



Man in the Maze from the Tohono O'odham Nation

The Legacy Project A Guideline Booklet for Leaving a Legacy

**Capturing the Memories of the Past
and
Planning for the Future**

Ernest H. Rosenbaum, MD

Paula Chung

Alexandra Andrews

Alexandra von Ehrenkrook

Stephanie Shapiro, BA

David Spiegel, MD

With Louise Maffitt, BFA

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Cover image: *Man in the Maze* from the Tohono O'odham Nation of southern Arizona. The figure represents an individual's path through life, with its many twists and turns in which he gains wisdom and knowledge. Before approaching death, he reflects on the wisdom he has gained and then, in harmony with the world, he accepts his fate.

Dedication

We wish to acknowledge three survivors whose legacies have made a difference to society by improving quality of life.

Ken Colvin, a cancer survivor who, as a 19-year-old Army surgical technician helped liberate Nazi death camps in 1945. He later supported student fellowships and many charities, and set an example for how to give back and live.

Annette Campbell-White, a valiant cancer survivor, has become a philanthropic executive to promote medical research projects and is a major supporter of the Arts, Music and Culture in California and in her native New Zealand, making a difference in many people's lives.

William Lowenberg, the sole member of his family to survive Auschwitz and Dachau, became a major financier and community activist, supporting and promoting medical, cultural, and social projects and serving on many charity boards.

John Kerner, MD, a survivor of World War II who led his medical corps team through D-day, Omaha Beach, France, and the Battle of the Bulge. All of his medical corps team survived. In November 2007 he received the French Legion of Honor Medal from the President of France.

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Summary of the Legacy Project

This booklet is a guide to help you create a life legacy for family and friends. This life legacy project will help you bring together your family's history, preserving the memories and events that represent your own and your family's life story. It is a way to pass on your thoughts, your values, and your jokes, as well as your knowledge of the events that shaped your ancestors' lives and your hopes for the future.

A legacy is a gift from one generation to the next.

This booklet provides descriptions of the various elements that can be included in your life legacy. The appendices provide extensive details on methods and tools that can be used to create and preserve your legacy.

Elements of the Legacy Project

Ethical Will: a personal, written and/or dictated record of your family stories, philosophic thoughts, values, and goals.

Family Tree: an organized outline of family members and ancestors showing marriages, children, births and deaths with photographs where available. Including medical history of your ancestors and family members provides valuable hereditary information which can help provide potential future guidance for prevention of illnesses.

Family History Recording: written, audio, or video recordings of stories and memories of past and current generations. These can be collected individually and/or at family gatherings.

Scrapbooks: albums with pictures, literature, documents, and articles about the family history and important events.

Legacy of Love: documentation of clear decisions and planned social, legal, financial, and end-of-life arrangements.

The goal of the legacy project is to help enable individuals and families to come to a clearer understanding of the meaning of their life history, love, and interrelationships, and to capture the memories of the past in a concrete way that satisfies the human need for symbolic immortality.

The term "symbolic immortality" refers to what remains from our lives after death. Most humans hope for some form of future immortality for their philosophy, their deeds and their souls. This project grew out of the Life Tapes Project working with cancer patients and their families in which we found that for some families the sharing of family history and philosophies became a turning point in their lives, affording them the chance to identify and understand their legacy to their family and, if necessary, make life changes to clarify relationships.

This booklet contains detailed information and directions on how to accomplish many of the tasks necessary to complete a comprehensive personal and family legacy.

The Legacy Project

Capturing the Memories of the Past and Planning for the Future

A legacy is a gift from one generation to the next. The Legacy Project provides a structured way to collect, save, and store a family tree with historical information and stories, photographs, audio and video recordings, articles, and documents of significant life events and achievements. This can be a practical way of “capturing” a family’s history and making a family legacy of many of the memories and precious events which represent a person’s and a family’s life story.

The project also provides guidance on how to plan end-of-life care, personal and financial affairs, and help simplify necessary family duties and vital decisions.

The Goals of the Legacy Project

The goals of the legacy project are to enable a family to come to a clearer understanding of the meaning of their life history, love and interrelationships, and to create a record that will hopefully exemplify the significance of the family’s life story. Personal interviews via audio and video camera recordings (transferred to CDs or DVDs) create a permanent life record of memories that can have great significance for future generations.

Over the last twenty years, there has been a growing interest in recording family histories and family trees. Computer programs are now available which can help organize a family tree and history (e.g., Ancestry.com, Familytreemaker.com, familytree.com).

Sometimes, a family history is documented because of family pride or interest in seeking information on where ancestors came from, their occupations, and how they lived. Other times it is done to obtain genetic or medical information which can be of vital value for family descendants.

We started the Life Tape Project in the early 1970s initially making audiotapes and, later, video recordings, CDs and DVDs of cancer patients and their families to record their memories and thoughts, family history and stories, philosophy of life, wishes, goals, legacy, and family medical information.

The Life Tape Project helped us appreciate the importance of family histories and stories. As the project progressed, we found that for some families the sharing of family history and philosophies became a turning point in their lives despite the fact that the interview was only 1½-2 hours. This gave patients the opportunity to reassess their personal philosophies and goals as they talked about their lives, affording them the chance to identify and understand their legacy to their family and, if necessary, make life changes to clarify relationships.

Elements of the Legacy Project

1. **Creation of an Ethical Will**, which is a personal, written or dictated record of your and your family's stories, life philosophy, legacy, and goals. Ethical wills are a way to share your values, achievements, blessings, life lessons, hopes and dreams for the future, love, and forgiveness with your family, friends, and community.

Ethical wills are not new. Initially, ethical wills were transmitted orally. Over time, they evolved into written documents.

The Hebrew Bible first described ethical wills 3000 years ago (Genesis Ch. 49). References to this tradition are also found in the Christian Bible (John Ch. 15-18) and in other cultures. Written for succeeding generations, the ethical will offers an opportunity to add to personal family knowledge and history to express one's life accomplishments, values, and legacy wishes for the family.

An 'ethical will' is not considered a legal document as compared to a 'living will' or 'last will and testament' which are legal documents.

Examples of categories for Ethical Will:

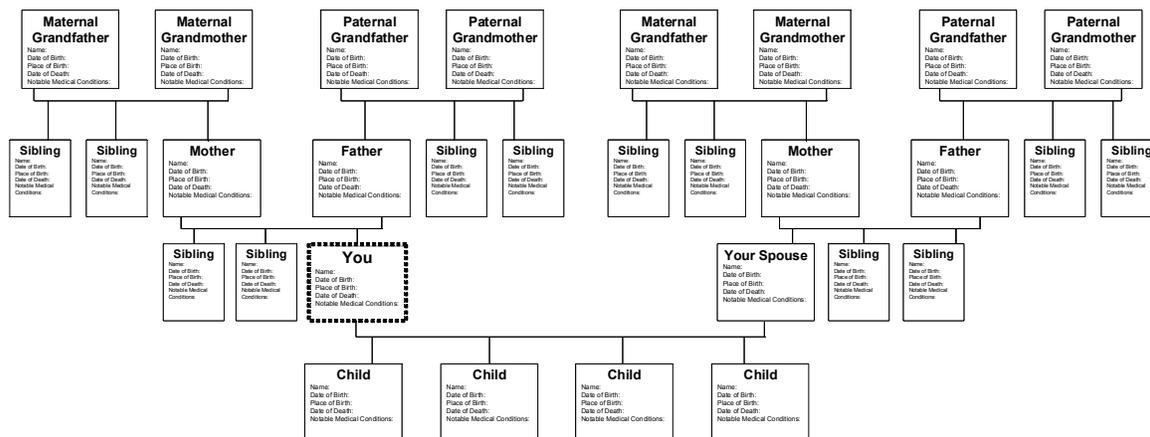
- Your personal philosophy
- Family
- Country
- Religious philosophy
- Thoughts about hope and the future
- Thoughts about your family legacy

For a suggested list of Ethical Will topics, see Appendix A.

2. **Creation of a Family Tree** with pictures of family members. An organized family tree provides a basic family history outline that can help prompt memories of early years, ancestors, and family stories. This has been made easier with the use of personal computers, the Internet, and commercial genealogy programs.

A diagram of a family tree is illustrated below followed by an example of the basic types of information to record. Your family's experience may include additional events, history and information that you want to include, such as dates of marriage or immigration from one country to another.

Sample Family Tree



Maternal Grandmother



Name:
Date of Birth:
Place of Birth:
Date of Death:
Significant Medical Conditions:

Maternal Grandfather



Name:
Date of Birth:
Place of Birth:
Date of Death:
Significant Medical Conditions:

Your Mother



Name:
Date of Birth:
Place of Birth:
Date of Death:
Significant Medical Conditions:

By including any medical history that you know for ancestors and family members, you provide very valuable familial hereditary information and potential future guidance for prevention of medical illnesses (such as heart disease, stroke, diabetes, obesity, osteoporosis and cancer) and/or help make a genetic reconstruction of your family’s heredity. In collaboration with other health agencies, the U.S. Surgeon General has created the Family Health Initiative to provide tools for families to enter and organize their family’s health history to share with their physicians. Appendix B contains details about this program, website information, and a copy of the Surgeon General’s Family Health Portrait forms.

3. **Appendix C** Information on Family Tree construction is available.
4. **Appendix D** contains information on creating and maintaining your own electronic medical history record in a portable format to share with your doctors.
5. **Record the Family History** with stories and examples of past and current

generations using the family tree as a guide (instructions for the Legacy Tape interview are available in Appendix F). Family stories can be linked to various persons on the tree, describing their relationship to the storytellers and the family. A guide sheet is provided so the family history interviews can follow a similar pattern, including, for example, name, age, relationship, birthplace, marriage (wife or husband or partner), birthday, where they lived, list of parents, grandparents and children and stories about each.

The Hallmark® greeting card company, in collaboration with Marcia Cross, has developed an inexpensive easy-to-use kit called ‘The Legacy Keeper’ to make digital audio recordings of your family history with interviews that can easily be transferred to your computer or to DVD. The kit includes a list of questions that can help you conduct your interviews, and also provides folders for special family documents and photographs. (More information on this kit is provided in Appendix D.)

6. **Organize audio and video recordings** on DVDs for family members. Videocamera recordings of current family members can be combined with photographs of ancestors and relations and edited to reflect the family growing up. Older movie films and recordings can be retrieved and added to future films, and video recording segments can be converted to DVDs as generations continue to grow and mature.

Photographic stores, copy stores, and many pharmacies provide reproduction services for those wishing to make multiple copies of family photographs. Walgreens®, for example, will transfer videotape, movie film, slides and photographs or other printed documents to digital files on DVDs.
7. **Creation of a Scrapbook** with pictures, literature, documents and articles about the family history and important events. All pictures, documents and articles can also be saved by digital photo scanning as memories for future generations which otherwise might be lost. Separate albums can be created for individual family groups, for instance, by generation or specific branch of the family line. For more on scrapbooking, see Appendix E.
8. A **Legacy of Love** for your family and friends can be created to provide clear decisions and planned social, legal, financial, and end-of-life arrangements to spare your survivors an inheritance of scattered papers and countless confusing details. (Example forms are provided in Appendix G.)
 - **Preparing a legal will is one of the most important responsibilities you have.**
 - Completion of the Advance Directives (Durable Power of Attorney for Health Care) form with treatments you might choose or reject such as:
 - CPR (cardiac chest compressions)
 - Mechanical breathing machines
 - Feeding and hydration, kidney dialysis
 - Medical or surgical therapy to help guide your medical team’s decisions.

- Other helpful forms include: life insurance, pension and profit-sharing plans including Keogh plans, IRAs, social security, Medicare and supplemental medical insurance, information about bank and savings assets, loans assets, liabilities, other insurance policy information, home and personal property inventory, and to whom personal items should be given. Talk to your lawyer and/or your executor about your estate.
- Some people may also wish to choose to complete end-of-life forms: funeral arrangements, obituary instructions, and a list of persons to notify upon your death.

By completing these important matters (forms) as a part of your legacy plan, you will help reduce family decision conflicts as they can more easily follow your instructions and you will have the knowledge that **your wishes** will be carried out. (Information on “Planning for Your Future by Getting Your Affairs in Order” and example forms are available in Appendix G.)

Thoughts About the Future

Being conscious of our potential mortality creates fear and anxiety concerning an uncertain future. Confronting death often gives one a greater appreciation of one’s life.

These thoughts and feelings were well expressed by Harvard psychiatrist Robert J. Lifton, MD, who discussed the human need for symbolic immortality and the confrontation with the nature of human existence when people contemplate death. His book, *The Broken Connection*, 1979, pointed out how important it is to understand how people, when facing a life crisis, such as a diagnosis of cancer, heart disease, a stroke, or a critical accident, become aware of their potential mortality.

Legacy Lessons of Symbolic Immortality

We can all imagine and anticipate concerns about our death and the uncertainty and anxiety common at the end of our lives. Death represents both the physical and mental annihilation of life. Most humans hope for some form of future immortality for our philosophy, our deeds and our souls.

The term “symbolic immortality” refers to what remains from our lives after death. These may be material (such as what we have built, created, or given birth to) or ephemeral (such as our thoughts, our values, our jokes, our network of friendships, or our acts of kindness: helping persons in distress, being generous with charity, or doing a good deed).

Freud, for example, after sixteen years of treatment for the painful and humiliating symptoms of mouth cancer, was more concerned about the possible loss of his theories than the loss of his life. He’d undergone a transformation from his earlier fear of death to its mastery, but worried, “What will they do with my theory after my death? Will it still resemble my basic thoughts?” His hope for symbolic immortality was that his theories would live on after his death. Jung, a Protestant visionary, on the other hand, believed

both in the pre-modern and modern Christian hope of resurrection and immortality. He was more concerned about the state of his soul.

There are four major types of Symbolic Immortality; the first three are the most universal.

1. Biologic Symbolic Immortality

Most people feel that even after dying, there is hope of an afterlife, with an immortal soul: "I can live on in mankind."

This provides continuity of a family's heritage and the passing of memories from generation to generation. The biological symbolic immortality of a family continues after one's death through the meaning of their life continuing as one's spirit lives on through one's children, grandchildren and family, emphasizing history, memories, stories and one's philosophy of life.

We'd like to transmit our thoughts and values to our family, children and future generations before we die so they will live on as our heritage. This legacy often reflects our cultural and ethical values, including information about our social inheritance and achievements reflecting the values of our family. Our biologic symbolic immortality legacy is a continuation of our lives through our descendants after we die.

2. Theological or Religious Symbolic Immortality

The belief in life after death is seen in most religions and spiritual practices. The family's belief in a higher authority is symbolized, for example, by the clergy of Western religions, or Shinto Buddhism, and also seen in the power of leaders and kings of the Roman, Greek and Egyptian empires. Life after death is not a traditional view in Buddhist or Jewish (other than Orthodox) religious philosophies.

In Christianity, there is a fundamental tranquility in spiritual achievement that is symbolized in Christ's story: life continues in heaven after death with an immortal soul.

Muslims have a somewhat different philosophy of a life after death. Islam makes it quite clear that life in the hereafter is of a physical nature, in which bodies will be restored to live either in Paradise or in Hell.

Buddha, Moses, Christ, and Muhammad all combine spiritual revelations with ethical principles. The afterlife, with an immortal soul, is an ancient mythological theme, involving death, rebirth and resurrection.

Many patients think about the afterlife and question – is there a heaven? There is no exact answer as philosophically it is a part of your religious or spiritual belief. Heaven for many is the image of God and the question is, is it everlasting? The dead are not lost, as they can remain as an everlasting memory of your family.

Of note is the statement by philosopher Joseph Campbell who believed:

“The power of belief includes both love and bliss, and if there is an inner voice you have inside of you, you are reflecting your spirit. The birth of compassion is how we learn to live each day through rituals, spiritual beliefs, and the life of a higher source.”

Schopenhauer, the great philosopher, felt that events in your life are part of your life plot - you are the agent influencing yourself, your life, and the lives of others, and this life has a purpose, which is what you follow. The journey is what counts, not the destination.

Joseph Campbell also believed that we don't know if there is a heaven, hell or afterlife, so we should act as if this life is all we will get.

3. Creative Symbolic Immortality

When one is creative through art, literature, a great discovery in science or in doing a humble, benevolent, kind act for someone in need, one has also created an example of creative symbolic immortality. In this way one escapes death by living afterwards through acts and accomplishments which will be remembered for generations and possibly centuries.

The creative domain can truly leave a long-term legacy; consider, for instance, Leonardo Da Vinci's creation of the Mona Lisa - this one act will have everlasting creative symbolic immortality.

Physicians, nurses, psychiatrists, teachers and others often provide another form of creative symbolic immortality through their acts which make a difference in other people's lives.

From this point of view, being creative through benevolence can make a lasting difference in another person's life. Each individual has the capacity to influence and help change another's future. In one of the Life Tape interviews, a patient remarked about a friend: “Her goodwill towards people in general and her family is something I really admire and have learned from - and other people have as well.”

Thus the recipients of a kindness may not only have their status improved, but also can help others.

In another Life Tape interview, a patient stated: “Since my cancer diagnosis, I have received more love from everyone I know. It's been an outpouring of love I never knew existed.” This experience not only had a positive impact through human kindness and appreciation but also was transmitted into helping others. One survivor said: “The fact that we are together has totally changed my outlook on what I am going to do with my life.”

This is called “passing down” a learned lesson through what is a common life struggle. Another patient said “I learned from your struggle too,” which led to a change in a family member, affecting not only himself but all the members of his family. Using the Life Tape Project with cancer patients showed how patients could serve as models to their families on how to better face life, dying and death. The proximity of their own death made many of them more, not less, important to their loved ones.

4. Symbolic Immortality of Nature

Nature also exemplifies symbolic immortality. It is everywhere and limitless and will survive forever. “The state may collapse, but the mountains and rivers will remain forever.” (Old Japanese saying)

Following the atomic bomb explosions in Japan in 1945 the trees appeared dead, but in the springtime, the cherry blossoms came back, reflecting the ability of nature to regenerate. In a sense, we participate in “eternity” through our appreciation and understanding of the persistent life and death cycles of nature.

Expressions of the first three of the four symbolic immortality domains were evident in Life Tape interviews. The patients’ values, achievements and thoughts were recalled and recorded to pass on to future generations, providing a continuation of their lives and values to be remembered after their death by their descendants.

Patients in the Life Tape Project appreciated the psychological and emotional value of symbolic immortality, which helped promote their feelings of their continuity with the future by identifying their ties to the family, and through their biologic, religious, spiritual and creative acts in art and science or acts of kindness for others.

Working through the Life Tape process with a focus on symbolic immortality helped patients reduce their existential (based on the experience of existence – life and death) anxiety about death, as well as promoting feelings of well-being and appreciation of life. It also helped promote better interfamily relationships through improved communication and emotional support and decreased isolation and anxiety. In addition, the experience helped promote a better sense of self-worth and improved understanding of their own life experience. Finally, it promoted dignity and closure, and helped support palliative care if needed for a better quality of life at the end of life.

Concepts of the Legacy Project

Using the concepts of symbolic immortality, it is proposed that the Legacy Project interviews can later be shared by many generations as a reflection of their heritage. A collection of family pictures, scrapbook of family events, stories, articles, documents and photographs, as well as audiotapes, CDs or DVDs can help portray a family history which might otherwise be lost after a person's death. The spirit and philosophy of one's family will live on. It also helps foster self-observation, which is a powerful coping tool for reviewing the value of one's life when dealing with age, illness or a life crisis, at a time when, life changes can still be made. This permanent record of one's family life history can be a marker for future generations to identify their roots and provide useful information about their ancestors.

Include any medical history which could be valuable for familial hereditary and potential future guidance for prevention of medical illnesses (such as heart disease, stroke, diabetes, obesity and cancer), and/or a genetic reconstruction of a family's heredity.

In conducting a Legacy Project recording, one is encouraged to conduct interviews with various family members. Often, a good time to do this is at special occasions such as Thanksgiving, Christmas, family reunions, or at events specifically scheduled for this purpose. These family meetings can often serve as a convenient opportunity for participants not only to convey and share their stories and information but also to add memories, as one story can bring other stories to mind.

In our experience with the Life Tape Project based on one-and-a-half to two-hour interviews with cancer patients, there was an imparting of personal philosophies in 70% of the participants, discussion of existential dread in 70%, a gained perspective and meaning of the family in 65%, and improved communication in 57%. The project provided a powerful, safe and accessible intervention that improved family communication, promoting not only personal growth but also reducing anxiety through the identification of "symbolic immortality."

Conclusion

The Legacy Project provides a powerful, safe and accessible intervention that improves family communications, relationships and connectedness by collecting a family life history, documents, pictures, audio/video/CD recordings and an ethical will.

This promotes not only personal growth but also reduces existential anxiety through the understanding of "symbolic immortality" and its concepts of a symbolic life-after-death. The legacy project also provides a way to preserve a person's and family's life stories, philosophies and the legacy of their life history and wishes for the future of their family and their descendants.

Additional resources and publications on this subject are listed in Appendix H.

APPENDIX A

Potential Topics for an Ethical Will

Dedication: To family or friends?
My reasons for making this ethical will
My feelings about my life
How I feel about today's world
My life philosophy
 My thoughts about what is good and what is bad
 The things for which I am grateful
 How I feel others should be treated
 My goals in life
 My rules and standards for living
 Standing up for what you believe
How I deal with emotional issues
 Despair
 Anger
 Faith
 Self-Importance
 Procrastination
How I have grown from past experience
 Live life to the fullest
 Devotion
 Happiness
 Charity
 Courage
 Compassion
 Luck and good fortune
 Loyalty
 Equanimity
 How I have tried to attain financial security
 Reviving memories and reflecting on the past
How I have learned to overcome
 Loneliness
 Finding fault
 Being overextended
 Facing unpleasantness
 Injustice
 Suffering
 Despair of our times
How faith and belief influenced my life
 Spirituality and religion, the role of prayer
 Controlling despair
My thoughts on Life and Death
My hopes for the future and my descendant's
My favorite poem, music, or other beloved writing

APPENDIX B

The Family History Initiative of the U.S. Surgeon General

(Synopsised from the Surgeon General's report at www.hhs.gov/familyhistory)

It is well-known that many diseases, such as heart disease, cancer, and diabetes, can run in families. This is true of even rare diseases such as hemophilia, cystic fibrosis, and sickle cell anemia.

High blood pressure in one generation may occur in the next generation or even skip a generation and reappear. Information on the medical conditions of your parents, grandparents, and other blood relatives can help your doctor predict the disorders for which you may be at risk and take action to keep you and your family healthy.

The U.S. Surgeon General, in cooperation with other agencies¹ and with the U.S. Department of Health and Human Services, has launched a national public health campaign, called the **U.S. Surgeon General's Family History Initiative**, to encourage all American families to understand the importance of family health history for their own lives and to gather whatever information they can.

A recent survey found that **96 percent** of Americans believe that knowing their family history is important. Yet, the same survey found that only **one-third** of Americans have ever tried to gather and write down their family's health history.

The Surgeon General has created a new computerized tool that helps make it fun and easy for anyone to create a sophisticated portrait of their family's health. (A paper version of the Family Health Portrait can be used if you don't have computer access at home or simply to begin the process before entering your history on the website; the form is reproduced on the following pages. You can review the entire site and download this form and the tool itself at www.hhs.gov/familyhistory) Note: This form is available in other languages besides English.

This updated version of the tool called My Family Health Portrait is a web-enabled program that runs on any computer connected to the Internet and running an up-to-date version of any major Internet browser. This new version of the tool can be run on computers running any operating system (Windows, Macintosh, Linux, etc.) and does not need to be downloaded to your computer. The Family Health Portrait portion of the website is secure, so others cannot view your information without your permission. No user information is saved on any computer of the U.S. Federal Government.

The Family Health Portrait tool helps users organize family history information to print it out to give to the family doctor. In addition, the tool helps users save their family history information to their own computers to share with other family members.

¹ The National Human Genome Research Institute (NHGRI) at the National Institutes of Health, the Centers for Disease Control and Prevention (CDC), the Agency for Healthcare Research and Quality (AHRQ), and the Health Resources and Services Administration (HRSA) are also involved.

When you are finished organizing your family history information, the tool will create a graphical representation of your family's generations and the health disorders that may have moved from one generation to the next which you can print out. This graph is a powerful tool for predicting any illnesses for which you should be checked. If users prefer, they can still download the My Family Health Portrait software (freely available to all users) directly onto their own computers. The downloadable version of the tool can be accessed at: www.hhs.gov/familyhistory/download.html.

The fourth **National Family History Day** was celebrated on Thanksgiving 2007. Over the holiday or at other times when families gather, the Surgeon General encourages Americans to talk about and write down the health problems that seem to run in their families. Learning about their family's health history may help ensure a longer, healthier future together.

For more information on other activities of the Office of the Surgeon General, please visit www.surgeongeneral.gov.

A five-minute presentation of the Surgeon General's Family History Initiative press conference can be downloaded at www.hhs.gov/familyhistory/download.html

Surgeon General's Family Health Portrait Form: from the
U.S. Surgeon General's Family History Initiative, www.hhs.gov/familyhistory

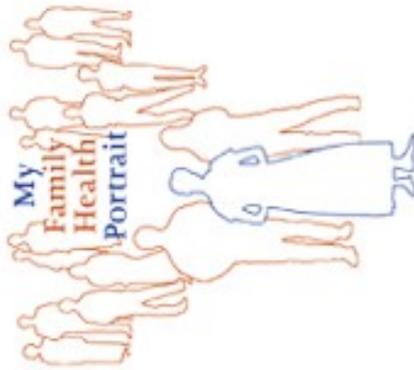


THE U.S. SURGEON GENERAL'S FAMILY HISTORY INITIATIVE
HOW TO CREATE MY FAMILY HEALTH PORTRAIT
KNOWING YOUR FAMILY'S MEDICAL HISTORY CAN SAVE YOUR LIFE.



WHAT INFORMATION DO I NEED?

- **Talk directly with your relatives.**
Explain to them their health information can help improve prevention and screening of diseases for ALL family members.
- **Ask about any health conditions they have had.**
If possible, get as much specific information as possible. Ask about chronic illnesses, such as heart disease and diabetes; pregnancy complications, such as miscarriage; and any developmental disabilities.
- **If possible, list formal names of conditions.**
It may be helpful to create a separate page with detailed information and descriptions about any medical conditions your relatives may have had. Also, list medicines your relatives may be taking.
- **Get help finding information.**
Ask relatives or health care professionals for information about health conditions that have affected you or your family members—living or deceased. If possible, get copies of medical records.
- **Is there cancer or a rare condition in the family?**
If so, it is important to collect information from as many family members as possible. If someone is deceased, ask other relatives or check to see if doctors have retained those medical records.
- **Are you planning to have children?**
You and your partner should EACH create a family health portrait and show it to your health care professional.



HOW DO I FILL OUT THE FORM?

- "My Family Health Portrait" will help you collect and organize your family information. No form can reflect every version of the American family, so use this chart as a starting point and adapt it to your needs.
1. **Write each of your relatives' names in the designated boxes. Circle whether they are male (M) or female (F).**
Some conditions are more common in people with a shared background or ancestry. So, if you know the ancestry of your relatives and/or the country they come from, note it on the form.
For twins, write "twin" on the first line. If the twins are identical, write "identical twin" on the first line for both. If your family includes half-brothers or half-sisters, write "half-brother" or "half-sister" on the first line, and note "same father" or "same mother" on the next line.
 2. **On the lines under the boxes, write the names of any health conditions your relatives have had.**
If you know the age at which the condition was diagnosed, also note it. For example, diabetes (diagnosed-age 37). If family members have died, write "deceased" and the age at which they died. For example, heart attack (deceased-age 63).
 3. **Once you have completed this form, take it to your health care professional.**
Your health care professional can use the information to better individualize your healthcare.
 4. **Make a copy for your records.**
Be sure to update the form as circumstances change or you learn more about your family's health.

TALK TO YOUR FAMILY

Most Important

Parents
Brothers and Sisters
Your Children

Also Important

Grandparents
Uncles and Aunts
Nieces and Nephews
Half-Brothers and Half-Sisters

Also Helpful

Cousins
Great Uncles and Great Aunts

YOU CAN ALSO FILL OUT THE FORM ONLINE AT: <https://familyhistory.hhs.gov/>

My FAMILY HEALTH PORTRAIT

YOU CAN ALSO FILL OUT THE FORM ONLINE AT: <https://familyhistory.hhs.gov/>

Name: _____

Date: _____



APPENDIX C
A Personal, Portable Health Record
J. Ben Davoren, MD, PhD

The idea of a personal, portable health record has been a goal for years.

However, the sheer volume of information in today's detailed medical records, especially one of a cancer survivor, has made the idea of a simple "health card" obsolete. Enter the World Wide Web. Web technology has created the best place to store personal information: on the Internet. The ability to (safely and securely) access the Internet from almost anywhere in the world ensures that the information cannot be lost or stolen along with your wallet. Further, new information can theoretically be posted at any time from anywhere so that one's health record can be as current as one's bank or credit card balance. The only thing that needs to be portable is the username and password information to access your account safely.

Unfortunately, in 2007, more than three-quarters of physician groups in the United States still use paper-based records to document and coordinate care. The good news is that there are multiple national and regional projects aiming to get medical care records online instead. Seemingly irrelevant web phenomena such as myspace.com or facebook.com have created examples where trust relationships can be explicitly created with minimal effort.

While waiting for the web to mature, even if your health plan does not yet have an online personal health record website, there are a number of free or low-cost websites that facilitate the creation of a personal health record online, and these can be used to create the basics of your own cancer survivorship plan. For now, the work of posting that information is all by the patient - you are, after all, the real hub of the plan. Encourage your providers of healthcare to give you copies of your information (you are always entitled to it, but sometimes there are hoops to jump through), including CT scans and MRIs on CD or DVD so that you can facilitate shared decision-making.

Other strategies can keep your information organized and accessible while medicine catches up on the Internet. Paper backup copies of critical information should be kept and can be inexpensively scanned into a personal computer and also stored on CD, DVD, or other portable media in a separate location away from home. One of the lessons of the Hurricane Katrina experience was that paper medical records were extremely vulnerable in a catastrophe. Create a simple spreadsheet or word processing document that you can update on a home computer, and then create a free Internet mail account, such as at google.com, yahoo.com, or another large, secure site. You can store your spreadsheet or document by starting an e-mail message to yourself, but instead of sending it, keep it as a "draft" message. That way, the content doesn't actually traverse the Internet where prying eyes might find it, and it's in a spot you can always access from anywhere there is an Internet connection.

The future of personal health information storage on the Internet is approaching, but starting your own collection now can help you and your future healthcare providers share the necessary information to plan the best care for you.

APPENDIX D

Creating Your Family Tree

Personal computers and Internet resources have made genealogy searches accessible to many people. Building a family history is easier now that information such as marriage and birth records, cemetery burial records, immigration records, and so forth have, in many cases, been made into electronic files. Newspaper and magazine articles are also largely searchable on the Internet, as are social security and military service records. In addition to these kinds of sources, the basic framework for building a family tree can be found at commercial websites - a great time and effort saver.

Many Internet sites offer genealogical information; perhaps the best known genealogical library in the world was first established by the Church of Jesus Christ of Latter-day Saints in Salt Lake City, Utah in 1894. Much of their library is available through their website at www.familysearch.org. RootsWeb.com, part of Ancestry.com, also provides many free historical searches, as do genealogy.org and usgenweb.org. Other commercial genealogical resources include FamilyTree.com and Ancestry.com.

The free search engines are a great way to begin family history and genealogical research. Each provides access to additional websites and links that can help you narrow your searches by focusing on members of specific religions and races. Due to the overwhelming number of tools now available online for this research, it is suggested that you begin at one of the generalized websites. From our investigation, ancestry.com and the Family Tree Maker® program seem to provide a reasonable approach to building a family history which includes the capability to add photographs, video, and audio clips to your tree. We suggest that you investigate a number of sites to compare resources before choosing the one that best suits your needs. It is good to prepare for your search with the following guidelines and subsequently use the suggested, available resources in research.

You can do a great deal to prepare for your search.

1. Get family members involved in the project to help you – family reunions, holiday celebrations, anniversaries, and birthdays are good times to enlist help.
2. Set up a form to better collect family information in an easy, organized way.
3. Enter names and information on known relatives.
4. Make an outline of the lives of specific family members.
5. Collect family documents.
6. Collect and scan photos for placement on the family tree.
7. Record your family history interviews (videocamera preferred) and make notes of information that comes out in the stories that could make searches easier.

If you are planning to make audio recordings, Hallmark's® 'Legacy Keeper' kit (\$50.00) provides an easy-to-use MP3 recorder/player to make digital recordings that can be transferred to DVDs for archiving. The kit comes in a storage box with a booklet of interview questions, instructions for using the recorder, organizing folders, and a photo album. More information can be found at www.hallmark.com.

8. Put together a historical data base on your computer.

Web Resources and Computer Programs for Family Tree Construction

Creating a family tree has been simplified with the use of modern technology. There are now computer programs and Internet sites that are solely dedicated to the recording and research of genealogy.

There is no one simple way to go about this task, yet a suggested start is given below.

1. Genealogy web sites available on the Internet can be used as tools for gathering information and recording/storing what you collect within an electronic framework. Family Tree Maker[®] is currently the leading program for creating family trees, and is available through www.ancestry.com for \$39.95. This program allows you to enter information, insert photographs and other documents, store audio and video clips, and create a family tree. You can either work on your tree right on the website or download the program to your own computer. By buying the Family Tree Maker[®] program and installing it on your own computer, your work will not be limited by website space constraints.
2. If you need to research your family history, subscribing to websites such as ancestry.com gives you access to both national and international records. The price for subscribing depends on how much data you need to collect and the length of time you wish to use the research site. If you buy the Family Tree Maker[®] program through ancestry.com, you can merge history files you find on the website into your tree – a simple and time-saving feature. Please note that it *is* possible for the program to work independently of the ancestry.com site. Pricing varies depending on what program you use. The *U.S. Deluxe Membership* ranges from \$19.95 for a single month fee to \$12.95 monthly for a yearly subscription. The *World Deluxe Membership* ranges from \$29.95 (single month) to \$24.95 per month for a year's subscription.
3. Once you have gathered the desired information (such as seen in the example family tree), it can be entered into the Family Tree Maker[®] program.
4. **Photographs** can be uploaded to the Family Tree Maker[®] program and attached to specific branches of the tree or individual persons. Please note that this requires that you have the correct camera cables and programs to upload digital photos. Existing print photographs will need to be scanned into digital form and stored on your computer for use in the program. (If you have many photographs, it might be wise to invest in an all-in-one printer, copier, scanner and fax to digitize your images. Alternatively, some photo labs will scan photographs and/or negatives or slides for a fee.
5. **Audio Clips** of stories, interviews, music, etc. can also be added to the family tree. The program also supports the inclusion of **Video Clips** (again, in order to use this function, you must have the proper cables and programs).
6. www.ancestry.com has recently added an easy-to-use publishing section which will print family tree posters or pages that you have designed. At this time (Fall 2007) you can order a 24-page family history book for an introductory price of \$29.95, and add up to 100 pages for an additional \$0.39 per page. Discounts are available when purchasing multiple copies. Introductory rates include 24x18 inch family tree prints for a fee of \$19.95, with discounts for multiple prints.

There are many ways to create family trees in order to preserve the legacy of your family. Appendix H provides a listing of selected resources for starting this project.

APPENDIX E Scrapbooking

A heritage scrapbook is a wonderful project for the whole family and a way to share precious memories down through the generations. The most common scrapbook album size is 12" x 12", but some prefer the smaller sizes of 8.5" x 11" or 8" x 8." If you will be making copies of the scrapbook, the smaller sizes may be more economical. Use acid-free, archival items for *everything* in your scrapbook.

A family tree will help you organize the pages of your scrapbook. Decide whether you want to highlight each member or group on a one- or two-page spread. You may want to Google "heritage scrapbook page layouts" for ideas and inspiration to help get you started.

Easy Steps to Making a Scrapbook Page:

1. Choose a number of photos. For single pages, choose 3 to 5 pictures, and for two-page spreads, choose 6-10.
2. Select papers that will complement your pictures.
3. If you crop your pictures, **never** use your originals in case you make a mistake and trim too much on the first try.
4. Add other family mementos like handkerchiefs, medals, newspaper clippings, ticket stubs, letters, locks of hair, lace, dried flowers, or recipes. Put these in acid-free memorabilia pockets to protect your pages.
5. Personalize your pages by adding *journaling* - answer the questions, who, what, when, why and where to describe the people and events in the pictures. Add stories and favorite memories when possible. Use full names. In addition to and/or instead of Uncle Ernie, say Ernest Harold Rosenbaum.
6. Embellishments are available to enhance your pages - stickers, mats, vellum, die cuts. These are offered in craft and book stores.
7. Experiment with different layout arrangements before adhering items permanently to the page.
8. Don't try to be a perfectionist. You are preserving important memories in your life to share with others. Enjoy the experience.

APPENDIX F

Conducting a Legacy Project Interview

The following is an outline of the basic requirements and procedures for conducting a Legacy Project interview.

In doing the Legacy Project, one is encouraged to do interviews with various family members in order to record thoughts of childhood, stories about various events in their lives, as well as events with the available family and with each specific parent, grandparent, brother, sister and cousin whom they wish to include. Thus, as the family dialogue unfolds it can include and emphasize social, emotional, cultural and significant events in one's life and the importance of his or her family's experiences together. This beginning can evolve into the continuing collection of memories, which can be shared and expanded upon with additions at various future get-togethers, and even become a tradition for succeeding generations.

A. Materials & Arrangement

Recording equipment needed: a tripod for camera, adequate lighting and inexpensive video camera equipment makes videotape recording the medium of choice, although audiotape recordings can still be used. The decreasing cost of digital video recording equipment makes it an ever more attractive option, particularly for its ease of editing and reproduction.

Seating should be arranged in a semi-circle such that participants can see each other and can be readily filmed by the interviewer. Make sure that room lighting is in front of the participants—**avoid strong back lighting**. Family members should sit fairly close together, sitting next to his or her significant other. Young children may often be held on their parents' laps.

B. Procedure

Pre-interview preparation

Provide a list of possible questions or topics one to several days prior to the scheduled interview to allow the subjects to think and list significant life events and to consider how much he or she wishes to disclose about coping with life problems. Review these topics with the person on the day of the interview. Find out the names of relatives (e.g., grandparents) that the person would like to talk about and create a brief family tree genealogy. Immediately prior to beginning, describe the process to all participants and encourage family members to volunteer their memories of and feelings about the family members—particularly the ways in which the family members have influenced them, and what they have learned or observed.

Conducting the interview

Begin the interview by having everyone introduce themselves and state their relationship to the person. Often filming memorabilia (e.g., photographs of forebears) with the person narrating their stories helps establish their role in the

family. Alternatively, this may be done at the end of the interview. Proceed by asking questions of key family members. Solicit family members' feelings, memories, and reactions that are stimulated by the stories being told. Camera time will be devoted to family members—particularly as they begin speaking. The camera should focus mostly on the key family members as they speak or react to the words of others. Continue to the end of the interview, pausing the recording when necessary for participants to get comfortable or for interruptions. Plan for about 90 minutes of interview time.

A five-minutes-to-go signal should be pre-arranged for the end of the interview in order to avoid an awkward or abrupt ending and to give participants a last chance to voice their feelings.

C. Structure of the Legacy Project Interview

The interview can be seen as having three phases.

Phase 1 – Beginning the interview; birth to young adulthood such as what are your earliest remembrances. Begin with somewhat more factual and “safe” questions about the participant’s ancestry, upbringing, and early life. For example, “What is your earliest memory of life?” Move on through high school and college.

Typical questions might include:

- Describe whatever you can remember of the life history of your parents, grandparents, and other family members.
- Describe your relationships and stories of your upbringing.
- What do you remember your family teaching you?
- What was it like being a teenager?
- What were you learning at this time in your life?
- What was college like for you? Did you have a favorite area of study?

Proceed to later periods in life and significant relationships and events.

- What did you do in your twenties/thirties?
- Talk about your job and family.
- Were there any significant others that came into your life at this time?
- How did they influence you?

Phase 2 – Middle of interview. This phase occurs naturally as the person begins to reveal himself or herself in detail. Explore major turning points in life and career up to a few years ago and important lessons learned. Bring out the significance of events and people who influenced who the person is today. Family participation is common during this phase—particularly when the interview turns to rearing children and important events that the family has shared.

- How/when did you meet your future husband/wife?
- What discoveries did you make during this time?
- How did that experience influence who you are today?
- How did having children affect you?
- What are you most proud of?

Phase 3 – End of interview. Questions “deepen.” Person discusses coping with life,

personal legacy, feelings about spirituality and the afterlife, regrets, etc.

- What has affected you and your family most?
- What has been the most significant change you see in yourself?
- What is a typical day like for you now?
- During this time, what is of most importance to you?
- Talk about your philosophy of life. What values do you hold most dear?

If you have agreed that a discussion of dying and/or the afterlife would be appropriate, guide the interview there. However, be aware that not all participants are prepared to talk about such matters directly.

- What do you think happens when a person dies? What do you believe?
- Do you consider yourself religious? Spiritual?
- Have you become more spiritual or religious lately?
- What is your legacy and lessons you hope to have passed to your children?
Ask children to comment.
- How do you hope you will be remembered?
- What kind of legacy would you like to leave with your family?

End the interview with a couple of final summary-type questions.

- If you were to live your life over again, what would you do differently or change? What would you keep the same?
- What are you most grateful for?
- What were your major achievements?
- What are your future plans?
- What is your family legacy?

These questions were modified for the Legacy Project from the Life Tape Project interviews developed by Alison Siegel, MFT.

APPENDIX G

Planning for Your Future by Getting Your Affairs in Order

Ernest H. Rosenbaum, MD, and Isadora Rosenbaum, MA
Adapted from *Everyone's Guide to Supportive Cancer Care* by E. and I. Rosenbaum

Whether you are healthy, just growing old or nearing the end of your life, it is a wise move and a gift of love to your family and friends to make arrangements for end-of-life care before you are either gravely ill or dying.

Your *Legacy of Love* for your family and friends can, with careful thought and compassion, be one of clear decisions and planned social and financial arrangements—a house swept clean of personal, financial and business cobwebs. By sorting out your affairs now, you can spare your survivors an inheritance of scattered papers and countless confusing details to be waded through. Instead, you can bequeath to them the gifts of clear direction, rich memories and unique insights.

Life is full of unplanned events. Perhaps the most challenging of these events to cope with is the death of a loved one. It's been estimated that 85-90 percent of families are not prepared when a relative dies. Important documents need to be located, funeral arrangements need to be made and vital matters need to be attended to. The following suggestions can be helpful.

It's important to realize that death is actually a shared experience. Although each of us must face our own death, our survivors are also affected and suffer. They are left to cope with both the emotional adjustment of losing a loved one and the responsibility of dealing with someone else's affairs.

How You Can Help Your Survivors

Many of the decisions that must be carried out by your survivors typically occur at a time of great stress. They often have to come up with answers to troubling questions—such as, what last-minute medical treatments to accept or reject on your behalf, whom to notify if you die, what burial arrangements to make, how to pay tribute to your life, how to settle liabilities and disperse assets, and what memories to embrace in order to best remember you.

By taking time and care now to attend to each of these areas of importance, you'll be providing benefits to yourself and those you love. In the short term, you'll reap the benefit of peace of mind, which comes from organization and control of your affairs, and in the long term, you'll know that what will be done is what you would have wanted.

Before considering the areas listed below, first plan where you are going to store this information file so that those who will need it will know where to find it easily. Then be sure to tell those who need to know the location of your records and safety deposit box and key.

- **Advance Directives**

By completing a Durable Power of Attorney for Health Care form or a Natural Death Act Declaration, you are providing your family and your health care and hospital team with guidance about your medical decisions. Forms are available at any hospital.

Here are some of the treatments you might choose (or reject) in a Durable Power of Attorney for Health Care or a Natural Death Act Declaration.

- CPR: Chest compressions, electric shock to keep your heart beating and drug supportive therapy.
- Mechanical breathing (respirator, ventilator).
- Feeding and hydration through a tube in your veins, nose or stomach.
- Kidney dialysis, chemotherapy or radiotherapy, pain medications, or the use of antibiotics.
- Painful diagnostic tests - should they be performed?

OR

- I do not want efforts made to prolong my life, and I do not want life-sustaining treatments to be provided or continued.

Be sure to include the name, address and phone number of your primary care doctor, any specialists, family members and the executor or trustee of your estate to have this medical information in their files. Have the Advanced Directive notarized or signed by two witnesses.

Your Advance Directive should be as clear as possible and kept available. In an emergency situation, there is often confusion and action is often needed immediately. Advance Directives may be difficult to interpret and can prevent your true intent from being carried out. A new directive form has been developed that will clearly communicate your choices for end-of-life care. It is called a Physician Orders for Life-Sustaining Treatment (POLST) form and can be found at www.polst.org.

- **Legal Will**

Preparing a legal will is one of the most important responsibilities you have. Make this a priority. Get in touch with your attorney.

Be sure to review your will periodically to keep your information up to date. Revise your will appropriately if you divorce, separate, remarry, or if the status of your named heirs changes.

Be prepared to include information about the executor (the person you name to carry out the terms of your will), your family and children, anyone you wish to “disinherit,” your assets, tax implications, gifts, trusts, revocable living trust, life insurance and charitable contributions.

- **Persons to notify**

Include the names, addresses and phone numbers of doctors, attorneys, employers, relatives, friends, business associates, the executor or trustee of your estate, religious and social organizations.

- **Arrangements for your body**

It is important to make decisions regarding organ donations and burial.

- **Obituary**

You can help your family by providing information about your place of birth, career background, education, special achievements, military service, involvement in organizations, hobbies, and memorial contribution preferences.

- **Memorial service and funeral instructions**

Your clergy can help provide guidelines regarding mourning or burial rituals. Notify a family member or friend regarding this information.

- **Benefit information**

List benefits from life insurance, pension and profit-sharing plans, including Keogh plans, IRAs, Social Security, Medicare, supplemental medical insurance, veteran's benefits or worker's compensation benefits.

- **Assets and liabilities**

Include information about bank and savings assets, loans and first or second notes.

- **Insurance information**

Provide the documentation for each insurance policy as well as contact names, addresses and phone numbers.

- **Home and personal property inventory**

A household inventory is a practical way of listing your belongings, identifying each item, specifying its location, estimating its value and naming the heir to whom you're giving it.

- **Your personal or "ethical" will**

This is a rare opportunity to take the time to express your innermost thoughts and life philosophy for your family and friends. You might also want to write a personal note or a rich family history for your loved ones or specific personal messages to each of them. You might want to record your thoughts on audiotape, videotape or DVD. Include any diaries, pictures or personal stories you'd like to pass on.

The goal is to live and die with dignity, minimal suffering, and a feeling of deserved honor, respect, and esteem.

Legacy of Love: End-of-Life Forms

The forms shown in this section were adapted from work developed by Elmo Peterle and formerly published in Everyone's Guide to Cancer Supportive Care (Reference in Appendix H). Please be aware that these are **only examples**. Some of these forms may vary by State or personal preference. These are just suggestions and can be used according to your personal will.

TO SEAL YOUR CARD AT HOME —WRAP IN SCOTCH TAPE			
MEDICAL EMERGENCY WALLET CARD			
NAME	SS NO.		
	DOB / /		
ADDRESS			
	TEL. /		
NEAREST RELATIVE	TEL. /	CITY	
PHYSICIAN	TEL. /	CITY	
CLERGY	TEL. /	CITY	
DIAGNOSIS			
MEDICATIONS			
LEGAL WILL YES <input type="checkbox"/> / NO <input type="checkbox"/>		LOCATION OF DOCUMENTS	

Advance Directives Location _____			
Durable Power of Attorney for Health Care			
Desig. Agent	Tel.	/ City	
Prehospital Do Not Resuscitate (DNR) (Declaration to Physician)			
Resuscitation:	Chest Compression	Mechanical Ventilation	Drug Therapy
Acute (Reversible)	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>
Chronic (Incurable)	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>	YES <input type="checkbox"/> NO <input type="checkbox"/>
Organ Donation:	Cornea Y <input type="checkbox"/> N <input type="checkbox"/>	Liver Y <input type="checkbox"/> N <input type="checkbox"/>	Bones Y <input type="checkbox"/> N <input type="checkbox"/>
	Heart Y <input type="checkbox"/> N <input type="checkbox"/>	Skin Y <input type="checkbox"/> N <input type="checkbox"/>	
	Kidney Y <input type="checkbox"/> N <input type="checkbox"/>	Middle Ear Y <input type="checkbox"/> N <input type="checkbox"/>	
Signature		Date / /	
Witness		Relationship	

← **Fold on dotted line**

**ADDITIONAL CONSIDERATIONS FOR THE ADVANCE DIRECTIVES
MY SPECIFIC PREFERENCES FOR LIFE SUPPORT (HEROIC MEASURES)**

People's preferences for use or non-use of life-sustaining measures may vary depending upon the specific life-sustaining measure being considered. In addition, preferences are influenced by different health conditions. Below are several health situations you may encounter. Please check which life-sustaining measures you want, do not want, or are undecided about for each of these different situations. In situation 5, you may put your own situation if it has not been covered. If you would like a limited trial only, place a T in the "I want" column.

NAME _____
 DATE _____
 WITNESS _____
 WITNESS _____
 (Please use the same witnesses as on Durable Powers Form)

	Situation 1			Situation 2			Situation 3			Situation 4			Situation 5		
	I WANT	I DO NOT WANT	UNDECIDED	I WANT	I DO NOT WANT	UNDECIDED	I WANT	I DO NOT WANT	UNDECIDED	I WANT	I DO NOT WANT	UNDECIDED	I WANT	I DO NOT WANT	UNDECIDED
LIFE-SUSTAINING MEASURES															
1. Cardiopulmonary Resuscitation															
2. Mechanical Breathing															
3. Artificial Food & Fluids															
4. Painful or Potentially Harmful Diagnostic Tests															
5. Antibiotics															
6. Include here any other directives important to you															

PERSONS TO NOTIFY AFTER DEATH	
Directory of Officials, Relatives, and Friends	
Clergy	
Telephone	
Office Staff	
Telephone Number(s)	
Funeral Director	
Telephone	
For Organ Donation	
Contact	
Telephone	
Attorney	
Telephone	
Accountant	
Telephone	
Executor/Executrix of Will	
Telephone Number(s)	
Life Insurance Agent	
Telephone	
Bank Trust Officer	
Telephone	
Social Security Administrator	
Veterans Administrator	
ALSO NOTIFY	
Other Relatives and Close Friends	Telephone Number(s)
Signature	Date
Spouse/Partner	Date

It is also a good idea to create a list that includes names and addresses of relatives, friends and associates who should be notified.

OBITUARY

Name	
Notes about life and achievements	
Birthplace	
Career	
Hobbies	
Organizations	
Names of Relatives	
Achievements	
College	Degree(s)
Military Service	
Memorial Donations	
Preferred Funeral Arrangements	
Place of Funeral Service	Time
Additional Information or Instructions	
Signature	Date
Spouse/Partner	Date

ARRANGEMENTS FOR YOUR FUNERAL/MEMORIAL SERVICE	
Type of burial memorial	
<input type="checkbox"/> Cremation <input type="checkbox"/> Casket	
In church/temple	
At funeral home	
Open or closed casket	
At the gravesite	
The Committal should be <input type="checkbox"/> public <input type="checkbox"/> private	
If cremation, instruction for ashes	
Specific desires for the service (i.e., suggested readings/music)	
Viewing	
Grave marker (tombstone)	
Decoration	
Flowers	
Inscription	
Casket: <input type="checkbox"/> wood <input type="checkbox"/> metal	
Burial: <input type="checkbox"/> shroud <input type="checkbox"/> street clothes	
Gravesite	
Family plot located	
Previously purchased gravesite location	
Memorial gifts/donations to agencies or foundations	
Other comments, instructions, or wishes	
Signature	Date
Spouse/Partner	Date

Forms adapted from *Getting Your Affairs in Order: Make Life Easier for Those You Leave Behind*, by Elmo Pettele, Robert C. Kahn, and Marianne Rogoff. Bolinas, CA, Shelter Publications, 1993.

APPENDIX H Additional Resources

Ethical Wills

Baines, Barry K., MD: "Ethical Wills: Preserving Your Legacy of Values,"
www.ethicalwill.com

-- *Ethical Wills: Putting Your Values on Paper, 2nd ed.* Cambridge, Da Capo Press: 2006.

-- *The Ethical Will Writing Guide Workbook* and *The Ethical Will Resource Kit*. – You can order this online at Amazon.com, or www.ethicalwill.com

Baines and Wm. Bradley Rouse, *Putting Your Values on Paper™: The Ethical Will Writing Guide* – "Computer software to help you complete a draft copy of an ethical will." Available directly from www.ethicalwill.com

Riemer, Jack and Nathaniel Stampfer. *So That Your Values Live On: Ethical Wills and How to Prepare Them*. Woodstock: Jewish Lights Publishing, 2006.

Turnbull, Susan B. *The Wealth of Your Life: A Step-by-Step Guide for Creating Your Ethical Will* (Spiral-bound). Benedict Press: 2005.

Personal Legacy Advisors, LLP: *Your Ethical Will: What you have learned is as valuable as what you have earned*, www.yourethicalwill.com/index.html, 2007.

The Legacy Center: an organization dedicated to preserving stories, values, and meaning for individuals, communities, and organizations. Contact at: 1629 W. 25th St. Minneapolis, Minnesota 55405 Tel: (612) 333-2833; E-mail: thelegacycenter@yahoo.com

Life Tapes

Rosenbaum, EH, Rosenbaum, IR. Improved communication technique for consultative interviews. Abstract Proc. of AACR and ASCO, 18:316, March, 1977.

Rosenbaum, EH, Rosenbaum IR. Achieving Open Communication with Cancer Patients Through Audio and Videotapes. *Journal of Psychosocial Oncology*. Vol 4(4), 1986, 91-105.

Rosenbaum EH, Garlan RW, Spiegel D, et al. The Life Tape Project: Increasing Family Social Support and Symbolic Immortality with a Brief Existential Intervention for Cancer Patients and their Families. *Omega* Vol. 53(4), 321-329, 2006.

Creation of a Family Tree

www.ancestry.com - Store where you can buy various resources, and the Family Tree Maker® software. The site also sells a "bundle" where it combines the software with "The Official Family Tree Maker Guide." Prices and editions are

subject to change so please check the website for the most up-to-date information.

www.genealogy.com

www.rootsweb.com

www.familysearch.org

www.genealogytoolbox.com

Family Tree Magazine - "Getting organized and knowing the proper way to address government agencies and organizations can help you get quicker, more effective results. Family Tree Magazine has created forms that can help you access and organize your family history information. All our research forms are available in two formats: text and portable document format (PDF). The text versions give you the basic form structure in files you can open in your word-processing software. You can print, edit or even type your information right in the file. The PDF versions are read-only files with snazzier designs—they're suitable for displaying or sharing your research with others"

www.familytreemagazine.com/forms/download.html

Access Genealogy - This site has a great list of resources divided by topic which you can search at www.accessgenealogy.com/library

Genealogy Books Online - "Welcome to our library. Feel free to grab a cup of java, pull up a chair, and enjoy the many manuscripts available from this one spot. We have embarked on a crusade to bring to you volumes and volumes of historical books and data unavailable elsewhere on the web. Everything in our own library is free for you to read. You may even take a page or two for your own personal use. But please, respect the work and effort that the many volunteers have exerted and respect their rights to their property. Some of the books listed here are located at different websites than our own, where this is the case, we provide knowledge of who published it online. Now sit back and enjoy!"

FamilyTree.com - "A Guide to climbing your family tree"

Hartley, William G. *The Everything Family Tree Book: Finding, Charting, and Preserving Your Family History*. Adams Media Corporation: Holbrook, 1998.

Mills, Elizabeth Shown. *Evidence Explained: Citing History Sources from Artifacts to Cyberspace*.

Creation of a Scrapbook

www.scrapbook.com - "Our mission is to guide people through the memory preservation process and to keep them motivated to document life through: Providing the products they need at the right price. Supporting them through education. Inspiring them through creative outlets such as galleries, forums and blogs. Giving them a home on the web where they can connect with Scrapbookers worldwide."

www.bhgscrapbooksetc.com - Official Scrapbooking site of the magazine *Better Homes and Gardens*.

www.creatingkeepsakes.com/scrap/basics - good site for scrapbooking beginners.

www.scrapbookexpress.com

www.busyissybeads.com - "My Family Tree Begins With Me" and "My Family Tree - Those Before Me" Journal Boxes available for \$10.00 each or \$18.00 for the set. Each box contains 60 questions or prompts to help you build a scrapbook of your family history.

Legacy of Love

www.acponline.org/ethics/papers.htm - Papers by the ACP (American College of Physicians)-ASIM End-of-Life Care Consensus Panel.

www.aarp.org/families/legal_issues/ - Legal issues are discussed in an AARP article, see "Make a Will" by Mary Randolph, J.D. - step-by-step instructions with links to additional resources.

www.nolo.com/index.cfm - great resource for finding simple programs for writing wills, organizing legal papers and completing other end-of-life matters.

Additional Resources and Readings

Albom, Mitch. *Tuesdays with Morrie: An Old Man, a Young Man, and Life's Greatest Lesson*. New York: Doubleday, 1997.

Callanan, Maggie and Patricia Kelley. *Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying*. New York: Bantam Books, 1997.

Canfield, Jack L. and Mark Victor Hansen, *Chicken Soup for the Grieving Soul: Stories about Life, Death and Overcoming the Loss of a Loved One*. Deerfield Beach: Health Communications, Inc., 2003.

Chopra, Deepak. *Life after Death: The Burden of Proof*. Harmony, 2006.

Coelho, Paulo. *Alchemist*. Trans. Alan R. Clarke. San Francisco: HarperCollins, 2005. Life Chronicles®, a California non-profit organization, records audio, video, and written messages of comfort, reassurance and lifetime memories for those with health crises or uncertain futures. Information is available at www.lifechronicles.org

Nuland, Sherwin B. *How We Die: Reflections on Life's Final Chapter*. Vintage, 2005.

Rinpoche, Sogyal, Patrick Faggney, Andrew Harvey. *The Tibetan Book of Living and Dying: The Spiritual Classic & International Bestseller*. New York: HarperCollins, 2002.

Ko, Andrew MD, Malin Dollinger, MD, Ernest Rosenbaum, MD. *Everyone's Guide to Cancer Therapy*, 5th ed. Kansas City: Andrews McMeel, 2008.

Rosenbaum, Ernest, MD, David Spiegel, MD, Patricia Fobair, LCSW, MPH, Holly Gautier, RN.. *Everyone's Guide to Cancer Survivorship: A Road Map For Better Health* Kansas City: Andrews McMeel, 2007

Rosenbaum Ernest MD, and Rosenbaum, Isadora. *Everyone's Guide to Cancer Supportive Care: A Comprehensive Handbook for Patients and Their Families*. Kansas City: HarperCollins, 2005.

-- *Inner Fire: Your Will to Live*. Plexus, 1999.

The Legacy Project

The legacy project provides a structured way to collect, save, and store family history information with stories, events, photographs, audio and video recordings, a family tree, and a scrapbook with stories, articles, pictures and documents. This can be a practical way of “capturing” a family’s history and make a family legacy of many of the memories and precious events which represent a person’s and family’s life story.

It also provides guidance on how you can plan your personal, financial and end-of-life care to help simplify necessary family duties and decisions so that your wishes are carried out.

Invictus

by William Ernest Henley

*Out of the night that covers me,
Black as the Pit from pole to pole,
I thank whatever gods may be
For my unconquerable soul*

*In the fell clutch of circumstances
I have not winced nor cried aloud.
Under the bludgeonings of change
My head is bloody, but unbowed.*

*Beyond this place of wrath and tears
Looms but the Horror of the shade,
And yet the menace of the year
Finds, and shall find, me unafraid.*

*It matters not how strait the gate,
How charged with punishments the scroll,
I am the master of my fate:
I am the captain of my soul.*