humankind in general, but Socrates, or Callius, or some other individual who happens to be sick. Each case is unique.

The tradition of forgoing extraordinary means of care is based upon these principles. Traditionally, therefore, suicide and euthanasia are considered immoral. These acts have been understood to violate both the dignity of the person and to undermine the duty to preserve life, which is certainly limited, but can never be made consistent with an intention to eliminate life.

I recognize that some disagree. But I would underscore that if anyone is serious about having advance directive legislation in Italy, that legislation must distance itself from the question of euthanasia. We should all agree about advance directives even if we disagree about euthanasia. In fact, most advance directive laws in the United States explicitly state that the statute is not to be construed as condoning, aiding, or permitting euthanasia,

assisted suicide, or other acts that are considered illegal elsewhere in the legal code. If you want an advance directive law to pass, it might be wise to include such language.

Despite the traditional prohibition of euthanasia, however, Western moral thinking has always recognized the fact of finitude. The duty to preserve life is limited. The Hippocratic Oath does not say to keep treating patients to the bitter end, but to use medicine for the benefit of the sick, keeping them from harm. Elsewhere Hippocrates urges physicians not to treat those who are overmastered by disease, recognizing that in such cases medicine is powerless. Today, we must recognize that even with the most sophisticated technology we cannot keep all patients alive forever. The function of medicine is not to relieve the human condition of the human condition.

It is from these principles, simultaneously affirming the dignity of the human person and recognizing our finitude, that the moral tradition of forgoing extraordinary means of care arose. In a general sense, to say that an intervention is extraordinary means that it is optional—that one need not use it. Extraordinary is used here as a technical term meaning non-obligatory. Do not be confused by the use of the words 'ordinary' and 'extraordinary' in everyday speech. In a technical, moral sense, ordinary means obligatory and extraordinary means optional. By tradition, an intervention is deemed extraordinary if it is futile (i.e., if it will not work; will not cure the patient, reverse the condition, or appreciably forestall an imminent death), or if the burdens imposed by the initiation or continuation of the intervention (physically, psychologically, socially, economically, morally,

and spiritually), outweigh the benefits of continuing the intervention. By tradition, one does not focus on the intervention itself, *a priori*, divorced from a case, but on the use of an intervention in a particular case. Here we see the importance of the principle of diversity. Each case is different. Hence, one can never say, this treatment is always ordinary or that treatment is always extraordinary. These judgments always depend upon the circumstances. So, for example, one can never say "ventilators are extraordinary and antibiotics are ordinary." If any of you were to have a ruptured appendix, right now, requiring surgery, physicians would anesthetize you, paralyze you, and put you on a ventilator before operating. Your duty to preserve your life and the great benefits of being on a ventilator would suggest, *ceteris paribus*, that a ventilator would be ordinary for you in such circumstances. But think about the case of a ventilator for a woman dying of cancer of the esophagus, in great pain, who develops pneumonia and has trouble breathing. Assuming she had been through multiple courses of surgery, radiation, and chemotherapy with no cancer treatments left to try, going on a ventilator might be simply futile for her—it would not cure her and might not appreciably forestall an imminent death. Even if not futile, the burdens could certainly be judged to outweigh the benefits and so the very same machine, a ventilator, would be extraordinary for her in her circumstances even though it would be ordinary for you in your circumstances.

To be sure this point is clear, consider another treatment—antibiotics. If any of you were to catch pneumonia right now, antibiotics would be medically indicated. Since the benefits are

so great compared with the burdens, *ceteris paribus*, these would be ordinary care and you would have a moral duty to take them. Yet consider again the woman with cancer of the esophagus. If the cancer had eaten a hole from the foodpipe to the windpipe, such that stomach juices were now flowing into the lung, and this were to cause pneumonia, would she be required to take antibiotics? I suspect you all agree that the answer is no—her duty to preserve her life is finite. Although antibiotics are often cheap and simple to take, since antibiotics would preserve her life perhaps a few hours at most, in this case even the burden of being stuck with a needle could be judged to outweigh the benefits. In such circumstances, antibiotics are extraordinary or morally optional. So, to repeat, the judgment always depends on the individual case. No intervention can be judged ordinary or extraordinary apart from the circumstances.

What interventions can be considered extraordinary? Any life-sustaining intervention, in the right circumstances, can be considered extraordinary. The list is not even limited to traditionally medical interventions. Centuries ago, when medicine could do very little, moralists were asked whether a patient would be required to follow medical advice to eat partridges or to leave Sicily for the Alps. These wise moralists said these interventions could be considered extraordinary. If the patient could not afford partridges, chicken would do. If moving to the Alps would isolate the patient from his family and leave his wife and children penniless, he could stay home and accept death. These interventions could be considered extraordinary or morally optional. Even fear of the state in which one would be left by a treatment could render a treatment

extraordinary. So, a monk who was not so much troubled by the pain of amputation as he was horrified by the possibility of life as an amputee could licitly refuse amputation as an extraordinary means. His abbot could not force him.

You will notice that I have been consistently using the term “extraordinary means” and not the term *accanimento terapeutico* (“therapeutic fury”). That has been very deliberate on my part. Please allow me to make an important digression regarding the difference between these terms. Sometimes it helps to have the perspective of a foreigner to point out very subtle linguistic turns that may be unapparent to native speakers who are immersed in a linguistic world, and how the words people use can very subtly shift their thinking. The term “therapeutic fury” is a recent addition to the Italian moral lexicon. It is not used in other languages such as German, English, or Spanish. As I understand it, this phrase entered Italian from the French *acharnement thérapeutique* in the 1980s. It is attributed to the French author, Patrick Vespieren, whose work was translated into Italian as *Eutanasia?: Dall'accanimento terapeutico all'accompagnamento dei morenti* in 1985. It is uncertain why this became popular so quickly, but this is the phrase now most commonly used in contemporary Italian.

Note, however, that *accanimento terapeutico* really does not fit well with the tradition as I have described it. Perhaps *entusiasmo* would have been a better translation from the French, but both the French *acharnement* and the Italian *accanimento* make some important deviations from the tradition. First,

these phrases put the emphasis on the moral responsibilities of the physician. Traditional morality, however, places the emphasis on the views of the patient, who is the one to decide what is extraordinary for him or for her.

Second, *accanimento* suggests a very high standard to be met before treatment can be stopped. *Accanimento* suggests the obstinacy of a dog, and by extension, "rabid and cruel persistence". A physician who recommends that a patient eat partridges or move to the Alps is hardly guilty of therapeutic fury! Yet eating partridges or moving to the Alps were considered extraordinary—morally optional—according to sound moral tradition and the norms of the day. The traditional way of thinking about these matters asks only whether what the patient is being asked to do, in the patient's circumstances and in the patient's judgment, is more than can be reasonably asked of a human being who has a strong (but ultimately finite) duty to preserve life. The interventions one forgoes need not be furious treatment.

Third, the phrase *accanimento terapeutico* focuses attention too much on the suffering the treatment itself is causing, rather than on the sum total of the suffering associated with continuing the treatment. Traditional morality takes account not only of the suffering caused directly by the treatment, but also the suffering caused by the underlying illness that is prolonged by the treatment; the suffering caused by the state in which the treatment will leave the patient; the effects of continuing treatment on the family and the community. The tradition includes all of these considerations and more when deciding whether a treatment is extraordinary. The

term, *accanimento terapeutico* tends to narrow the scope of what one can consider in making a decision to forgo life-sustaining treatment.

Please do not misunderstand me. I hope that you will not consider this digression yet another example of the arrogance of the hyper-power—an American who speaks Italian poorly telling Italians how to speak their own language. I offer for your consideration, however, that recent, subtle linguistic shifts in Italian have created a culture that now unnecessarily constrains possibilities for patients, families, and physicians—possibilities that were traditionally open to them in making decisions about care at the end of life. I would hope that your advance directive legislation might open some of these possibilities for the Italian people, using more appropriate terms such as *mezzi straordinari o sproporzionati*.

Advance directives help put the focus back where medicine should have its focus, where families and friends should have their focus, and where the law should have its focus—squarely on the patient.

Because, traditionally, the patient has been the one to decide whether the burdens were disproportionate to the benefits, at least within the bounds of reason and the judgment of the community. That is to say, the patient has been given wide berth in deciding what is extraordinary. The limits were always drawn very broadly, and wisely, not because of any notions of unrestrained autonomy imported from North America, but because of the fact of diversity. People do, in fact, differ. They have different pain thresholds. They react differently to the same medicine. They have

differing psychological, social, economic, moral, and spiritual resources. And no one quite understands this as well as the patient. Thus, if a patient had lymphoma, and had failed five treatments, all with terrible side-effects, and the oncologist were to offer a sixth treatment, a patient might well judge this to be too much to ask—an extraordinary treatment. Yet another, similar patient with the same lymphoma, having failed the same five treatments, although without such bad side-effects, who might be looking forward to a daughter's marriage in two months' time, might consider the treatment worthwhile. It would depend upon each of them as individuals, not upon a *priori* judgments about chemotherapy abstracted from the individual's case. The individual is almost always the best judge of his or her case.

By tradition, the only time the physician, acting unilaterally, could declare something extraordinary would be if the intervention were futile—i.e.—if it would not work. Even then, of course, the physician should speak with the patient about the goals of therapy, since futility is always relative to a goal. A ventilator might be ineffective in curing a patient but effective in keeping the patient alive long enough for a son to return from overseas to see his mother before she dies.

And according to this same tradition, if the patient becomes unable to think or communicate, treatment decisions have rested not with the physician but with the family. The traditional moral viewpoint assumed by the family was always that of the patient. "Knowing our son"; "knowing my wife"; these burdens are too great relative to the

benefits. This is natural. This is traditional. The family knows the patient better than the physician.

It is against this background that we must consider legislation about advance directives. What makes such a law a good idea? Traditional morality remains reasonable and adequate to the analytical task, but the situation in which that moral analysis takes place has changed dramatically. For many reasons, advance directives become useful instruments for carrying out traditional morality in the 21st century.

The first reason that advance directives have become useful is that so many more people now die having lost decision-making capacity. Medical successes against cancer and heart disease mean that more people live long enough to succumb to Alzheimer disease. People used to be dead in hours of septic shock. Some can now survive in intensive care units, but the price of success is that most still die, only after having spent weeks on life support, unable to speak for themselves. Studies have shown that 78-86% of decisions to attempt cardiopulmonary resuscitation are made at a time when the patient cannot participate in the decision. Therefore, there is almost a moral imperative for people, realizing that they very well might die in a state of mental incapacity and aware that each is the best judge of his or her own limits, to execute advance directives in order to assist those who will be left making decisions for them.

The second reason why advance directives are useful aids for those making traditional decisions at the end of life is that in developed nations (with the exception of the United

States) all citizens have access to advanced medical technology. Making such decisions is thus not just an issue for the wealthy.

The third reason is the power of medical technology. With so many possible treatments, studies now demonstrate that 84-89% of hospitalized patients die after a decision not to do something that could have been done. Thus, an advance directive is not an arcane abstraction. One of the burdens of medical technology that accompanies its many benefits is the burden of needing continually to decide when not to use it. Otherwise we will become prisoners of our own technology.

The fourth reason follows from the first three. Because so many decisions must be made, and made so often for people who cannot speak for themselves, a great burden falls upon loved ones. This is precisely the situation advance directives are meant to address, providing guidance and assistance to families, friends, and physicians. Studies have shown that making these decisions is exceedingly stressful for families—equivalent to the stress of having survived a house fire or other calamity. These studies also show that if the patient had filled out an advance directive, the stress levels of loved ones are significantly lower.

Fifth, increasing numbers of persons have no families to make decisions for them as they are dying. Sometimes this is caused by social ills—drug addiction, broken families, and the like. Sometimes this is because women often outlive all the persons for whom they had cared over most of their lives, dwell alone, and have no one they would trust to make decisions for them. How else are decisions to be made for such persons?

Sixth, sometimes because of these same social ills, families are often unable to agree on decisions at the end of life. The dying process sometimes simply exposes old family wounds and the result becomes, as a default, the continuation of life-sustaining treatment. That decision may not be what the patient would have wanted. It may not be what the physician thinks is in the patient's best interests. It may not be what most of the family thinks is right. But without some way short of recourse to the courts (which is always a bad idea), the treatment continues because the alternative is irreversible. Advance directives can provide a simple way of settling such disputes.

Advance directives thus provide an important opportunity for realizing the goals of the tradition of forgoing extraordinary means in the 21st century: fostering decision making by those who know and love the decisionally incapacitated patient, focused on the needs and wishes of the individual patient.

How do these instruments work in practice? As I am sure you all understand by now, there are two basic types of advance directive—the living will and the durable power of attorney for health care (or health care proxy). Briefly, the living will lists the patient's preferences for or against certain treatments at the end of life. The health care proxy names a person (and generally an alternate) to whom the physicians should turn for making medical decisions in the event that the patient is unable to do so. I will not say more at the present time. But the overwhelming preference of ethicists and clinicians is for the health care proxy. It is much easier to talk to a person who knows that patient and has been selected by the patient than to try to interpret a piece of paper.

Now, perhaps, I can illustrate how these documents work in clinical practice.

Consider the case of Mr. Q, a sixty year-old man who had been beaten and robbed 25 years ago. As he recovered from these head injuries, he regained his ability to move and speak, but he suffered from profound memory loss. He could not remember what he had eaten for breakfast if asked at lunchtime, although he remembered most of his life before his injury and understood the nature of his injury and subsequent disability. Because of his brain damage, he could not continue his job as a professor of history at the University of Montana. He had not been married. Over the ensuing years his parents, who were his caretakers, died. Sadly, he drifted to New York City and became homeless, wandering the streets, eating at soup kitchens, and sleeping in cardboard boxes over the heating grates on sidewalks next to large buildings. Four years ago, a church-affiliated agency for the homeless began to look after his needs. Gradually he grew to trust this agency enough that he agreed to accept their offer of housing in a supervised setting. During his first six weeks in this facility he seemed to fit in well. He was cheerful and could engage in polite small-talk, but never extended conversation. His greatest joy appeared to be reading the *New York Times* in its entirety every day.

Eight weeks ago, while at breakfast with several other residents in this supervised housing setting, he suddenly collapsed. His fellow residents gasped. Staff called for an ambulance and began cardiopulmonary resuscitation. However, a pulse could not be restored until he was in the emergency room. Initially, not even the functions of his

brain stem, controlling the size of his pupils and the reflexes to blink and to breathe were working. He was dependent on a ventilator. A day later he developed a fever and possible pneumonia. Gradually, his fever subsided. He remained completely unresponsive and unable to breathe enough to be free of the assistance of the ventilator. He was not brain dead, but severely damaged. He regained some function in his pupils and some ability to blink, but remained in a coma and could not be weaned from the ventilator. He has at least a 50% chance of dying, and if he does survive, the very best scenario would be the persistent vegetative state. But it takes six months of intensive support even to make that diagnosis. And it was likely that his condition would be somewhat worse than vegetative.

The cardiologists wondered whether continued intensive care was for the best. They said, "Strictly speaking, treatment is not physiologically futile since there is a real possibility of survival. But the prognosis is very poor, and if the patient does survive, it will be in a state that many people would consider profoundly burdensome." The head cardiologist knew he could not make the judgment that this was extraordinary care by himself, because that judgment would depend on the patient. Yet who could speak for the patient? He had neither family nor friends.

The ethics committee was consulted. In New York State, one needs to meet a high legal evidentiary standard to say that someone would not want to continue on a ventilator—a standard known as "clear and convincing evidence" of the patient's wishes. But Mr. Q was new to the special housing unit and as I mentioned, something of a loner. He had

spoken to no one about his wishes in such a situation. The staff of the housing unit said that they had advance directives for 80% of their clients, but that they had not yet gotten around to talking to this patient about his wishes. If they had an advance directive from Mr. Q stating that he would not wish to continue treatment under these circumstances or naming someone to speak for him who could refuse the ventilator on his behalf, it could have been discontinued in mid-February. Instead, the church-affiliated agency has filed a petition with the courts to appoint them as his medical decision makers. The outcome is unclear. It is awkward to need to go to a judge to ask such questions. In the meantime, Mr. Q still languishes on a ventilator in our intensive care unit, brain damaged twice in his life—once by thieves and now a second time by medicine, unable to find the release that most persons suspect he would want. All because he has no advance directive.

Let me illustrate with a second case to show how such directives can help.

Consider the case of Mrs. Z, a 79 year-old woman with advanced Alzheimer disease. She is blessed with a devoted husband who is still in reasonably good health at the age of 82 and has five children who care about her deeply. They have all contributed time and money and have lovingly cared for her at home. Ten years ago she filled out an advance directive naming her oldest son as her proxy.

"I know your father," she said to him. "He will have too much trouble letting go. That's why I'm picking you. If I am ever so sick that I cannot speak for myself, with no hope of recovery, I do not want any medical interventions that

would only prolong my dying process. No ventilators. No hospitals. No feeding tubes. Just call the priest and let me die in peace. If I can't pray the rosary anymore, what kind of life would that be? If I can't recognize your father, what kind of life would that be? It would be painful for him to see me so. He'd think it his duty to keep me alive, but he shouldn't think that way. None of you should have to ruin your lives to keep me going, what, for a few more months? No way. If it comes to this, let me go home to Jesus."

She repeated this conversation with her eldest son five years ago, shortly after her diagnosis, and initialed and dated the form to indicate that it still expressed her wishes. She gradually passed from being forgetful to being bed-bound. She had a urinary tract infection and was hospitalized a year ago, and was hospitalized for pneumonia six months ago. She became unable to recognize anyone in the family and began to develop bedsores. For the last 3 months, Mrs. Z has been spoon-fed by her family but now is not able to eat well even with assistance. The food sits in her mouth and she can't seem to remember how to swallow. She chokes frequently when given sips of water.

Mrs Z then develops another fever and is hospitalized with pneumonia again. Her doctor says she needs a feeding tube because she has trouble swallowing, and asks her husband for permission. He agrees, saying, "Anything that will help her." However, later that day her oldest son arrives. He learns of the plans and remembers the conversations he has had with her about such decisions. Before he is able to speak to his father about this, the gastroenterologist, the specialist who

will place the tube, appears in the room. The gastroenterologist explains that he has been asked to evaluate Mrs. Z for a feeding tube.

The husband says to him, "Wonderful—the primary doctor said this will stop her from having pneumonia and keep her alive."

The gastroenterologist then sits down with the husband and son and explains that this is probably not so. "This procedure still puts food into the stomach, which travels back up the foodpipe and can go down the windpipe and cause pneumonia again. The only way really to stop pneumonia would be to tie off her vocal cords also and have her breathe through a tube in a hole in her neck. I don't think we should do that."

"But she'll starve to death without a feeding tube, won't she, doctor?" asks the husband.

"Actually, that won't happen. She'll become dehydrated first. It is very natural. It is the way most human beings have died of chronic diseases for most of human history. You can still feed her little morsels—whatever she can take. If you feed her this will mean something to her—and she will taste the food. And you can wet her lips with ice chips and glycerine. These are very intimate and human moments. She can't understand much else right now, but such gestures will carry the meaning of love. Putting food in her stomach by continuous drip through a tube through a hole in her stomach, however, has no such interpersonal meaning. She would not even feel the sensation of satiety—the stomach never distends with a feeding tube. Food poured directly into the stomach is never tasted. And besides, her body is shutting down. She has little appetite

to begin with. In fact, data have shown that patients with Alzheimer disease who live long enough to lose the ability to eat don't seem to live any longer with a tube than without one. My advice is that you take her home."

Her eldest son then intervenes. "And you know, Papa, Mama knew how hard this would be for you. She told me she wouldn't want one of these tubes anyway. And look, she signed one of these advance directives and named me to make the decisions on her behalf—because she knew you loved her too much to be put in the position of being asked to let her go. The feeding tube is an extraordinary means of care. She told me she would not want one of these tubes—not for her sake, not for your sake, and not for our sake. Let's take her home."

"Your mama, you know, is that kind of woman. So beautiful. So loving. So many years together. OK. I see. You are right. No tube. She deserves her rest. We'll take her home."

This is traditional decision making, made easier in the 21st century by the use of advance directives. One did not need such a document in the 16th century in order to forgo a doctor's advice to move to the Alps. But to reclaim that tradition in the 21st century, the people of Italy would be well-served by legislation authorizing the use of advance directives.

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Telephone: (02) 8382 2869 Facsimile (02) 9361 email: plunkett@plunkett.acu.edu.au

Editor: Bernadette Tobin

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