CME

Creating a living will

Experience at a multilevel geriatric facility

DAN LEVITT, MS
MICHAEL GORDON, MD, FRCPC

PROBLEM How to ensure that residents of a multilevel long-term care facility are able to indicate treatment preferences for the future (when they will be unable to participate in decision making).

OBJECTIVE OF PROGRAM To review the methods used to create a "living will" document suitable for a long-term care population that can be used as a guide and template for other long-term care populations.

MAIN COMPONENTS OF THE PROGRAM The process includes gathering information, developing possible models, designing the document, the review process, and implementing the document.

CONCLUSIONS Developing a living will document is not a simple process. The design should suit the population for whom the document is developed. Primary care physicians, other health care providers, and clergy should provide input.

PROBLÈME Comment s'assurer que les pensionnaires d'un établissement de soins prolongés offrant plusieurs niveaux de services soient en mesure d'indiquer leurs préférences pour les traitements futurs (lorsqu'ils ne pourront plus participer aux décisions).

OBJECTIF DU PROGRAMME Passer en revue les méthodes utilisées pour créer un «testament biologique» applicable aux pensionnaires d'un établissement de soins prolongés et qui pourrait servir de guide et de modèle pour d'autres populations nécessitant des soins prolongés.

PRINCIPALES COMPOSANTES DU PROGRAMME Le processus comprend notamment la cueillette d'informations, l'élaboration de modèles applicables, la rédaction, la révision et la mise en application du document.

CONCLUSIONS L'élaboration d'un testament biologique n'est pas un processus simple. Sa forme doit convenir à la population à laquelle il est destiné et nécessite la contribution des médecins de première ligne, des autres intervenants et des membres du clergé.

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Mr Levitt *is Manager of Residential Services at the British Columbia Association of Community Care in Vancouver.* **Dr Gordon** *is Vice President of Medical Services and Head of Geriatrics and Internal Medicine at the Baycrest Centre for Geriatric Care, Head of the Division of Geriatrics at Mount Sinai Hospital, Member of the University of Toronto Joint Centre for Bioethics, and Professor of Medicine at the University of Toronto, Ont.*

With the advent of modern medical technology that can prolong life and postpone death, many people no longer assume that physicians always know what is in the best interest of patients.[1,2] Patients now frequently participate actively in personal health care decisions. Traditional professional attitudes are being challenged as patients exert their right to decide.[3] Patients, their families, and physicians now must decide together whether pneumonia treatment or cardiopulmonary resuscitation (CPR) should be provided during end-stage or terminal illness.[4]

As the population ages, heavy demands will be made on the health care system and more emphasis placed on advance health care directives to help avoid costly but relatively futile treatments.[5] The elderly, who are at risk of losing their ability to participate in medical decision making because of cognitive impairment, are prone to many chronic illnesses for which treatment outcomes vary greatly. Primary care physicians, because of their long-term relationships with patients, can play an important role in ensuring continuity of care and expression of treatment wishes.

The desire to maintain some personal autonomy in health care decisions is an important aspect of contemporary care planning.[6] In line with this, Toronto's Baycrest Centre for Geriatric Care made a commitment to improve access to and assistance with

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formulating and documenting personal wishes in a living will document especially developed at the Centre for its residents. This document would address secular and religious needs and be specific to the clients and programs at the Centre.[7,8]

Other documents already available were thought by the Centre's working party to be too cumbersome and detailed for Baycrest's clients and families, to have complicated formats, or to address religious choices inadequately. Although existing generic documents would be useful for many people, the working party thought a strongly ethnic or religiously affiliated facility, such as the Baycrest Centre, should custom design a document and an information and implementation program directed specifically to the needs of residents at the facility.

Process

Development and implementation of living will documents is challenging.[9-12] A multidisciplinary working party, made up of administrators, family and geriatric physicians, nurses, social workers, and clergy, examined many existing documents and determined the format most suitable for Baycrests's elderly population. The working party considered numerous living will models that allow individuals to extend their autonomous decision making into the future.[13]

The development process included presenting the living will document to community members for feedback on clarity, ease of completion, lack of ambiguity, importance of the questions, and relevance to common situations. Because of the Jewish framework of the Centre, the document was presented also to a panel of community rabbis for comment and input. Later drafts of the document were circulated to key health care professionals, and input and comments were sought from the Centre's primary care and specialist physicians, many of whom have community practices as well as their Baycrest and University of Toronto affiliations.

Types of living wills

Most living wills instruct surrogate decision makers in broad terms and express wishes to withhold or withdraw treatments in certain, often end-of-life, situations. Instructional living wills can be explicit for specific situations, and ranges of treatments often are structured as a grid. Living wills that combine checklists with alternative scenarios are sometimes confusing and too abstract for elderly patients and health care providers. So-called "values history" documents allow individuals to express personal beliefs and values in narrative form. The working party decided that, although it can help guide decision makers, the narrative form might be hard to interpret in clinical situations.

In addition to treatment instructions, living wills usually designate substitute decision makers (also known as proxies or durable power of attorney). The working party thought that this item would have the advantage of providing substitute decision makers not only for end-of-life decisions but also for decisions in a range of situations, including during temporary incapacity. The problem with designating substitute decision makers is that some individuals do not have a suitable person available or, in fact, anyone with whom they discuss their values and wishes.[14]

Baycrest Centre living will

Because Baycrest Centre's population is heterogeneous, the living will was tailored to meet diverse needs and wishes. It incorporates instruction and proxy directives; leaves room for personal wishes, beliefs, values, and spiritual consultation; and provides for organ donation (see page 2420).

Proxy directive. In this section, patients designate substitute decision makers. This is especially important if the desired decision maker is not the one designated in most consent-to-treatment legislation (spouse, child, etc). Proxies make decisions for treatments that require consent (if there are no clear instructions) and interpret treatment wishes. The instruction directive should guide proxies' decisions.

Because treatment wishes can be interpreted different ways, a dispute resolution mechanism should be established when patients name more than one proxy.[15] Options include proxies making

decisions one at a time in the order of listed authority; proxies deciding collectively and patients indicating how they want disagreements resolved (eg, eldest child has the final word); patients limiting proxies' authority only to certain decisions (eg, one proxy makes decisions about medical care and another about personal care). Patients might indicate how they want their primary care physicians to interpret treatment decisions with their proxies in cases of differences in interpretation.[16] Preferences specified in the instruction directive ideally should be discussed with proxies; unaddressed issues must be dealt with by proxies on their best understanding and with the best interests of patients in mind.

Instruction directive. In this section, residents indicate their wishes for life-maintaining treatments. Treatment options are presented along with explanations that provide a context for exploring residents' wishes and views of life and death. Discussing this section with patients provides primary care physicians with a unique opportunity to educate patients about life-sustaining treatments and how they reflect people's wishes.[17]

Options permit refusal of treatment and requests for interventions if clinical conditions warrant potentially beneficial interventions. Patients can choose to defer to their proxies for all decisions or only for certain decisions.

Religious preferences. The document contains a short section dealing with health-care–related religious preferences. This is especially important in organizing care for individuals with strong religious affiliations and preferences.

Additional instructions. The document provides space for a personal statement. In the process of completing a living will, a patient's personal values and beliefs should be discussed. Because personal values cannot always be captured as defined decisions, additional instructions should elaborate on the specific treatment options selected in the instruction directive.

This section gives primary care physicians an opportunity to open up discussion with patients. Patients have an opportunity to express their personal views on health care to their proxies, their primary care physicians, and other health care providers before critical illness and at the end of life.[18]

Procedure. During development of the document, the working party decided that the Centre's Department of Social Work should coordinate the process. During admission, social workers would inform patients and their families of a patient's right to participate in clinical decision making, including the right to accept or refuse medical treatments and the right to formulate a living will, and would provide copies of the living will document to applicants. Before admission and during patients' annual quality-of-life reviews, or at the request of residents, living wills can be modified and changes documented on health care records. Actual living wills are placed in a clearly marked section of patients' health records.

Implementation and evaluation

As part of the process of implementation, we surveyed the Centre's physicians on their knowledge of living wills; their attitudes about the importance of such documents for decision making; and their professional, ethical, and legal responses to advance instructions under various circumstances. Of the 22 (of 23) physicians who completed the survey, 14 (64%) were able to determine from the document who the substitute decision maker was and indicated that they would comply with that person's treatment decisions; three (14%) were able to determine who the substitute decision maker was but were not sure whether they would carry out the proxy's treatment directive; three (14%) were unable to identify the substitute decision maker and were also unsure whether they would accept his or her treatment decisions; and two (9%) were unsure how to identify the substitute decision maker and would not comply with his

or her treatment decisions if they conflicted with their own principles.

These issues have been approached through various information and education programs for physicians and other staff. Physicians' input, recommendations, and acceptance of the final document have been important in assuring all concerned that the process meets the needs of patients and their families and is congruent with the responsibilities of the medical staff, especially primary care providers.

Since implementation in summer 1995, the Department of Social Work has been responsible for presenting the living will document to new applicants and offering the option of completing it and for reviewing the document with clients already residing in Baycrest Centre. Thus far, applicants to and residents of Baycrest Terrace, the apartment complex for those with the highest level of function, have responded most positively. Many of these residents have chosen to use a descriptive living will rather than our more formal document. Applicants to the Jewish Home for the Aged, which serves a much frailer population, have been reluctant to use the document as such and have designated proxies only by saying, "Leave it to my children." For the purposes of consent, this is sufficient and fulfils the proxy component of the document. However, it does not address the details.

In our continuing care units, we have begun discussing with competent patients the importance of detailed instructions and of including family members in discussions so they are prepared for future events. The process is progressing slowly as clients struggle with the necessity for such a document and understanding its purpose.

The social workers involved think there is a lag between understanding, interest, and desire among our population to provide formal and detailed instructions when they feel secure in the care of Baycrest Centre with their families acting on their behalf. It will probably take more time and more awareness of the potential importance of living wills before this population uses the document more frequently than at present.

Discussion

The Baycrest Centre's living will initiative has three goals. It aims to empower capable patients to maintain some control over future life-sustaining treatments; it hopes to facilitate communication among patients, proxies, and health care providers about end-of-life decisions; and it aims to determine whether incapable patients already have living wills and, if so, to ensure that they are available to care providers.

For many reasons, older people are reluctant to complete living wills and appoint proxies for personal and health care needs. Growing evidence suggests that, with a concerted effort, older people can be helped to understand the importance of having living wills that at least designate substitute decision makers.[18-22] Our experience at Baycrest Centre supports the premise that, with time and effort, many people, who would otherwise not broach the subject, are willing to discuss the issues, make their wishes known, and then complete living wills, even if only to formally name proxies or use descriptive rather than objective terms to define their end-of-life preferences.

The Baycrest Centre initiative was an attempt to develop a document suitable to our client population, to educate staff and the community about living wills, to help applicants and residents obtain suitable information and advice, and to emphasize the importance of discussion with families, proxies, primary care physicians, and other care providers. Baycrest Centre applicants and residents can request alternative types of living wills if they prefer. The living will initiative is expected to enhance patient decision making and patient satisfaction progressively and, ultimately, to contribute to enriching the quality of life of the elderly population served by Baycrest Centre.

Conclusion

Decisions to limit end-of-life treatments are an increasingly common feature in the clinical management of long-term care patients.[19] Even if the proportion of patients who complete living wills does not increase noticeably, primary care physicians especially can improve patient care

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by initiating discussions about future treatment decisions and appointing substitute decision makers.[20,22] The process should help older people to express personal views on the meaning of quality of care and quality of life. The usefulness of living wills in long-term care facilities will depend undoubtedly on the expectations that patients, physicians, and the community have of them.[21] In order for the Centre to honour residents' wishes, these expectations must be discussed, clarified, and documented. ■

Correspondence to: *Dr Michael Gordon, Baycrest Centre for Geriatric Care, 3560 Bathurst St, North York, ON M6A 2E1; email* **M.Gordon@utoronto.ca**

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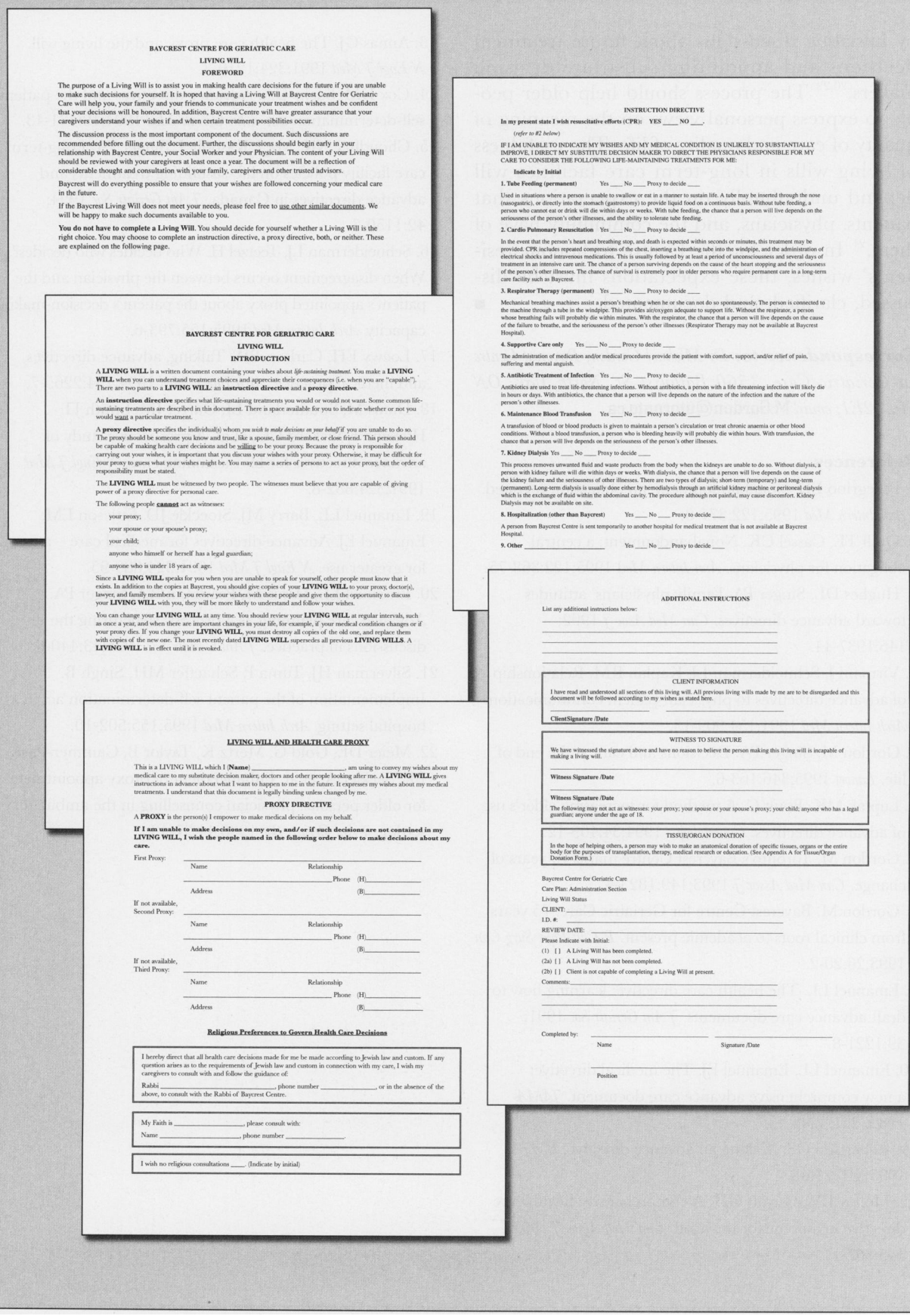
Appendix 1. Baycrest Centre's living will



BAYCREST CENTRE FOR GERIATRIC CARE

LIVING WILL

FOREWORD

The purpose of a Living Will is to assist you in making health care decisions for the future if you are unable to make such decisions for yourself. It is hoped that having a Living Will at Baycrest Centre for Geriatric Care will help you, your family and your friends to communicate your treatment wishes and be confident that your decisions will be honoured. In addition, Baycrest Centre will have greater assurance that your caregivers understand your wishes if and when certain treatment possibilities occur.

The discussion process is the most important component of the document. Such discussions are recommended before filling out the document. Further, the discussions should begin early in your relationship with Baycrest Centre, your Social Worker and your Physician. The content of your Living Will should be reviewed with your caregivers at least once a year. The document will be a reflection of considerable thought and consultation with your family, caregivers and other trusted advisors.

Baycrest will do everything possible to ensure that your wishes are followed concerning your medical care in the future.

If the Baycrest Living Will does not meet your needs, please feel free to use other similar documents. We will be happy to make such documents available to you.

You do not have to complete a Living Will. You should decide for yourself whether a Living Will is the right choice. You may choose to complete an instruction directive, a proxy directive, both, or neither. These are explained on the following page.

BAYCREST CENTRE FOR GERIATRIC CARE

LIVING WILL

INTRODUCTION

A **LIVING WILL** is a written document containing your wishes about *life-sustaining treatment*. You make a **LIVING WILL** when you can understand treatment choices and appreciate their consequences (i.e. when you are "capable"). There are two parts to a **LIVING WILL**: an **instruction directive** and a **proxy directive**.

An **instruction directive** specifies what life-sustaining treatments you would or would not want. Some common life-sustaining treatments are described in this document. There is space available for you to indicate whether or not you would want a particular treatment.

A **proxy directive** specifies the individual(s) whom *you wish to make decisions on your behalf* if you are unable to do so. The proxy should be someone you know and trust, like a spouse, family member, or close friend. This person should be capable of making health care decisions and be willing to be your proxy. Because the proxy is responsible for carrying out your wishes, it is important that you discuss your wishes with your proxy. Otherwise, it may be difficult for your proxy to guess what your wishes might be. You may name a series of persons to act as your proxy, but the order of responsibility must be stated.

The **LIVING WILL** must be witnessed by two people. The witnesses must believe that you are capable of giving power of a proxy directive for personal care.

The following people **cannot** act as witnesses:

- your proxy;
- your spouse or your spouse's proxy;
- your child;
- anyone who himself or herself has a legal guardian;
- anyone who is under 18 years of age.

Since a **LIVING WILL** speaks for you when you are unable to speak for yourself, other people must know that it exists. In addition to the copies at Baycrest, you should give copies of your **LIVING WILL** to your proxy, doctor(s), lawyer, and family members. If you review your wishes with these people and give them the opportunity to discuss your **LIVING WILL** with you, they will be more likely to understand and follow your wishes.

You can change your **LIVING WILL** at any time. You should review your **LIVING WILL** at regular intervals, such as once a year, and when there are important changes in your life, for example, if your medical condition changes or if your proxy dies. If you change your **LIVING WILL**, you must destroy all copies of the old one, and replace them with copies of the new one. The most recently dated **LIVING WILL** supersedes all previous **LIVING WILLS**. A **LIVING WILL** is in effect until it is revoked.

LIVING WILL AND HEALTH CARE PROXY

This is a LIVING WILL which I (**Name**) _____, am using to convey my wishes about my medical care to my substitute decision maker, doctors and other people looking after me. A **LIVING WILL** gives instructions in advance about what I want to happen to me in the future. It expresses my wishes about my medical treatments. I understand that this document is legally binding unless changed by me.

PROXY DIRECTIVE

A **PROXY** is the person(s) I empower to make medical decisions on my behalf.

If I am unable to make decisions on my own, and/or if such decisions are not contained in my LIVING WILL, I wish the people named in the following order below to make decisions about my care.

First Proxy: _____

Name Relationship

_____ Phone (H)_____

Address (B)_____

If not available, Second Proxy: _____

Name Relationship

_____ Phone (H)_____

Address (B)_____

If not available, Third Proxy: _____

Name Relationship

_____ Phone (H)_____

Address (B)_____

Religious Preferences to Govern Health Care Decisions

I hereby direct that all health care decisions made for me be made according to Jewish law and custom. If any question arises as to the requirements of Jewish law and custom in connection with my care, I wish my caregivers to consult with and follow the guidance of:

Rabbi _____, phone number _____, or in the absence of the above, to consult with the Rabbi of Baycrest Centre.

My Faith is _____, please consult with:

Name _____, phone number _____.

I wish no religious consultations ____. (Indicate by initial)

INSTRUCTION DIRECTIVE

In my present state I wish resuscitative efforts (CPR): YES ____ NO ___.

(refer to #2 below)

IF I AM UNABLE TO INDICATE MY WISHES AND MY MEDICAL CONDITION IS UNLIKELY TO SUBSTANTIALLY IMPROVE, I DIRECT MY SUBSTITUTE DECISION MAKER TO DIRECT THE PHYSICIANS RESPONSIBLE FOR MY CARE TO CONSIDER THE FOLLOWING LIFE-MAINTAINING TREATMENTS FOR ME:

Indicate by Initial

1. Tube Feeding (permanent) Yes ___ No ___ Proxy to decide ___

Used in situations where a person is unable to swallow or eat in a manner to sustain life. A tube may be inserted through the nose (nasogastric), or directly into the stomach (gastrostomy) to provide liquid food on a continuous basis. Without tube feeding, a person who cannot eat or drink will die within days or weeks. With tube feeding, the chance that a person will live depends on the seriousness of the person's other illnesses, and the ability to tolerate tube feeding.

2. Cardio Pulmonary Resuscitation Yes ___ No ___ Proxy to decide ___

In the event that the person's heart and breathing stop, and death is expected within seconds or minutes, this treatment may be provided. CPR includes repeated compressions of the chest, inserting a breathing tube into the windpipe, and the administration of electrical shocks and intravenous medications. This is usually followed by at least a period of unconsciousness and several days of treatment in an intensive care unit. The chance of a person surviving depends on the cause of the heart stopping and the seriousness of the person's other illnesses. The chance of survival is extremely poor in older persons who require permanent care in a long-term care facility such as Baycrest.

3. Respirator Therapy (permanent) Yes ___ No ___ Proxy to decide ___

Mechanical breathing machines assist a person's breathing when he or she can not do so spontaneously. The person is connected to the machine through a tube in the windpipe. This provides air/oxygen adequate to support life. Without the respirator, a person whose breathing fails will probably die within minutes. With the respirator, the chance that a person will live depends on the cause of the failure to breathe, and the seriousness of the person's other illnesses (Respirator Therapy may not be available at Baycrest Hospital).

4. Supportive Care only Yes ___ No ___ Proxy to decide ___

The administration of medication and/or medical procedures provide the patient with comfort, support, and/or relief of pain, suffering and mental anguish.

5. Antibiotic Treatment of Infection Yes ___ No ___ Proxy to decide ___

Antibiotics are used to treat life-threatening infections. Without antibiotics, a person with a life threatening infection will likely die in hours or days. With antibiotics, the chance that a person will live depends on the nature of the infection and the nature of the person's other illnesses.

6. Maintenance Blood Transfusion Yes ___ No ___ Proxy to decide ___

A transfusion of blood or blood products is given to maintain a person's circulation or treat chronic anaemia or other blood conditions. Without a blood transfusion, a person who is bleeding heavily will probably die within hours. With transfusion, the chance that a person will live depends on the seriousness of the person's other illnesses.

7. Kidney Dialysis Yes ___ No ___ Proxy to decide ___

This process removes unwanted fluid and waste products from the body when the kidneys are unable to do so. Without dialysis, a person with kidney failure will die within days or weeks. With dialysis, the chance that a person will live depends on the cause of the kidney failure and the seriousness of other illnesses. There are two types of dialysis; short-term (temporary) and long-term (permanent). Long-term dialysis is usually done either by hemodialysis through an artificial kidney machine or peritoneal dialysis which is the exchange of fluid within the abdominal cavity. The procedure although not painful, may cause discomfort. Kidney Dialysis may not be available on site.

8. Hospitalization (other than Baycrest) Yes ___ No ___ Proxy to decide ___

A person from Baycrest Centre is sent temporarily to another hospital for medical treatment that is not available at Baycrest Hospital.

9. Other _____ Yes ___ No ___ Proxy to decide ___

ADDITIONAL INSTRUCTIONS

List any additional instructions below:

_____

_____

_____

_____

_____

CLIENT INFORMATION

I have read and understood all sections of this living will. All previous living wills made by me are to be disregarded and this document will be followed according to my wishes as stated here.

_____ _____

ClientSignature /Date

WITNESS TO SIGNATURE

We have witnessed the signature above and have no reason to believe the person making this living will is incapable of making a living will.

_____

Witness Signature /Date

_____

Witness Signature /Date

The following may not act as witnesses: your proxy; your spouse or your spouse's proxy; your child; anyone who has a legal guardian; anyone under the age of 18.

TISSUE/ORGAN DONATION

In the hope of helping others, a person may wish to make an anatomical donation of specific tissues, organs or the entire body for the purposes of transplantation, therapy, medical research or education. (See Appendix A for Tissue/Organ Donation Form.)

Baycrest Centre for Geriatric Care

Care Plan: Administration Section

Living Will Status

CLIENT: _____

I.D. #: _____

REVIEW DATE: _____

Please Indicate with Initial:

(1) [ ] A Living Will has been completed.

(2a) [ ] A Living Will has not been completed.

(2b) [ ] Client is not capable of completing a Living Will at present.

Comments:_____

_____

_____

_____

Completed by: _____ _____

Name Signature /Date

_____

Position