

# Episcopal Health Ministries @ St. Andrew's

# RESOURCE LIST

- UPDATED DECEMBER 2020 -

## GENERAL MEDICAL

**Websites about medical conditions** – just a few of the many websites that provide health care information. Be aware that there is a lot of incorrect information on the internet, so choose a site that is associated with a health care institution for accurate information.

<http://www.michiganhealthblog.org>

<http://www.mayoclinic.org/>

<http://my.clevelandclinic.org/health/default.aspx>

## ADVANCE CARE PLANNING

### Advance Care Planning – Selected Resources for the Public

<http://www.cdc.gov/aging/pdf/acp-resources-public.pdf>

A resource list representing a broad array of materials to assist the public in better understanding advance care planning and related topics such as hospice and palliative care, caregiving, cognitive impairment, and legal issues. *Produced by the Center for Disease Control*

### Five Wishes

*User-Friendly Advance Directives and Living Wills*

About Five Wishes: <http://www.agingwithdignity.org/five-wishes.php>

Aging with Dignity introduced *Five Wishes* in Florida in 1997, and a year later, to the nation. *Five Wishes* meets the legal requirements in 42 states [including Michigan] and has helped literally millions of people plan for and receive the kind of care they want. *Five Wishes* is unique among all other advance directives and living wills because it is user-friendly and easy to complete. *Five Wishes*

Online was introduced in 2011, allowing people to complete *Five Wishes* on screen and print out a personalized document immediately.

Aging with Dignity is a national non-profit organization with a mission to affirm and safeguard the human dignity of individuals as they age and to promote better care for those near the end of life. *Produced by Aging with Dignity*

### CaringInfo

<http://www.caringinfo.org>

*CaringInfo* provides information and support for anyone who is planning ahead, caregiving, living with a serious illness or grieving a loss. Advance directives specific to Michigan are available here.

### The Conversation Project

<http://theconversationproject.org/>

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care. We believe that the place for this to begin is at the kitchen table—not in the intensive care unit—with the people we love, before it's too late.

### Conversations of a Lifetime

<http://www.conversationsofalifetime.org>

Learn how to talk about the end of life. Information on starting the conversation, resources for taking action, and options for end of life.

### OktoDie.com

<http://oktodie.com/>

Our mission is to create conditions in which people: plan ahead, make their peace, understand that it is *OK to die* naturally, and make educated choices which allow them to pass away peacefully and comfortably surrounded by those who love them most. We believe that public discussion of issues related to death and dying will have the added benefits of healing personal relationships,



strengthening communities, and politically unifying the nation. Preparation prevents suffering, but also creates opportunities for peace, closure, and even healing. At OKtoDie.com the goal is to educate and empower you with tools, checklists and resources.

## Death Cafe

<http://deathcafe.com/>

At a Death Cafe people, often strangers, gather to eat cake, drink tea and discuss death. The objective is 'to increase awareness of death with a view to helping people make the most of their (finite) lives'. A Death Cafe is a group directed discussion of death with no agenda, objectives or themes. It is a discussion group rather than a grief support or counseling session. Information about the Ann Arbor Death Cafe can be found on this website or speak to Marilynne Rush, a member of St. Andrew's.

# PALLIATIVE CARE

## Palliative Care Video

<http://www.palliativecarevideo.com/>

This video explains palliative care in the words of a palliative care patient and several care providers. They will talk about the many facets of palliative care, including pain and symptom control, the team approach, keeping your own doctor, and communication with patients and their family members.

## Get Palliative Care

<http://getpalliativecare.org/>

Get Palliative Care provides clear, comprehensive palliative care information for people coping with serious, complex illness. Key components of the site include a Palliative Care Provider Directory of Hospitals, a definition of palliative care and detailed descriptions of what palliative care does and how to get it. It also provides an interactive questionnaire to assist you in determining whether palliative care might be appropriate for you or a loved one. *Produced by the Center to Advance Palliative Care*

# HOSPICE INFORMATION

## Arbor Hospice, Ann Arbor, MI

<http://www.arborhospice.org/>

Arbor Hospice annually serves more than 9,000 patients and their families at home, in hospitals and care facilities, and has been a leader in end-of-life care and family support for more than 25 years. Arbor Hospice is non-profit and has a residence for patients in Ann Arbor; it is one of a handful of hospice organizations that also serves pediatric patients and their families.

## Hospice Foundation of America

<http://www.hospicefoundation.org/>

Hospice Foundation of America is a non-profit, grassroots foundation dedicated to providing leadership in the application of hospice principles, informing the public about end-of-life care, and training healthcare workers and the families they serve in issues related to loss.

## Perinatal Hospice

<http://perinatalhospice.org/>

Perinatal hospice and palliative care is an innovative and compassionate model of support that can be offered to parents who find out during pregnancy that their baby has a life-limiting condition.

## National Hospice and Palliative Care Organization (NHPCCO)

<http://www.nhpco.org>

The National Hospice and Palliative Care Organization (NHPCO) is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. The organization is committed to improving end of life care and expanding access to hospice care with the goal of profoundly enhancing quality of life for people dying in America and their loved ones.



# OTHER ADVANCE PLANNING

## Funeral Consumers Alliance

<https://www.funerals.org/>

“Funeral Consumers Alliance is a non-profit organization dedicated to protecting a consumer’s right to choose a meaningful, dignified, affordable funeral. We do for funeral purchases what Consumer Reports does for products.”

## Durable Powers of Attorney for Finances

<https://www.sjpcommunications.org/images/uploads/documents/michpoafinances.pdf>

Information and for to document your wishes regarding durable power of attorney for finances.

## After Death Home Care

<http://afterdeathhomecare.com/>

Contrary to popular belief, embalming, cremation or burial is not required within 24, or even 48, hours of death under most circumstances. Families can care for their own loved one in the home after death. This is what everyone did three to four generations ago, and what many people still do throughout the world. It’s called a “home funeral.” With proper care it is safe, simple, inexpensive and legal. The benefits of home funeral and green burial include personal expression of grief in a relaxed and loving atmosphere, the love and honor that only family members can provide, inclusion of the family and the community, and an easier grief journey for those involved. *Run by Merylynne Rush, a member of St. Andrew’s*

# SUGGESTED ARTICLES

## 5 Questions Every Patient Needs to Ask

<http://www.kevinmd.com/blog/2012/07/5-questions-patient.html>

A physician recommends five questions every patient should ask when a doctor offers them a treatment of any kind.

## 4 Perfect Questions When Facing an End of Life Situation

<http://www.kevinmd.com/blog/2012/04/4-perfect-questions-facing-life-situation.html>

Four questions Dr. Susan Block mentally carries around that guide her through the difficult but important conversations.

## When Medical Wishes Are Respected

<http://www.kevinmd.com/blog/2014/02/medical-wishes-respected.html>

Tom had the elusive good death. He was home, with the woman he loved, in the house they’d built together. His medical treatment had been driven by his wishes, and these were respected by everyone involved.

## Change the Warfare Metaphors When It Comes to Illness

<http://www.kevinmd.com/blog/2013/04/change-warfare-metaphors-illness.html>

“There are . . . other metaphors which can be employed. We are not, as we seem to feel, locked in to using only warfare imagery which offers only the polarities of victory or defeat. Michael J. Fox, for example, says of living with Parkinson’s disease: ‘I don’t look at life as a battle or as a fight. I don’t think I’m scrappy. I’m accepting. I say ‘living with’ or ‘working through’ Parkinson’s.’”

## How Successful is CPR in Older Patients?

<http://newoldage.blogs.nytimes.com/2012/08/09/how-successful-is-cpr-in-older-patients/?module=Search&mabReward=relbias%3Aw>

“Most of us have watched too much television – one minute the heroic medical worker pumps the victim’s chest and grabs the defibrillator paddles and yells ‘Clear!’, and in the next scene the victim is sitting up, chatting with detectives – to have any realistic idea.”



## Can connected health improve the lifestyle challenges patients face?

<http://www.kevinmd.com/blog/2014/12/can-connected-health-improve-lifestyle-challenges-patients-face.html>

We're now in an era where chronic illness management and prevention accounts for 70 percent of health care costs. Of the forces responsible for illness — bad luck, bad genes and lifestyle — lifestyle is the predominant cause of chronic illness. Consumers by and large still do not understand this. They still mostly seek care when there is some symptom or acute need. This is problematic because so much lifestyle-driven illness is silent for years.

## Spelling out your views for end-of-life care is a 'spiritual' act

<http://www.religionnews.com/2013/11/22/spelling-views-end-life-care-spiritual-act/>

The author sees a spiritual value to urging people to think about their end-of-life wishes, talk about them and write them down. She calls these actions of autonomy and self-respect. "Throughout all of our lives, we are constantly trying to make sense of the beyond, whatever that may be. It's an honor and a responsibility to participate in such conversations in this world so we make that transition in a way that reflects how we lived our lives," she said.

## When the Patient Won't Ever Get Better

[http://well.blogs.nytimes.com/2016/04/28/when-the-patient-wont-ever-get-better/?smid=nytcore-ipad-share&smprod=nytcore-ipad&\\_r=0](http://well.blogs.nytimes.com/2016/04/28/when-the-patient-wont-ever-get-better/?smid=nytcore-ipad-share&smprod=nytcore-ipad&_r=0)

There are about 100,000 chronically critically ill patients in the United States at any one time, and with an aging population and improving medical technologies, this number is only expected to grow. The outcomes of these patients are staggeringly poor. Half of the chronically critically ill will die within a year, and only around 10 percent will ever return to independent life at home.

## The Dirty Secret about CPR in the Hospital (That Doctors Desperately Want You to Know)

<https://kvscruggs.wordpress.com/2016/04/11/the-dirty-secret-about-cpr-in-the-hospital-that-doctors-desperately-want-you-to-know/>

When patients and families have unrealistic expectations about what their doctors can accomplish, many people die in a way they never planned for or wanted: in the hospital, dependent on strangers for the basics such as eating and bathing, and often hooked up to machines.

## Doctor wants patients to reclaim dying as part of living

<http://www.spokesman.com/stories/2015/oct/25/doctor-wants-patients-to-reclaim-dying-as-part-of-/>

Dr. Ira Byock is calling for a revolution, where health consumers — especially patients and their families — demand a better death on their terms. That means accepting that death is a natural part of life and that at some point medicine can't save people. It means keeping people out of pain and at home so they can be present in this poignant time that is often sacred for families.

## Health Care for Seniors Often Goes Beyond Their Desires

<http://www.npr.org/sections/health-shots/2016/03/08/469538699/health-care-for-seniors-often-goes-beyond-their-desires>

As people get older, their health care goals may shift from living as long as possible to maintaining a good quality of life: quality over quantity. In many cases, the medical treatment older people receive often doesn't reflect this change in priorities. A wide-ranging report from the Dartmouth Atlas Project uses Medicare claims data to examine aging Americans' health care. Among other things, the researchers found five key areas where too many older people continue to receive treatments that don't meet established guidelines or, often, their own goals and preferences.

## Dying to Know Day: Your Final Checklist

<https://static1.squarespace.com/static/5707abcfb6aa60ac258606f8/t/59783baa6f4ca3e9c15016c2/1501051821491/D2KDay+checklist.pdf>



## **The Long Goodbye: Katy Butler On How Modern Medicine Decreases Our Chance Of A Good Death**

<https://thesunmagazine.org/issues/460/the-long-goodbye>

In 2001 journalist Katy Butler's father suffered a stroke at the age of seventy-nine. A year later a hurried decision was made to equip him with a pacemaker, which kept his heart going while doing nothing to stop his descent into dementia. In 2007 Butler's mother, exhausted from being her husband's full-time caregiver and distressed by his suffering, asked her daughter for help getting the pacemaker turned off. Butler agreed, and so began a long investigation into how modern medicine has changed the way we approach the end of life. In this interview, she shares her thoughts and insights into this important topic. *By Sam Mowe*

## **A Growing Movement Of 'Death Doulas' Is Rethinking How We Die**

[http://www.huffingtonpost.com/entry/end-of-life-doulas\\_us\\_591cbce2e4b03b485cae51c2](http://www.huffingtonpost.com/entry/end-of-life-doulas_us_591cbce2e4b03b485cae51c2)

For end-of-life doulas, accompanying the dying is anything but morbid. "Doula" derives from the Greek word for a female servant, but has been re-appropriated in recent decades by trained individuals of all genders who offer support and comfort to people during pregnancy and, now, to those who are dying. *By Antonia Blumberg*

For more information, please contact Marilynne Rush, a member of St. Andrew's

## **You Could Pay Thousands Less For A Funeral Just By Crossing The Street**

<http://www.npr.org/2017/02/07/504020003/a-funeral-may-cost-you-thousands-less-just-by-crossing-the-street>

Report of an investigation by NPR reporters. Includes a list of funeral shopping tips. *By Robert Benincasa*

## **What the End-of-Life Movement Can Learn from the Natural Childbirth Movement**

[http://www.huffingtonpost.com/karen-m-wyatt-md/what-the-end-of-life-movement-can-learn-from-the-natural-childbirth-movement\\_b\\_9352650.html](http://www.huffingtonpost.com/karen-m-wyatt-md/what-the-end-of-life-movement-can-learn-from-the-natural-childbirth-movement_b_9352650.html)

Back in the 1970's the Baby Boom generation changed the way babies are born in the U.S. by demanding a more natural approach to pregnancy, childbirth, and postnatal care. This momentous transformation came about through a "perfect storm" of forces that converged over several decades to result in maternity care that was more humane, less medicalized, and more family-centered. Today a similar "perfect storm" seems to be brewing as Baby Boomers approach the later years of their lives and face aging and dying in a society that is fearful and avoidant of these realities.

## **When End-of-Life Plans Are Just Hopes**

<https://www.nextavenue.org/end-of-life-plans/>

Why her mom's living will turned out to be useless. *By Lola Butcher*

## **Advice From Health Care's Power Users**

<https://www.nytimes.com/2018/10/20/upshot/advice-from-health-cares-power-users.html?smtyp=cur&smid=tw-upshotnyt>

When you're sick, the health care system can be scary and confusing. But in a recent survey, seriously ill Americans shared some hard-won wisdom. *By Margot Sanger-Katz*



## BOOKS

*The Best Care Possible*  
by Ira Byock, MD.

*Handbook for Mortals*  
by Joanne Lynn, MD, Janice Lynch Schuster,  
MFA, and Joan Harrold, MD

*A Grace Disguised: How the Soul Grows Through Loss*  
by Gerald Sittser

*How Doctors Think*  
by Jerome Groopman, MD

*Knocking on Heaven's Door*  
by Katy Butler

*Caregiving: A Step-By-Step Resource for Caring for the  
Person with Cancer at Home*  
by Peter S. Houts, PhD and Julia A. Bucher,  
RN, PhD

*The Caregiver's Book: Caring for another, Caring for  
Yourself*  
by James E. Miller

*Can't We Talk About Something More Pleasant?*  
by Roz Chast

*Being Mortal: Medicine and What Matters in the End*  
by Atul Gawande, M.D.

*Public Faith in Action: How to Think Carefully, Engage  
Wisely and Vote with Integrity*  
by M. Volk and R. McAnnally-Linz  
Chapter 12: Health and Sickness;  
Chapter 13: Aging Life; and  
Chapter 14: Ending Life

*Extreme Measures: Finding a Better Path  
to the End of Life*  
by Dr. Jessica Nutik Zitter, M. D.

*When Breath Becomes Air*  
by Paul Kalanithi

*Twelve Breaths a Minute: End of Life Essays*  
by Lee Gutkind, Francine Prose, Karen  
Wolk Feinstein

*Women Rowing North: Navigating Life's Currents and  
Flourishing As We Age*  
by Mary Pipher

*Advice for Future Corpses (and Those Who Love  
Them): A Practical Perspective on Death and Dying*  
by Sallie Tisdale

## PODCASTS

Wisconsin Public Radio and *To the Best of Our  
Knowledge* presents **DEATH (A Five-Part Series)**

[Hour One: The Reckoning](#) [Aired 11/9/14]

[Hour Two: Exit Plan](#) [Aired 11/16/14]

[Hour Three: The Last Moment](#) [Aired 11/23/14]

[Hour Four: The Wake](#) [Aired 11/30/14]

[Hour Five: After Life](#) [Aired 12/7/14]



