END OF LIFE

Project Overview

Jan 2015
This document serves as an introduction to the End of Life project. Outlined are the issues and subject matter to be addressed, as well as the approach regarding the storytelling process, engagement strategies, impact potential, and key contributors.

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To foster practices allowing us to lead more meaningful as well as connected lives until our death by bringing clarity to the ways we confront and support the dying.
Dying has remained in the shadows of our cultural conversations.
END OF LIFE is a non-fiction moving image project focusing on intimate stories of the end of life, illuminating the systems or cultures that surround the terminally ill both in the U.S. and abroad.

The dying process is very much a part of living - of being alive. However, we so often consciously and unconsciously create distance and division - physically, intellectually, and socially, from those approaching end of life, thus positing dying persons into the realm of death while death has yet to occur.

Conversations about dying can often be suppressed as they stir uncomfortable feelings and fear. This crucial aspect of our lives remains mostly hidden, thus people experiencing the end of life can be marginalized - experiencing fear, loneliness, and even shame. The general public is not very aware of the various ways the dying are cared for, or of the difference the compassionate approach, as practiced by the hospice movement, can make in allowing for a dignified end of life. As death is inevitable, it remains a curiosity as to why so many aspects of culture work to limit our potential for exercising intentionality in having a ‘good death’.

To paraphrase Helen Stanton Chapple from her book No Place for Dying: A distance, and often tension, exists between safe places that support a dying situation such as hospice or palliative care and the wider social invisibility and dismissal that adheres to these places. Our contemporary attitudes most often characterize this seclusion as “privacy”, however this position raises serious questions: (1) How does this line-drawing between public and private, between rescuable and dying, occur? (2) How does the culture of the United States, and other cultures, both benefit from and reinforce such removal of the dying experience? (3) How might the answers to these questions help illuminate the marginalization of the hospice experience?
How might our society evolve to actively address the cultural and systemic deficiency of compassionate care for the dying?

How might we embrace end of life in ways that do not marginalize the terminally ill?

In what ways might we shift from our current lack of information and resources regarding ways to navigate options for end of life?
The composition of the U.S. population in regard to age will shift dramatically in the 21st Century: for the first time in the nation’s history more than 20% of people in U.S. will be 65 years old and over. The rate of this shift is occurring at an unusual pace due to the impact of aging Baby Boomers. For example, in 2007 the U.S. population age 65 and over was 12%, with projections for this demographic to reach 20% before the year 2040. The systemic strain on an already complex and flawed health care infrastructure can be profound.
Our story focuses on people at the end of life, the spaces they inhabit, the lines that are drawn between the systems surrounding life and the systems surrounding imminent death. It is this created distance between the living and the dying that we wish to illuminate in order to move conversations concerning end of life toward perspectives that will further our humanity. We will focus on ideas of space and place impacting the end of life process through an ethnographic approach of empathetic participation with a collection of end of life situations in a variety of contexts.

Our exploration of people experiencing end of life will include persons representing a variety of groups with regard to age, socio-economic status, and ethnicity. The role of various religious faiths, practices, and end of life rituals will factor into some of these cases, as well as a variety of urban, suburban and rural contexts. While most stories will take place in America, we will also capture stories in India, Canada, Thailand, and Mexico.

We will approach the filming process with a “beginner’s mind,” being open to the person experiencing end of life as well as remaining alert to our own preconceived notions and fears as they arise. In this way those who are “actively” dying - the characters of our project, and those whose death is not yet imminent - the filmmakers, may come to inhabit a shared space. We sense that this space may become the true subject of the film.

The portraits of the dying will also sometimes involve the caregivers such as physicians, nurses, aides as well as family members. We will document the dying as they relate to others, and also alone, during moments of silence and introspection. Whether they feel like speaking to the camera or not, we will record both situations equally. We aspire to be silent witnesses, cognizant of the fact of our intrusion into an inconceivably challenging situation. Our aim is to produce a work that is a quiet, formally rigorous testament to the dignified, mysterious, potentially frightening and wondrous experience that dying can be.
Doris Johnson, age 82, recognizes the beauty of her son Richard’s eyes whenever he smiles, “they crinkle, like you’re another Clark Gable.” Yet, a moment later she believes that he is her brother, the result of the dementia she suffers. Most of the time, Doris is chipper and playfully sarcastic when we visit the Bronx nursing home where she has resided for the past three years. She reaches for her ID bracelet, over and over, wondering why she can’t tell the time, as though it were a wrist watch. An arrangement of plastic flowers might need water, she warns, despite Richard’s gentle and repeated explanation that the arrangement is fake.

As organ failure progresses, Doris could transition quickly into an active dying phase. She has had a challenging family life, save for Richard who has long been her support. “We’re old friends,” he says about his mother. “I’m always happy to help you with your projects,” she gestures to our cameras. Richard, an artist, has involved Doris in many of his films and performance pieces over the years. Now, he navigates the many decisions surrounding Doris’ comfort versus simply keeping her body alive. Richard and Doris communicate in a graceful dance around history and the present moment.
Ram Dass, originally Richard Alpert, is joyous and hospitable despite his diminished vitality at the age of 82, as compounded by a near-fatal stroke he experienced more than 15 years ago that paralyzed the entire right side of his body. He has dedicated much of his life to the teaching of aging and dying with grace.

“In our culture, almost everybody is afraid of death,” he said upon emerging from a meditative silence of many minutes during one of our first afternoons together, filming at his home in Maui. He communicates his wisdom and experiences with us in speech, silence, and gesture.

Touching his head, he says “that’s the result of perceiving our lives... up here... from our egos.” From the moment of birth begins a tension of being separate - of doing things within the struggle of reckoning with past or future. He thinks of the moment of death, and then he expresses his delight in a profound and elongated “wow!!!” followed by an expansive gesture of his hand and a broad smile.
Carol Virostek, age 71, was diagnosed with terminal abdominal sarcoma 11 years ago, and has come close to death on two occasions since that time. Carol remains active and is leading a very full and rich life in Connecticut, while the experimental drugs keeping her alive could cease to be effective, and thus cause a rapid progression toward active dying. While she has embraced the reality of her situation, her husband Paul remains too uncomfortable to address the practical matters of how Carol wishes her final weeks, days, and hours to be lived.

We have been spending time with Carol since October 2013, and continue to make regular visits, often struggling to keep up with her as she speeds (literally, sometimes cruising at 90 mph on the highway), between bible study meetings, lunch dates, and outings with her daughters and grandchildren. In between the frenetic actions of her life, Carol contemplates how she might “go gently” into that good night of the end of her life despite being a person more comfortable within the determined caring and control of a sturdy matriarch and teacher.
Miriam Cohen had a vibrant career as a children’s book author, and social justice activist. Her son Jem Cohen is a celebrated documentary filmmaker. Miriam suffered a massive stroke two years ago, and can only move her right arm and her head, a bit. She can still converse, and is a lively raconteur. Jem and Miriam appreciate our presence as storytellers and doulas, as we are able to engage Miriam in conversations around her past and her will for her future.

Miriam’s current activist cause is to use the vehicle of our project to express how much better she would feel if she were allowed to have had her pet dog Gabby join her at the nursing home. She points to our cameras and expresses that she feels hope for the world as long as we keep telling stories, and showing the truth of our lives. Miriam wants to keep working, as she has all of her life, for social justice and progress. She breaks into signing several verses from “This train is bound for glory,” the Woody Guthrie song, and then holds out her hand to me, and asks, “would you like a ticket?”
Matt Freedman is an acclaimed artist, writer, and curator. Throughout his career, he received a National Endowment for the Arts fellowship in sculpture and New York Foundation for the Arts fellowship in fiction writing. He’s housed recent solo shows in Pierogi, FiveMyles, Big&Small/Casual, Valentine and Studio 10 galleries in Brooklyn.

In 2012, he underwent radiation and chemotherapy for treatment of adenoid cystic carcinoma, a rare cancer that had spread from his tongue to his neck to his lungs by the time it was discovered. He has since turned his graphic novel *Relatively Indolent but Relentless: A Cancer Treatment Journal* about his treatment into a live performance piece reflecting on his time in treatment.
Dying has remained in the shadows of our cultural conversations. Through an intimate illumination of the dying process in a series of varying contexts, our project provides a call to action for individual and institutional evolution – shifting norms to make the issues approachable, and stimulating service providers to create options for care within a reframed understanding of this part of life.

A transmedia approach to storytelling will increase engagement and provide vital resources to the terminally ill and their loved ones, scholars and professionals in the care-giving fields, and the public at large. The project will utilize traditional and new media story formats and modes of participation: a feature-length documentary film sparking discussion; a traveling multi-channel installation inviting in-person contact at programmed events; and an interactive online platform supporting collaborations with a diverse collective of active strategic partners and a wide user-base. This approach creates a variety of opportunities to experience stories, access information, as well as contribute and share information and stories, in generative and sustainable online and offline community activity.
One day, she was sitting in her wheelchair, drinking tea, when suddenly she called me over to where she was, picked up a piece of lemon rind and squeezed it. A light spray mist filled the air and my mother, with a look of delight and wonder, said: “Smell this!” We both inhaled deeply and sat there, amazed. I feel that events like this, uncanny openings induced by the proximity of death, need to be brought to light, so that the living may be inspired and taught important lessons by those facing death directly.

My experience of being a resident at a Zen Buddhist monastery for a year and a half (from Fall 1998 to 2000) may have prepared me for the task of filming “End of Life.” The arduous discipline of sitting in meditative silence, day after day, facing whatever arises, forms the core of Buddhist monastic practice. Sitting with the dying can become an extension of such practice, its application in “ordinary” life. In the case of the present project, the filming would likely acquire a meditative quality, the finished film becoming an extended meditation on dying.
The “dividing line” – the process of deciding when to end treatment and shift to palliative care was especially challenging to navigate within a steep learning curve and compressed timeframe. Elaine was alert, calm, conscious, and participatory for 13 of the 14 days. While medical treatment was still an option, I was able to discover a plethora of information about available cancer treatment options, case studies, medical insights, doctor and hospital reviews, etc. However, as my mother’s situation evolved toward end of life, I was required to use every ounce of my strategic acumen to navigate what little information was available in order to make the right decisions. I was struck by the contrast: I could grab my smart phone and within a minute find the best fish taco within a 5 mile radius, as vetted by more than 2 dozen people, yet being able to find qualitative information of palliative care options was severely limited. Eventually, a hospice care was arranged, and my mother’s end of life was peaceful and dignified. Afterward, I wondered how well others, perhaps with less resources, were able to handle such challenging decision-making moments.

John Bruce, Co-director

In the spring of 2011, my mother, Elaine Bruce, was physically and socially active, and loved her work in continuing education at the local community college, when she learned that cancer had metastasized throughout her entire body. This discovery was 14 days before her death. During these two weeks, I experienced, as my mother’s advocate, a concentrated and accelerated first-hand tour of the machinations of medical science rescue efforts and the subsequent work – emotionally, intellectually, socially, and systemically, involved in the segue to hospice care.
Paweł Wojtasik, Co-director

Paweł Wojtasik is a filmmaker and video artist born in Łódź, Poland and currently residing in Brooklyn, NY. Paweł lived in Tunisia before immigrating to the U.S in 1972. He received an MFA from Yale University in 1996. From 1998 until 2000 Paweł was a resident at Dai Bosatsu Zendo Buddhist monastery. Paweł’s films and video installations are poetic reflections on our environment and culture. Referring to his film Dark Sun Squeeze (2003) Holland Cotter of The New York Times said: “Paweł Wojtasik delivers the final word on the absolute value of news, money, politics and just about everything else.” Paweł’s work The Aquarium (2006), a collaboration with writer Ginger Strand, deals with the destruction of the oceans; while his 360° panoramic video installation Below Sea Level (2009) concerns itself with the plight of New Orleans. Next Atlantis, a collaboration with composer Sebastian Currier, had its world premiere at Carnegie Hall in 2010. Also in 2010 Paweł had a solo exhibition at Smack Mellon in Brooklyn, NY, featuring a five-screen video installation At the Still Point with footage shot in India and with soundscape by Stephen Vitiello. Paweł’s Pigs was included in the 2010 New York Film Festival, and in the 2011 Berlin International Film Festival. The film had its Asian premiere at the 2011 Hong Kong International Film Festival, where it won the Grand Prize in the short film category. Paweł was a featured artist of the 2009 Robert Flaherty Film Seminar. In 2012 he was awarded a Fulbright fellowship to make a feature-length film on the theme of labor in India. Paweł has been named a 2012 New York Foundation for the Arts (NYFA) fellow in Video/Film. His upcoming large-scale video Single Stream (a collaboration with Toby Lee and Ernst Karel) will be installed at the Museum of the Moving Image in Astoria, New York from July to November 2013. Paweł Wojtasik’s work is represented by Video Data Bank.

John Bruce, Co-director

John Bruce is a filmmaker, researcher, and experience designer. He spent over a decade working in feature film and television production, serving in a variety of roles for maverick producers. His first film Apple Juice (1990), a short documentary about downtown Manhattan skateboarding culture, aired on PBS and Showtime, and was revived at BAM in 2013. John also directed and produced a number of award-winning short films and music videos. Recently, he served as design strategist for Shelbyville Multimedia and Immigrant Nation, both projects are transmedia storytelling platforms addressing immigration and welcoming. He also served as the platform producer for Far From Afghanistan, a film addressing the U.S. war in Afghanistan, organized by John Gianvito with contributions from acclaimed political filmmakers, along with footage from Afghan media makers. John co-founded the whole-systems strategy firm Forward Mapworks, helping organizations and artists design greater engagement for positive impacts. Previously, he co-founded the architecture and design firm super-interesting! – an awarded Brooklyn-based practice focusing on design for sustainable communities. John teaches strategy for IMPACT: Design for Social Change at the School of Visual Arts. He is faculty for strategy and ethnography at Parsons, The New School for Design, and serves as Assoc. Director of Strategic Design and Management. John serves on the Board of Trustees for the Robert Flaherty Film Seminar. He earned a BFA from the School of Visual Arts, and an MBA in Sustainable Systems from Pinchot/Bainbridge Graduate Institute. John was recently named a fellow at the Graduate Institute for Design, Ethnography & Social Thought, at The New School.

John and Pawel completed the End of Life Doula training program led by program founder Henry Fersko-Weiss.
Key Contributors >

Steve Holmgren, Producer

A Minnesota native, Steve Holmgren is a graduate of Boston University’s School of Management. He is the event Programmer at the documentary microcinema/arts space UnionDocs in Williamsburg, Brooklyn, as well as an independent film producer at Steady Orbits. He began his career in cinema at Mark Cuban and Todd Wagner’s production company HDNet Films. Following this, he worked in international documentary sales with Cactus Three. He also has spent time in institutional distribution with silent and experimental films at the boutique outfit Gartenberg Media Enterprises.

In addition, Holmgren has worked with several film festivals in a variety of capacities including Sundance, Tribeca, Sound Unseen, and the Robert Flaherty Film Seminar. He has served on festival juries at places like the Oberhausen International Short Film Festival and the Black Maria Film Festival, and spoken on panels at Sundance, Rotterdam, and the Berlin International Film Festival. Holmgren’s producing credits include Matt Porterfield’s Putty Hill and I Used To Be Darker; Marie Losier’s The Ballad Of Genesis and Lady Jaye; Cory McAbee’s Crazy & Thief; and Far From Afghanistan, the recent omnibus project conceived of by John Gianvito (with filmmakers Minda Martin, Soon-Mi Yoo, Jon Jost, and Travis Wilkerson contributing segments along with Gianvito and Afghan Voices). In 2013, he was a visiting Professor at Pratt Institute in the Film/Video department.

Lori Hanau, Advisor, Associate Producer

Lori Hanau grew up in New England in an entrepreneurial family that taught her the value of self-reflection and caring in fostering leadership and healthy, collaborative relationships. She draws on these essential qualities in her work as an advisor, human centered designer and facilitator. Lori’s early career in business, including presidency of a manufacturing company, offered opportunities to observe and engage with diverse leadership styles and organizational structures. During this time, she began to differentiate between the qualities and behaviors that support the vibrancy of organizations and their social ecosystems and the qualities and behaviors that lead to dysfunction. In a two year break from the corporate world, Lori pursued the study of these qualities through an exploration of the service sectors of society, including health, science, philanthropy, spirituality and mission-driven business. Here, she found herself among innovators who were working in all aspects of whole systems change.

In 2002, Lori founded Global Round Table Leadership (GRTL) whose mission is to build the personal and shared leadership capacities required to foster thriving environments. GRTL envisions a world in which individuals, groups and organizations come together through the greatness of our humanity and diversity. To this end, GRTL engages people across all sectors in leadership, collaborative and cultural development. Lori works with people and teams to build the empathetic, creative and strategic “muscles” required for elevated success. Lori is a community builder and faculty member within Marlboro College Graduate School’s MBA program “Managing for Sustainability.” She is also honored to serve as an advisor to the End of Life Project, and be part of the Advisory Boards for the Southeastern Environmental Education Alliance, the Of Many Institute at the NYU Center for MultiFaith Leadership. She also serves on the Board of Directors of Social Venture Network. Lori is the co-founder of the Mindfulness Practice Center in Keene, NH. Lori resides in Keene New Hampshire and Brooklyn New York.
Lucien Castaing-Taylor: Director, Film Study Center, Harvard University, Professor of Visual Arts and Anthropology, Director of Graduate Studies, Director: Sensory Ethnography Lab (SEL), Harvard University. Directed acclaimed films: Leviathan (2012) and Sweetgrass (2010).

Robert Chodo Campbell and Koshin Paley Ellison are co-founders and co-executive directors of the New York Zen Center for Contemplative Care, as well as serving on the core faculty of its Buddhist Chaplaincy Training Program.

Yiming Gao, MD: Resident specialist, Beth Israel Deaconess Medical Center BIDMT, Harvard Medical School Teaching Hospital. Boston, MA

Mary Kerr is a documentary film producer. She is a former film programmer at Sundance, SILVERDOCS: AFI/Discovery Channel Documentary, and, until last year, the Executive Director of the Robert Flaherty Film Seminar.

Rachael Rakes is the Assistant Curator of Film at the Museum of the Moving Image, and the Film co-editor for the Brooklyn Rail. As a programming advisor for UnionDocs, she mines her past lives in non-fiction publishing and non-fiction film for innovative cross-media presentations and conversations.

Daniela Alatorre is the general producer and head of the documentary selection committee for the Morelia International Film Festival, and has produced the films: El General, directed by Natalia Almada; De Panzazo, directed by Juan Carlos Rulfo and Carlos Loret de Mola; and El Ingeniero, directed by Alejandro Lubezki.

Chi-hui Yang is film programmer for MoMA’s Doc Fortnight and POV, and is also the president of the Board of the Robert Flaherty Film Seminar.

Gautam Chatterjee, Ph.D, is the author of numerous books on consciousness and Kashmir Shaivism, playwright and filmmaker, professor at Banaras Hindu University, Varanasi, India.

Nan Goldin is a renowned photographer. She has a deep concern for the marginalized populations, including persons with AIDS and hospice patients.

Felicity Aulino, Ph.D, is a medical anthropologist and ethnographic filmmaker who works on issues related to care for the elderly in Thailand. She is currently a Mellon Postdoctoral Fellow in Global Health at Umass Amherst (Anthropology) and the five college consortium (CHS).

Dr. Brenda Shoshanna, Ph.D, is a rabbi, psychologist and therapist for 28 years, author of “Journey Through Illness and Beyond”.