

Dignity Therapy



FINAL WORDS
for FINAL DAYS

Harvey Max Chochinov

OXFORD

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"The Curtain," by Robert Pope, acrylic, 1980. With permission of the Robert Pope Foundation.

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Published by Oxford University Press, Inc.

198 Madison Avenue, New York, New York 10016

www.oup.com

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Library of Congress Cataloging-in-Publication Data

Chochinov, Harvey Max.

Dignity therapy : final words for final days / Harvey Max Chochinov.

p.; cm.

Includes bibliographical references and index.

ISBN 978-0-19-517621-6 (hardcover : alk. paper) 1. Terminally ill—Psychology. 2. Palliative treatment.

3. Terminal care—Psychological aspects. I. Title.

[DNLM: 1. Palliative Care—methods. 2. Terminally Ill—psychology. 3. Personhood. 4. Quality of Life.

5. Right to Die. WB 310]

R726.8C483 2012

616'.029—dc23 2011016652

9 8 7 6 5 4 3 2 1

Printed in the United States of America on acid-free paper

PREFACE

Jacob, grandson of Abraham and son of Isaac, is the third patriarch of the Jewish people. Toward his final days, as he sensed his own death approaching, he summoned his family to provide them with some final thoughts and reflections. It is hard to imagine how he might have known where to begin. Over the course of his 147 years, he had taken four wives, Rachel, Leah, Bilhah, and Zilpah. Between them, they had borne him thirteen children, with the offspring of his sons destined to become the twelve tribes of Israel, following the Exodus, when the children of Israel settled in the Land of Canaan. As a young man, he had deceived his father and his older brother Esau by receiving the blessing of the first-born. Later, during a vision of a ladder reaching unto heaven, he heard the voice of God and obtained His blessings. While returning to Canaan, hearing that Esau and his army were on their way, he again encountered God, this time in the form of an angel with whom he fought through the night.

Once his family had gathered by his side, history does not record whether Jacob recalled any of these events. What we do know is that he used this occasion to bless his children, each in their own special way. No doubt, his parting words for Reuben, his first born, were tempered by the not so minor issue of incest; Reuben had slept with Bilhad years earlier, and they had never spoken of it, at least not up until now. Between Jacob and his second and third sons, Simeon and Levi, there was the matter of Shechem. To avenge their sister's rape, Simeon and Levi had killed all the men of Shechem, plundered their property, women and children. Jacob did not approve of their actions, and for this reason, saved his primary blessing for his fourth born, Judah. From his eleventh child, Joseph, whom he fathered at the age of 91, Jacob extracted the promise to have his remains placed in the Cave of the Patriarchs with Leah, and Abraham, Sarah, Isaac, and Rebecca. Following his final instructions, Jacob—or as he was then known, Israel—died and soon after, was buried in Canaan.

In Jacob's final words to his family, history records its first *Ethical Will*. Ethical wills, which were initially conveyed orally, were designed as a way of passing traditions and values from one generation to the next. What might Jacob have been feeling over three thousand years ago as he undertook this task? On the one hand, he no doubt saw this as a way to pass along moral values for generations to come.

Perhaps he took some comfort in knowing that, in spite of death, the lessons and insights he most cherished would transcend his departure. In this way, perhaps he felt he was denying death its ability to destroy those parts of him—those beliefs, insights, and lessons—that defined his very essence. There must also have been a feeling, a sense that in spite of his advanced age and fragile health, he was still valued and his life, or whatever little of it that remained, was cherished by those closest to him.

Unlike Jacob, most people have not spoken directly with God, nor taken multiple partners, nor spawned a bevy of children destined to become an entire nation. On the other hand, is it not conceivable that, like Jacob, mere mortals might find comfort in knowing their final thoughts and words are deemed precious; that in spite of illness, they are still valued; and, perhaps, that it is possible to leave something, which will outlive them and be a remembrance to those left behind?

These, of course, are not new ideas. As long as humankind has grappled with mortality, it has found ways to leave behind testimony of its prior existence. Whether one considers prehistoric paintings on cave walls or contemporary monuments that dot the modern landscape, each declares: “*We were here! Don’t forget us.*” Ways of affirming this declaration are intricately woven into the human drama. A poem, a piece of music, a work of art, an achievement of technological ingenuity—these can outlive their maker, as can the stories each of us has to tell. And might the sharing of these stories provide a source of comfort, for those about to die, as well as those soon to be bereft?

Over the past few decades, the potential for meaning, purpose, and affirmation to assuage suffering has received careful attention in the field of palliative care. Dame Saunders, the founder of the modern hospice movement, said, “You matter because you are you, and you matter to the end of your life.”¹ The challenge is how to transform this credo into the delivery of better palliative care. That someone *thinks* you matter *matters naught*, unless they are able to convey that in a way that can readily be perceived and internalized. Jacob’s family managed to accomplish this by gathering at his side and taking in his every word, as if each were a precious gem to be held and treasured forever.

Throughout his lifetime, Jacob’s inspiration came from heaven above. On the other hand, the inspiration for Dignity Therapy—a novel, individualized psychotherapy targeting people with life-threatening and life-limiting conditions—came from patients taking part in a program of palliative and end-of-life care research.²⁻⁵ While Dignity Therapy may resemble the Ethical Will, life review, personal narrative, or other existential psychotherapies, what differentiates it is its empirical basis. Dignity Therapy can promote spiritual and psychological well-being, engender meaning and hope, and enhance end-of-life experience. It can help people prepare

for death and provide comfort in whatever little time they have left. As ephemeral as these outcomes may seem, it is important to recognize that the components of Dignity Therapy, its mode of administration, and the arguments affirming its efficacy—for patients and for their families—are based exclusively on careful, detailed, and novel studies focused on palliative end-of-life care.

Since the conceptual framework underpinning Dignity Therapy was first published in the *Journal of the American Medical Association* in 2002,⁶ this therapeutic modality has begun to take hold in many countries around the world. To date, Dignity Therapy has been studied, or is being studied, in Canada, Australia, the United States, China, Japan, Denmark, Sweden, Scotland, Portugal, and England. In addition, Dignity Therapy training workshops have been held in Hong Kong, Taiwan, Argentina, and New Zealand. Despite some minor regional issues and subtle cultural variations, palliative care clinicians worldwide have enthusiastically embraced Dignity Therapy. More important, patients approaching death and their



Rembrandt Harmensz van Rijn (1606-1669). Jacob blessing his grandchildren Ephraim and Menasse in the presence of their parents Joseph and Anath. Canvas.

Photo Credit: Erich Lessing / Art Resource, NY

Germaeldegalerie Alte Meister, Museumslandschaft Hessen Kassel, Kassel, Germany.

families from far and wide have been able to benefit from this brief palliative care psychotherapy.

As with any new treatment, there is tension between wanting to disseminate its use as widely as possible and safeguarding its integrity. Hence, the need for this handbook. *Dignity Therapy: Final Words for Final Days* is the most comprehensive description of Dignity Therapy to date. Readers are offered a detailed accounting of how Dignity Therapy evolved, the current state of evidence supporting its application, and most important, a complete description of how to do Dignity Therapy. Over the years, those of us closely involved with this therapeutic approach have come to respect its potency and its ability to help patients and families from all walks of life and from all regions of the world. We have also come to appreciate that Dignity Therapy, like any other psychotherapy, takes time to master. While this manual will provide you the basics, your therapeutic skill and effectiveness will no doubt evolve over time.

Jacob's final words to his family consisted of sacred blessings and instructions for his burial. Since its inception, Dignity Therapy has been used hundreds if not thousands of times to capture a myriad of circumstances that human beings find themselves in as they exit this world. It is my sincere hope that the practice of Dignity Therapy enriches your work. Most of all, I hope that Dignity Therapy enhances your patients' quality of life and quality of dying, as they confront the inevitability of death.

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ACKNOWLEDGMENTS

While dying is inevitable, dying poorly ought not to be. As a psychiatrist and researcher working in palliative care, I am humbled by the capacity of human beings to cope with various painful things, which life invariably brings. I am also humbled by my clinical colleagues' abilities to alleviate pain, lessen suffering, and provide comfort to patients nearing their final days, which is why I think most people have the wrong idea about palliative care. If life is akin to walking a tightrope, the chance of falling increases toward the end. Think then, of palliative care as a safety net. No one escapes falling, but palliative care can provide a softer landing. Those of us who work in this field are focused on how to help patients and families achieve that softer landing. Knowing that it is indeed possible makes this work intriguing, rewarding, and, more than occasionally, awe inspiring.

Of the things I have done in palliative care over the past twenty years, none have been quite as gratifying and personally engaging as Dignity Therapy. Before that work began, my research had examined various dimensions of end-of-life care. Given my training, my natural inclination has been to study the emotional aspects of approaching death. At the outset of my research career, this meant a careful examination of clinical depression in the terminally ill. This led to developing ways to screen for depression, along with studies examining desire for death, will to live, and factors that might influence a patient's wish to go on living in the face of a dire prognosis.

Although this was useful in its own way, it was largely descriptive. In other words, it helped those of us working in palliative care to identify various problems facing dying patients and their families, without necessarily offering any particular solutions (this may be the reason I decided not to become a neurologist; the diagnosis to treatment ratio just seemed too high to be all that much fun). Little did I realize that studying dignity was going to change everything. It is difficult, if not impossible, to respond to problems before being able to clearly articulate what those problems are. The early work on dignity began to identify some of the things that influence a patient's sense of dignity, thus placing those issues on the palliative care radar.

As the work on dignity was coming together, so too was my wonderful research team. One of my dearest friends and colleagues, Dr. Linda Kristjanson, was there from the very outset of the dignity work. Her research skills, integrity, and support

have been, and continue to be, a blessing. Dr. Susan McClement is someone that I often refer to as my academic spouse. We share our ideas and work side by side, seeing to it that the research emanating from the Manitoba Palliative Care Research Unit is meaningful and honest. Dr. Thomas Hack has been a core part of our “dignity team” from its very inception; he and I and Sue spent more hours conducting the qualitative data analysis that resulted in the Dignity Model—which forms the basis of Dignity Therapy—than it took to collect the data itself. Dr. Mike Harlos is one of the most talented palliative care clinicians I know. He provides our team an astute clinical eye and a perspective informed by years of providing care to countless patients and their families. Dr. Tom Hassard is our biostatistics maven. His gentle manner, skill, and humanity make him yet another delightful member of our team.

Then there is my team of research nurses. In case anyone has ever wondered why a place like Winnipeg manages to host a successful palliative care research program, the simple answer is this: my research nurses are the best. Katherine Cullihall is compassion personified. She helped me sort through many of the details of the Dignity Therapy protocol as we observed what did and did not work. At this point in time, no one has more experience delivering Dignity Therapy than Katherine. Beverley Cann participated in the randomized control trial of Dignity Therapy. Her combination of honesty and intellect make her an invaluable member of our team; she was also instrumental in organizing and editing this current text. Last but certainly not least is Sheila Lander. Sheila was my very first research nurse and the person who helped gather data for so many of our team’s earliest studies. After a brief hiatus, she returned to our team to coordinate the international randomized control trial of Dignity Therapy. As a result, her winning smile and winning ways are now well known and appreciated by my colleagues in New York City and Perth, Australia.

While other members of my team were not directly involved in Dignity Therapy, they deserve mention, as they are part of what makes coming into work each day such a joy. Dr. Nancy McKeen is my research psychologist, and helps ensure that funding keeps coming into the unit to support our work. Miriam Corne is my newest research nurse; if caring came in a bottle, it would surely be called Miriam. Dr. Genevieve Thompson was my postdoctoral student and is now a research associate. Her talent—like her capacity to produce outstanding work—is enormous. Dr. Shane Sinclair is my current postdoctoral student; his enthusiasm and enquiring mind are encouragement to keep looking at the world as a place filled with possibility. Angela Saj is my extraordinary administrative assistant. Without her savvy and guidance, I am convinced nothing would ever get done!

For nearly 25 years, I have been blessed to call Dr. William Breitbart my friend and mentor. In so many ways, Bill is the brother I never had. He was my supervisor

when I first came to train at Memorial Sloan-Kettering many years ago. To this day, he can make me laugh like no one else can. Bill and his team took part in the international randomized controlled trial of Dignity Therapy. Other key mentors and supporters along the way include Drs. Jimmie Holland, Keith Wilson, Kathleen Foley, Dhali Dhaliwal, Brent Schacter, William Bechuk, Samia Barakat, Murray Enns, Brian Postl; Jill Taylor-Brown and John Farber; Senator Sharon Carstairs, Shelly Cory, and Josette Berard.

It is hard to write a book that deals with mortality and the innate vulnerability of human beings without reflecting on my own life. In so many ways, I have been lucky. My parents, Dave and Shirley Chochinov, raised me in a loving and secure home. I married my best friend, Michelle; and our children, Lauren and Rachel, have grown into kind, grounded, intelligent young women. Like most people who have lived into midlife, I have experienced my share of loss. Never to be forgotten include my grandparents, Joseph and Florence Wolodarsky, Max and Pessa Chochinov; my in-laws, Sam and Sheila Sellers and brother-in-law, Shep Nerman; aunts and uncles Jack and Shirley Wolodarsky, Marilyn and Martin Levitt, Fred Lacovetsky, Sid Bagel, Larry Usiskin, Harold Shukster, Norman Chochinov; and my dear sister Ellen Chochinov, to whom this book is dedicated.

Finally, I want to acknowledge the patients and families who took part in Dignity Therapy. Each participated despite profound vulnerability, when time itself was a scarce and ever-decreasing commodity. In doing so, they helped demonstrate how Dignity Therapy can be applied to those whose lives are drawing to a close. I am so grateful for their generosity. I can only hope that they considered having Dignity Therapy a fair exchange for their precious time. You, the reader, are about to hear many of their stories. Determining whether Dignity Therapy might play a role in your practice, and perhaps provide patients nearing death a softer landing, will be for you to decide.

Harvey Max Chochinov
December 12, 2010

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CONTENTS

1. Dignity and the End of Life	3
Why Study Dignity?	3
Dignity and Empirical Research	5
The Model of Dignity in the Terminally Ill	8
Illness-Related Concerns	9
Dignity-Conserving Repertoire	13
Social Dignity Inventory	27
References	34
2. Moving Dignity into Care	36
How the Dignity Model Informs Dignity Therapy	37
Form	37
Tone	40
Content	42
Dignity Therapy Revealed	42
The First Clinical Trial Is Published	43
What About Families?	46
Gold Standard Evidence	48
Time to Move On	51
References	52
3. Introducing Dignity Therapy to Patients and Families	54
Patient Selection for Dignity Therapy	54
Who Should Be Approached to Take Part in Dignity Therapy?	56
Who Should Not Take Part in Dignity Therapy?	58
A Typical Dignity Therapy Introduction	61
Some Common Questions and Responses	62
The Dignity Therapy Question Protocol	70
References	73
4. Doing Dignity Therapy	74
Setting Up the Dignity Therapy Session	75
Answering Remaining Questions	75

Arranging the Therapeutic Setting	75
Using an Audio Recorder	76
Family or Friend Participant	77
The Role of the Dignity Therapist	77
References	99
5. The Generativity Document	100
The Rationale for Editing Dignity Therapy Transcripts	101
Transcribing the Audio Recorded Interview	102
Editing the Verbatim Transcript	107
Cleaning Up the Transcript	108
Clarifying the Transcript	110
Correcting Time Sequences	112
Finding a Suitable Ending	113
The Patient Has the Final Say	114
6. From Start to Finish	118
Dave's Dignity Therapy	119
Dave's Generativity Document	138
Bill's Dignity Therapy	145
Bill's Generativity Document	164
7. Moving Forward	173
Is There Currently Sufficient Evidence to Support the Application of Dignity Therapy?	174
How Do I Become Skilled Enough to Implement and Improve My Abilities to Deliver Dignity Therapy?	175
How Much Does Dignity Therapy Cost and How Can Resources to Support It Be Found?	176
What If Family Members or Volunteers Want to Take on This Work? Is That an Option?	177
Can Dignity Therapy Be Done by a Therapist Who Knows the Patient Well?	179
Are There Still Things About Dignity Therapy Worth Studying? If So, How Might Researchers Take Up This Work?	181
What About Other Modes of Generativity?	183
What About Dying Children? Does Dignity Therapy Have a Role to Play?	183

What About the Issue of Culture and Dignity Therapy?	184
How Should Dignity Therapy Be Evaluated?	185
Closing Thoughts	185
References	187
Index	189

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Dignity Therapy

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1

DIGNITY AND THE END OF LIFE

The greatest mistake in the treatment of diseases is that there are physicians for the body and physicians for the soul, although the two cannot be separated.

— Plato

WHY STUDY DIGNITY?

Imagine for a moment you are nearing the end of life. There is no way of knowing exactly when this might occur. You could be in the prime of life, when there is still so much to live for, or in your twilight years, after you have had the opportunity to make of your life what you will. Nevertheless, try to imagine what would determine the quality of your remaining days. Perhaps it might be how comfortable you can be made or your sense of personal autonomy. Perhaps the desire to squeeze out life's final drops would depend on the presence of people you love and cherish, and those who love you in return. What would it take, however, to arrive at an impasse when you no longer wished to go on?

Reflection of this sort begins the journey toward understanding dignity-conserving care and the underpinnings of Dignity Therapy. In fact, studies that examined the experience of people who sought help to end their lives provided our first clue to the importance of dignity in patient care. For people considering this stark choice, living, breathing, facing another day might start to feel redundant. Perhaps the most tangible understanding of this choice comes from Holland, where euthanasia and assisted suicide have been practiced for several decades. The Act regulating its practice came into effect in 2002. This Act allows physicians, under certain conditions, to grant the request to hasten death of patients with “unbearable

suffering.” In order to study the consequences of this legislation, the Dutch government commissioned an examination of the prevalence of Medical Decisions to End Life or MDEL.

The first nationwide Dutch study on euthanasia and other Medical Decisions to End Life (MDEL) consisted of three data sets, including mailed questionnaires to the physicians of 7000 deceased persons, a prospective survey of physicians regarding 2250 deaths, and detailed interviews with 405 physicians who had participated in hastening their patients’ deaths by euthanasia or physician-assisted suicide.¹ Alleviation of pain and symptoms with high dosages of opioids that might shorten the patient’s life was the most important MDEL, accounting for 17.5% of all deaths. In another 17.5% of patients, death could be ascribed to a non-treatment decision. These were instances when a decision to withhold or to withdraw a treatment no longer deemed to be justified preceded the patient’s death. Euthanasia, that is, the administration of lethal drugs at the patient’s request, was reported in 1.8% of all deaths. Death from physician-assisted suicide was reported in less than one half of 1%. Another study in 2005 reported that of all deaths in the Netherlands, 1.7% resulted from euthanasia and 0.1% from physician-assisted suicide.² The authors speculated that this particular decrease in MDEL might have resulted from the increased use of other end-of-life care interventions such as palliative sedation.

Most health care providers would rather avoid being drawn into conversations about euthanasia and physician-assisted suicide. They assume that a patient’s expressed wish to die will force them to walk a dangerous line between not yielding to taking part in a felony on the one hand, while staving off feelings of helplessness and impotence on the other. The legal, moral, and philosophical complexities of these issues are ones that lawyers, ethicists, and policy makers will continue to argue; that said, until quality palliative care is universally available, these arguments may sometimes ring hollow. In the face of an expressed wish to die, however, the role of the health care provider is entirely unique. Clinicians must always try to appreciate the full clinical picture and respond in as therapeutically effective a way as possible. However, to respond empathically to circumstances in which patients have lost their will to live, clinicians need to understand the physical, psychological, spiritual, and existential landscape of the wish to die.

Our research has demonstrated that those who express a wish for an earlier death are more likely to be depressed, experience significant discomfort due to uncontrolled pain, and report less social support.³ Existential considerations, such as hopelessness, burden to others, and sense of dignity, also have a marked influence on patients’ will to live. The Dutch experience, however, offers some important clinical insights, not only about how many patients avail themselves of MDEL, but also why these patients seek out this particular means of ending their lives. Paul van der Maas

and his colleagues¹ faced a difficult challenge—the people whose motivation to die was of central interest were no longer alive to share their experiences. To address this rather significant methodological problem, the researchers contacted physicians who had signed death certificates, indicating that the patient had died either as a result of euthanasia or assisted-suicide. While not an ideal research design, under the circumstances, it was likely the best choice available. According to these physicians, “loss of dignity” was the most common reason given for hastening the death of their patient, cited in 57% of cases. Other reasons included pain alone in 5% of cases, pain as part of a constellation of symptoms (46%), being dependent on others (33%), tiredness of life (23%), and unworthy dying (46%).¹

The reported connection between “sense of dignity” and how it might inform the wish to go on living is as problematic as it is interesting. After all, in the van der Maas study, physicians, rather than patients themselves, were the primary informants describing the role that loss of dignity played in the wish for earlier death. This study raises another question: how does one define a concept as nebulous as “dignity?” Without having given them an a priori definition of how to apply the term dignity to the experiences of their now-deceased patients, physician respondents were left to their own devices, to their own idiosyncratic interpretations of what dignity meant and to determine if, or how, it had been undermined or even violated. These questions were encouragement enough for our research team to launch a new series of investigations; after all, if dignity is worth dying for, surely, it is worth carefully studying.

DIGNITY AND EMPIRICAL RESEARCH

Defending dignity in health care is a bit like defending motherhood and apple pie. At first glance, it might seem unnecessary and perhaps not even worth the bother. After all, dignity, and all that it implies, strikes a chord that resonates with most health care professionals. Like *love* or *joy* or *faith*, one might conclude that *dignity* should be left to intuition and certainly not placed under an empirical lens. While the health care literature is replete with references to dignity as it relates to quality medical care, there is little consistency with how the term is applied. So, for example, people might hold diametrically opposed opinions on various health care practices—euthanasia, assisted suicide, terminal sedation, artificial hydration and nutrition—and ultimately argue that *dignity* is their trump card. Hence, the *right to die* argument may be framed as the ultimate expression of individual autonomy and, therefore, consistent with human dignity, while opponents of this argument see the purposeful taking of human life as an egregious assault on human dignity.

The concept of dignity is afforded a high profile in end-of-life care. Most palliative care providers would agree that dignity is a philosophical cornerstone of their