



SIoux FALLS AREA
Palliative Care & End of Life
Resource Directory
2009



Dear Colleague-

Through the generosity of a grant through the Wellmark Foundation, the Palliative Care Directory has been developed to assist health care professionals who care for persons with life limiting illness. This resource lists services that are available in the Sioux Falls area. It is one of the first directories to be developed that has services and information specific to Sioux Falls and the surrounding area, with a focus on palliative care. You have been selected to receive the directory, as you have been identified as someone who cares for this patient population.

The directory contains information specific to the following topics:

- LifeCircle
- Palliative Care
- Hospice
- Hospice and Palliative Care: Web and Education
- Children: Pre-birth through Adolescents
- Community, Family & Caregiver Resources
- Cultural Diversity/Resources & Information
- Financial
- Legal
- Special Topics
- Veterans' Resources
- Appendix containing references for talking with patients/families, funeral planning check lists, etc.

Our hope is that the information contained in the directory will benefit you in your daily practice. An electronic version of the directory can be found at (<http://www.LifeCircleSD.org>). You can also request additional hard copies by contacting Becky Hinton at 605-357-1331 or Becky.Hinton@usd.edu.

As a part of the grant requirements to evaluate the effectiveness of the directory, we would appreciate your feedback. Please complete the postage paid postcard found inside the cover of the directory. Thank you.

Sincerely,

A handwritten signature in cursive script that reads "Charis Poppens".

Charis Poppens, CNS
Chair, Life Circle SD/Sioux Falls Chapter



LifeCircle South Dakota
Sioux Falls Area Palliative Care & End of Life
Resource Directory
2009

The Palliative Care and End of Life Resource Directory was developed for healthcare professionals who provide care and services for individuals and their families facing a chronic illness or terminal diagnosis. This directory is a compilation of services, programs, educational resources and funding mechanisms available to Sioux Falls area patients and families in need of support in managing chronic illness or end of life issues.

Please share this information with colleagues and patients. It is our hope that this tool will help providers guide patients and families as they navigate the complexities of our healthcare system, and increase awareness of services and programs that will ultimately improve quality of life – and care – at the end of life.

LifeCircle South Dakota

We are grateful for the contributions of the following LifeCircle Sioux Falls Subcommittee members:

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We would also like to acknowledge the following individual for her work on this resource directory: Miriam Blauth, MSW



An Independent Licensee of the Blue Cross and Blue Shield Association

This project was funded by the Wellmark Foundation.

This directory is dedicated to all caregivers - personal, professional and family, paid and unpaid. Being a caregiver can and does frequently become a chronic situation. Caregivers provide hours, days, weeks, months and years of services, often unpaid and under-recognized. Their selfless acts of caring and compassion are extraordinary. Perhaps George Bernard Shaw had caregivers in mind when he said,

“I am of the opinion that my life belongs to the community...and as long as I live, it is my privilege to do for it whatever I can. I want to be thoroughly used up when I die, for the harder I work, the more I live. I rejoice in life for its own sake. Life is no brief candle to me. It is a sort of splendid torch which I have got hold of for a moment and I want to make it burn as brightly as possible before handing it on to future generations.”

George Bernard Shaw

Disclaimer: The information listed in this resource directory is accurate at the time of publication. Inclusion in this directory should not be construed as an endorsement of specific programs, services, equipment, or agencies by LifeCircle South Dakota or the Wellmark Foundation. We regret if there are inadvertent errors or omissions.

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Section I:



What is LifeCircle South Dakota: Partners Improving End of Life Care?

In 1999, Sanford School of Medicine of The University of South Dakota initiated a Board of Visitors (an invited group of professionals and community members) to engage in dialogue about end of life care in South Dakota. Representatives from a broad array of South Dakota institutions, organizations, and disciplines concerned with quality of life at end of life attended the session and indicated continuing interest in this important topic. With assistance from the Sanford School of Medicine's Department of Neurosciences, **The Partnership for Improving End of Life Care in South Dakota** evolved from that initial meeting. In February, 2006, the group was renamed **LifeCircle South Dakota: Partners Improving End of Life Care**, and a logo was developed to reflect the statewide nature of the organization. Initial interest areas identified in 1999 led to three distinct work groups, Public Policy, Professional Education, and Community Education. As an organization based in Sioux Falls, LifeCircle South Dakota is now statewide and interdisciplinary in membership and focus. It has a 501 (c) (3) status as an entity of Sanford School of Medicine of The University of South Dakota. An interdisciplinary and multi-institutional Advisory Committee oversees LifeCircle South Dakota. A website describing statewide end of life activities, calendar, resources, and current issues in palliative care is maintained by LifeCircle South Dakota (www.LifeCircleSD.org).

The Mission of LifeCircle:

The people of South Dakota will receive the care needed to complete their lives and die peacefully, their loved ones will receive the support they need, and healthcare professionals in the state will be prepared to provide excellent palliative/end of life care in keeping with the needs and preferences of individuals and families.

Section II:

Palliative Care

What is Palliative Care?

Palliative care (pronounced pal-lee-uh-tiv) specializes in the relief of symptoms and stress of chronic, serious, or life threatening illness. It recognizes that cure is not always possible. The goal is to prevent and relieve suffering and to ensure the best possible quality of life for patients and families. It is appropriate at any stage of serious illness and can be provided at the same time as curative treatment.

Types of diseases that may be included in palliative care are: advanced heart disease (such as congestive heart failure), advanced lung disease (such as chronic obstructive pulmonary disease), advanced kidney disease, cancer, end stage liver disease, multiple sclerosis, Alzheimer's, Parkinson disease (along with other neurological diseases), and congenital diseases.

Palliative care is provided by a healthcare team consisting of a physician, nurse, and social worker. Chaplains, therapists, pharmacists, and dieticians may also be members of the team. The team addresses physical, emotional, social, and spiritual needs in an effort to improve a person's daily functioning and life expectancy.

Palliative care teams can provide coordinated care in the hospital and, in some areas, provide outreach services in the home. Providers may offer comprehensive care or specialize in children or adults. Many palliative care programs require a physician referral.

Some common consult triggers are:

- Code status or advance directive discussion
- Patient and family are struggling with end of life decisions
- Patient and family could benefit from the support of the multidisciplinary team
- Complex symptom management
- Physicians often consult nephrologists for a kidney issue or a cardiologist for a heart issue. Using a similar framework it would be appropriate to consult the palliative care team for assistance with end of life management.

Palliative Care Providers:

Avera McKennan Palliative Care:

800 E. 21st St, Sioux Falls, SD 57117
(605) 322-8993

Provides coordinated care for hospitalized persons who have chronic, life-threatening, or terminal illnesses and support for their families.

The Palliative Care Team provides services to infants, children and adults.

Sanford USD Medical Center, Adult Palliative Care Team:

1305 W. 18th Street, Sioux Falls, SD 57105
(605) 333-7028

Provides coordinated care for hospitalized persons who have chronic, life-threatening, or terminal illnesses and support for their families.

Sanford Children's Hospital, Pediatric Palliative Care Services:

1305 W. 18th Street, Sioux Falls, SD 57105
(605) 333-3576

Provides coordinated care for hospitalized infants and children who have chronic, life-threatening, or terminal illnesses and support for their families. Perinatal palliative care is available for families whose fetus/infant is diagnosed with a life-limiting/threatening condition.

Veterans Administration Medical Center (VAMC):

2501 W. 22nd Street, Sioux Falls, SD 57105
(605) 336-3230, extension 7071

At the VAMC, palliative care is often referred to as "Advance Care Planning". Multidisciplinary teams provide assistance with decision making regarding quality of life issues. Services are provided for both inpatients and outpatients. This includes bereavement support.

Section III:

Hospice

What is Hospice?

Hospice provides comprehensive end of life (EOL) care for people of all ages. Hospice care focuses on comfort and support rather than curative treatments. Hospice is a service which provides comfort care to patients when a physician has deemed that they have six months or less to live. Deciding when a patient has six months or less to live can be a difficult decision. It can be helpful to ask the question, “Would I be surprised if this patient would die during the next six months?” If the answer is “No,” then hospice would be an appropriate service for this patient. A patient can be either a full code or Do Not Resuscitate (DNR) status.

Hospice care is provided by a healthcare team which includes: physician, pharmacist, nurse, social worker, chaplain and volunteer. The team addresses physical, emotional, social, and spiritual needs to improve quality of life at end of life. Hospice care can be provided in the home with family or friends as primary caregivers. Hospice care is also available in an alternative setting such as a residential hospice, nursing home, assisted living facility, prison facility, congregate living or group home, and at times, in the hospital.

Admission Criteria:

Admission to hospice has two main criteria:

- The physician must indicate to the best of his/her ability that if the disease progresses as expected s/he believes the patient will have a life expectancy of six months or less.
- Enrollment in hospice requires a physician’s order.

Hospice Payment Coverage:

- Medicare
- Medicaid
- VA
- Insurance
- Self Pay

Hospice Benefit Periods:

The hospice benefit includes two 90-day periods and has an unlimited number of 60 day periods. *Patients are not necessarily discharged from hospice if they live longer than 6 months as long as their condition still meets the admission criteria.*

For example: Should a patient who originally qualified for hospice care stabilize or improve while receiving hospice care, and yet there is still a reasonable expectation of continued decline and life expectancy is less than six months, the person remains eligible for hospice care.

However: If a patient on hospice care improved or stabilized sufficiently that s/he no longer has a prognosis of six months or less, the patient would be evaluated for discharge from the Medicare hospice benefit. If the patient's condition declined again s/he may re-enroll.

Services provided may include:

- Physician services
- Nursing care
- Social worker services
- Medical equipment
- Medical supplies
- Home health aide and/or homemaker services
- Medications for symptom control or pain relief
- Spiritual counseling
- Grief and loss counseling for the individual and/or his/her family members
- Respite care in a approved facility or hospital
- Acute care in a hospital
- Dietary counseling
- Physical therapy, occupational therapy or speech-language pathology services
- Volunteers to provide companionship, assist with errands and other needs

Hospice Providers:

Not for-Profit:

Avera McKennan Hospice
4509 Prince of Peace Pl, Sioux Falls, SD 57103
(605) 322-7705
www.mckennan.org/amck/services/hospice/HospiceCare.aspx

Sanford USD Medical Center Hospice/Home Care
1305 W. 18th Street, Sioux Falls, SD 57105
(605) 328-4440
www.sanfordhealth.org/Services/HomeCare/HospiceCare/

Veterans Administration Medical Center
2501 W. 22nd Street, Sioux Falls, SD 57105
(605) 336-3230, ext 7071

For-Profit:

AseraCare
4101 S. Westport Ave, Sioux Falls, SD 57106
(605) 361-0700
www.aseracare.com

Compassionate Care
5200 S. Cliff Ave, Sioux Falls, SD 57108
(605) 338-2066
www.Compassionate-care.com

Residential Hospice:

Dougherty Hospice House, (Residential facility)
4509 Prince of Peace Pl, Sioux Falls, SD 57103
(605) 322-5490
www.doughertyhospice.org

Sanford Hospice Cottages, (Residential facility)
6309 & 6301 W. 43rd St. Sioux Falls, SD 57106
(605) 328-4440

Berakkah House
400 N. Western Ave, Sioux Falls, SD 57104
(605) 332-4017

A residential group home for individuals with AIDS and HIV. While not a hospice provider, the Berakkah House does provide end-of-life care and housing for individuals with AIDS and HIV.

Please refer to the yellow pages for other listings of hospice services in the Sioux Falls area.

Section IV:

Hospice and Palliative Care: Web and Educational Resources

Web Resources:

American Academy of Hospice and Palliative Care Medicine (AAHPM): AAHPM is dedicated to expanding access of patients and families to high-quality palliative care and advancing the discipline of hospice and palliative medicine through professional education and training, development of a specialist workforce, support for clinical practice standards, research and public policy. The AAHPM has an on-line bookstore and offers items such as the AAHPH Pocket Guide to Hospice/Palliative Care and the Unipac Series: Hospice/Palliative Care Training for Physicians, an eight-part series of self-instructional books covering physical and psychological symptoms, ethics and legal aspects of end of life care.

www.aahpm.org or www.aahpm.org/bookstore/index.htm/#guide

Americans for Better Care of the Dying (ABCD): A Washington, DC based organization dedicated to ensuring that all Americans can count on good end of life care. The goal of ABCD is to improve end of life care by learning which social and political changes will lead to enduring, efficient, and effective programs. www.abcd-caring.org

American Hospice Foundation: Community Outreach Resources: educational courses, DVDs, videos, CD-ROMs, training guides, brochures, booklets and other materials for professionals and consumers. (202) 223-0204. www.americanhospice.org

Caring Connections: A program of the National Hospice and Palliative Care Organization (NHPCO): a national consumer engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation. 1-800-658-8898. www.caringinfo.org

Centers for Medicare & Medicaid Services: www.cms.hhs.gov/center/hospice.asp

The Center for Practical Bioethics: Community-State Partnerships to Improve End of Life Care: Books and products for Bio Ethics as well as links to caring connections. caringcommunity.org

Center to Advance Palliative Care (CAPC): Provides health care professionals with the tools, training and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings. Located at Mount Sinai School of Medicine, CAPC is a national organization dedicated to increasing the availability of quality palliative care services for people facing serious, complex illness. www.CAPC.org or www.capcmssm.org

Education for Physicians on End of Life Care (EPEC): Mission is to educate all healthcare professionals, especially physicians, on the essential clinical competencies in palliative care. www.epec.net

Education and Training Curriculum for Pediatric Palliative Care: This core curriculum can be used to design, develop and implement individualized educational and training programs. Contents are designed to be relevant to the needs of varied populations of healthcare professionals and others who work with or wish to work with children or adolescents who are diagnosed as having, living with or dying from a life-threatening condition. www.nhpco.org

End of Life Physician Education Resource Center (EPEC): The purpose is to share educational resource materials among the community of health professional educators involved in palliative care education, and foster the continued development of palliative care education. Includes “Fast Fact and Concepts:” Are one page key clinical information sheets ideal for brief educational encounters, self-study or handouts. www.eperc.mcw.edu

End of Life Nursing Education Consortium (ELNEC): National nursing education initiative to improve end-of-life care in the United States. The project provides undergraduate and graduate nursing faculty, continuing education providers, staff development educators, specialty nurses in pediatrics, oncology, critical care and geriatrics, and other nurses with training in end-of-life care so they can teach this essential information to nursing students and practicing nurses. www.aacn.nche.edu/ELNEC/

Growth House: Keep up with news by accessing this news guide to death, dying, grief, bereavement & end of life. www.growthhouse.org/

Harvard Medical School Center for Palliative Care Program in Palliative Care Education and Practice (PCEP): Offers an intensive learning experience for physician and nurse educators who wish to become experts in the clinical practice and teaching of comprehensive, interdisciplinary palliative care, as well as gain expertise in leading and managing improvements in palliative care education and practice at their own institutions. www.hms.harvard.edu/cdi/pallcare

The HealthCare Chaplaincy: A multifaith community of professionals from many cultures dedicated to caring for persons in spirit, mind, and body. Members are committed to excellence and leadership in pastoral care, education and research. www.healthcarechaplancy.org

Hospice and Grief Resources: To improve access to quality hospice care through public education, professional training, and advocacy on behalf of consumers. www.americanhospice.org

Hospicelink: Maintains a computerized database and an up-to-date directory of all hospice and palliative care programs in the United States. A free telephone number 1-800-331-1620 offers referrals to hospice and palliative care programs, and provides general information about the principles and practices of good hospice and palliative care. Hospicelink also makes Cooperative Education Grants, holds seminars for healthcare professionals and volunteers, books, pamphlets, and free advice and assistance for professionals working to begin or looking to improve end of life care. www.hospiceworld.org

Hospice Foundation of America (HFA): Provides programs for professional development, public education and information, research, publications and health policy issues. HFA offers programs for health care professionals to assist those who cope either personally or professionally with terminal illness, death, and the process of grief, on a national or regional basis. The programs for the public assist individual consumers of health care who are coping with issues of caregiving, terminal illness, and grief. www.hospicefoundation.org

Hospice Minnesota: Serves as a vital resource to community members, hospice providers and healthcare professionals. www.hospicemn.org

Innovations in End of Life Care: This international, online journal features peer-reviewed promising practices in end-of-life care, useful tools, selected bibliographies, and other resources. www.edc.org/lastacts

Last Acts - Robert Wood Johnson Foundation: Publication and research related to end of life care. www.lastacts.org

Missoula Demonstration Project (Life's End Institute): www.lifes-end.org/

The National Center for Complementary and Alternative Medicine at the National Institutes of Health: This database lists a full range of alternative therapies such as aromatherapy, reiki, therapeutic touch, massage, meditation, biofeedback, herbs, and vitamins. www.nccam.nih.gov

National Hospice & Palliative Care Organization (NHPCO): Committed to improving end of life care and expanding access to hospice to enhance quality of life for people at the end of life. Founded in 1978, NHPCO advocates for terminally ill persons and their families. The organization develops educational programs and materials for the public and professionals, conducts research, monitors Congressional and regulatory activities, provides technical information to members, hosts meetings and symposia on emerging issues and works collaboratively with organizations with shared interests in end of life care and issues. www.nhpc.org

On Our Own Terms: Moyers on Dying: Bill Moyers goes from the bedsides of the dying to the front lines of a movement to improve end-of-life care in ON OUR OWN TERMS: Moyers on Dying. Two years in production, this four-part, six-hour series crosses the country from hospitals to hospices to homes to capture some of the most intimate stories ever filmed and the most candid conversations ever shared with a television audience. www.thirteen.org/onourown/terms

Palliativedrugs.org: listserv available at this site. www.bulletinboard@palliativedrugs.org

Partnership for Caring - America's Voices for the Dying: A national consumer and community engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation. www.partnershipforcaring.org

Project on Death in America (PDIA): As of December 2003, this group has distributed \$45 million in grant awards to organizations and individuals working to improve care for dying patients and their families. The program is working to make sure that the progress it spearheaded continues. www.soros.org/death/index.htm

Promoting Excellence in End of Life Care: Dedicated to making long term changes to improve health care for dying people and their families. Through the work of innovative demonstration projects and national workgroups strives to address particular challenges to existing models of hospice and palliative care. www.promotingexcellence.org

The RAND Center to Improve Care of the Dying: The RAND Corporation is a nonprofit institution that helps improve policy and decision-making through research and analysis. www.rand.org/index.html

Resource for Hospice & Palliative Care: The vision is to help to increase and optimize the availability of and access to hospice and palliative care for patients and their families throughout the world. www.hospicecare.com

Robert Wood Johnson Foundation: The mission is to improve the health and health care of all Americans. The goal is clear: To help Americans lead healthier lives and get the care they need. www.rwjf.org

The Social Work in Hospice and Palliative Care Network: A network of social work organizations and leaders who seek to further the field of end-of-life and hospice/palliative care. www.swhpn.org

South Dakota Hospice Association: Serving members of the South Dakota Hospice Association. www.southdakotahospice.org

Supportive Care of the Dying: Committed to excellence in palliative care. The focus is assisting Catholic health care organizations and their health care professionals to address the physical, emotional, psychosocial and spiritual needs of those suffering from life-threatening and/or chronic illness as well as those approaching the end of life. Advocates for cultural and social policy changes so that all patients can experience living well until death. www.careofdying.org

Toolkit of Instruments to Measure Care at End of Life: With funding from the Nathan Cummings Foundation and the Robert Wood Johnson Foundation, assembles an authoritative bibliography of instruments to measure the quality of care and quality of life for dying patients and their families. Toolkit instruments are available on this site at no charge. www.chcr.brown.edu/pcoc/toolkit.htm

Toolkit for Nurturing Excellence at End of Life Transition (TNEEL): An educational package designed for nurse educators. www.tneel.uic.edu

Educational Materials and Information:

American Academy of Hospice & Palliative Medicine. (2003). Pocket guide to Hospice/Palliative Medicine. Glenview, IL: AAHPM

Barbara Karnes Publishing:

- A Time to Live (Palliative Care)
- The Final Act of Living
- Living with a Life Threatening Illness
- Gone From My Sight
- My Friend I Care
- Dynamics of Dying
- Grief: Exploring the Process

Available in English and Spanish. Booklets, DVD & videos. Contact information: PO Box 189, Depoe Bay, OR. (541)765-7659. www.bkbooks.com

Berzoff, J., & Silverman, P. *Living with dying*. New York: Columbia University Press. 2005

Byock, Ira. *Dying Well: The Prospect for Growth at the End of Life*. New York, NY. Riverhead Books. 1997. www.dyingwell.org

Callanan, Maggie, Patricia Kelly. *Final Gifts*. New York. Poseidon Press. 1992.

Curtis, J. R., & Rubenfeld, G. D. *Managing death in the intensive care unit: The transition from cure to comfort*. New York: Oxford University press. 2001.

Morris, Virginia. *Talking About Death Won't Kill You*. New York. Workman. 2001.

Nuland, Sherwin B. *How We Die: Reflections on Life's Final Chapter*. New York. Vintage Books. 1995.

Rosen, Elliott J. *Families Facing Death: A Guide for Healthcare Professionals and Volunteers*. San Francisco. Jossey-Bass. 1998.

Walsh-Burke, K. *Grief and loss. Theories and skills for helping professionals*. Boston, MA: Allyn & Bacon. 2005.

Communication Teaching Modules for the End of Life Educator: A six-part educational curriculum that includes educational objectives, role plays, learner handouts, Power Point slides videotape and evaluation instruments to assist instructors in teaching about communication issues in palliative care. Sections include: "Breaking Bad News," "Setting Treatment Goals," "Conducting a Family Conference," "DNR Orders," "Referral to Hospice," and "Spiritual Issues". www.eperc.mcw.edu

South Dakota's Dying to Know: End of Life Research 2004-2007: Exploring South Dakotans' knowledge, attitudes, and preferences at end of life. Findings from the study are catalysts for conversation and charting a future for palliative care education and public policy formation. Available as a PDF file at the website: www.LifeCircle.org

National Consensus Project for Quality Palliative Care. *Clinical practice guidelines for quality palliative care: Executive summary.* Available from: www.nationalconsensusproject.org

Section V:

Children: Pre-birth through Adolescents

Hospice Providers:

Not for-Profit:

Avera McKennan Hospice
4509 Prince of Peace Pl, Sioux Falls, SD 57103
(605) 322-7705
www.mckennan.org/amck/services/hospice/HospiceCare.aspx

Sanford USD Medical Center Hospice/Home Care
1305 W. 18th Street, Sioux Falls, SD 57105
(605) 328-4440
www.sanfordhealth.org/Services/HomeCare/HospiceCare/

For-Profit:

AseraCare
4101 S. Westport Ave, Sioux Falls, SD 57106
(605) 361-0700
www.aseracare.com

Compassionate Care
5200 S. Cliff Ave, Sioux Falls, SD 57108
(605) 338-2066
www.Compassionate-care.com

Residential Hospice:

Dougherty Hospice House, (Residential facility)
4509 Prince of Peace Pl, Sioux Falls, SD 57103
(605) 322-5490
www.doughertyhospice.org

Sanford Hospice Cottages, (Residential facility)
6309 & 6301 W. 43rd St. Sioux Falls, SD 57106
(605) 328-4440

Please refer to the yellow pages for other listings of hospice services in the Sioux Falls area.

Child Life Specialist:

Child Life Specialists: are experts in child development, who promote effective coping through play, preparation, education, and self-expression activities. They provide emotional support for families, and encourage optimum development of children facing a broad range of challenging experiences, particularly those related to healthcare and hospitalization. Understanding that a child's wellbeing depends on the support of the family, child life specialists provide information, support and guidance to parents, siblings, and other family members. They also play a vital role in educating caregivers, administrators, and the general public about the needs of children under stress. Child Life services are available at:

Avera McKennan Children's Hospital and Clinics

800 E. 21st St, Sioux Falls, SD 57117
(605) 322-7595

Sanford Children's Hospital and Sanford Children's Specialty Clinic

1305 W. 18th Street, Sioux Falls, SD 57105
(605) 333-1000

Bereavement Programs and Services:

Area Churches: Local churches may offer grief support groups.

Camp Bring it On: Is a residential camp for kids with cancer. All of the activities at Camp Bring It On are designed to let the children have fun and feel like carefree kids again. This is the feature that makes this camp a unique escape for kids with cancer. (605) 328-7157

Camp Jess: This is a one day experience for children ages 6-14 that have experienced the death of a parent, sibling, grandparent or close friend. It is held in the fall, and the camp is sponsored by Sanford Hospice. (605) 328-4440

Camp Love's Embrace: This is an overnight children's grief camp for children ages 7-14 who have experienced the death of a parent, sibling, grandparent, best friend, or other person of significance in their lives. www.camplovesembrace.com

Now I Lay Me Down to Sleep: This is a volunteer organization that networks with local photographers that will take special photographs of the baby or child that is dying or has died. www.nowilaymedowntosleep.org

Sad Isn't Bad: Grief support series for children and the adults who care for them and who are learning that it's OK to be sad when someone close to us dies. This program is sponsored by a community non-denominational taskforce. (605) 332-0094

When a Child/Teen Grieves a Loss: These four evening sessions are held periodically for children and teens. This support program is sponsored by Catholic Family Services & Miller Funeral Home. (605) 988-3775

Financial Resources:

Angel Lee Cronen Memorial Fund of South Dakota: This fund assists with arrangements and financial support to provide a Christian burial. Families experiencing financial hardship upon the loss of their pre-term or full-term infant can utilize this service. The fund is not limited to a specific religion. Families are requested to ask their local funeral home to make the contact for this fund.

Children's Miracle Network: The Children's Miracle Network Direct Child Family Assistance Program helps children with medical needs. This includes travel expenses and lodging for families traveling to receive medical care for a child and medical equipment to be used in the home. Located at Sanford USD Medical Center. 1305 W. 18th St. Sioux Falls, SD 57105. (605) 333-3232

Department of Social Services: Contact the Department of Social Services (DSS) to inquire about specific programs for birth to adolescents such as Medicaid, Children's Health Insurance Program (CHIP) and Temporary Assistance for Needy Families (TANF). 811 E. 10th St. Sioux Falls, SD 57105. (605) 367-5400

Help!line Center: Maintains lists of support groups for children and adults. 211 or (605) 339-4357. www.helplinecenter.org

Laney Bear Care: Laney Bear Care was established to be the light in the darkness for families with children with chronic and critical illnesses. 225 E. 11th St, Suite 2025 Sioux Falls, SD 57105. (605) 275-6301

Make A Wish: Since 1984, the Make-A-Wish Foundation® of South Dakota has been making very special wishes come true for South Dakota children facing life-threatening medical conditions. They are a chartered chapter with the Make-A-Wish Foundation® of America, the world's largest wish granting organization. Each year, Make-A-Wish® grants thousands of wishes to children around the world. 1010 W. 18th St. Sioux Falls, SD 57104. (605) 335-8000, 1-800-640-9198. www.wishsd.org

Ronald McDonald House Charities of South Dakota: Founded with a mission to provide aid and support to seriously ill children and their families as they receive treatment at health care facilities. The Ronald McDonald homes provide a "home away from home."

- **Ronald McDonald House:** Currently located at 2001 S. Norton Avenue, Sioux Falls, SD 57105. The new Ronald McDonald House will be built approximately one block north of the new Sanford Children's Hospital. This home will provide 18 bedrooms. 825 S. Lake Ave, Sioux Falls, SD 57105. (605) 336-6398
- **Walsh Family Village:** Ronald McDonald House: Located on the Avera McKennan Campus this home provides eight bedrooms. 808 E. 24th St, Sioux Falls, SD 57105. (605) 322-3550

Palliative Care Providers:

Avera McKennan Palliative Care

800 E. 21st St, Sioux Falls, SD 57117
(605) 322-8993

Provides coordinated care for hospitalized persons who have chronic, life-threatening, or terminal illnesses and support for their families. The Palliative Care Team provides services to infants, children and adults.

Sanford Children's Hospital, Pediatric Palliative Care Services:

1305 W. 18th Street, Sioux Falls, SD 57105
(605) 333-3576

Provides coordinated care for hospitalized infants and children who have chronic, life-threatening, or terminal illnesses and support for their families. Perinatal palliative care is available for families whose fetus/infant is diagnosed with a life-limiting/threatening condition.

Web Resources:

Caring Bridges: Free personal websites that connect patients, family and friends during a serious medical condition, treatment and recovery. www.CaringBridge.org

Centering Corporation: A non-profit bereavement resource center for books and other printed material, and tools useful to use when working with grieving children. P.O. Box 4600, 1531 N. Saddle Creek Road, Omaha, NE 68104, (402) 553-0507. www.centering.org

Children's Project on Palliative/Hospice Services (CHIPPS): a pediatric listserv for NCHPP or eNCHPP members who provide services for children with life-threatening conditions and their families. www.nhpc.org/i4a/pages/index.cfm?pageid=3409

Compassion Books: Resources to help children and adults through serious illness, death, loss, grief and bereavement. 1-800-970-4220. www.compassionbooks.com

Diaper Assistance: Up to 40% discount on name brand diapers for babies and adults. 1-800-342-7377. www.1800diapers.com

Erin's House: Provides supportive services and information for parents, professionals, friends and teachers to promote healing and recovery of children, teens and young adults who have been affected by the death or terminal illness of a friend or loved one. www.erinshouse.org

Growth House Inc: The primary mission is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration. Has a search engine that provides access to a comprehensive collection of reviewed resources for end-of-life care. In addition has an online bookstore. www.growthhouse.org

Initiative for Pediatric Palliative Care: Provides educational information on caring for pediatric patients at end of life. www.ippcweb.org

Peach Bandana Studios: Offers children's books related to grief and loss. The site also offers patterns for Memory Bears (sewing patterns and instructions are offered to create a Memory Bear like the one described in the Teddy Bear book) and gives information about starting a Hospice Bear Program. www.peachbandana.com

The Dougy Center: Offers peer support groups, education, and training locally, nationally and internationally to individuals and organizations seeking to assist children in grief. The Center also has a book store and other resources available on their web site. www.dougy.org

The Center for Grieving Children, Teens and Families: A training and resource center for professionals and others who interact with grieving children and teens. www.grievingchildren.org

The National Alliance for Grieving Children: Provides education and resources for individuals who want to support children and teens grieving a death. Also, provides a network for nationwide communication between hundreds of children's bereavement centers who want to share ideas, information and resources with each other to better support the families they serve in their own communities. In addition, the Alliance provides information on current topics and a schedule of professional workshops across the country. www.nationalallianceforgrievingchildren.org

Educational Materials

Christ, G. *Healing children's grief: Surviving a parent's death from cancer*. New York: Oxford University Press. 2000.

Section VI:

Community, Family & Caregiver Resources

Who is a Caregiver?

A caregiver may be family, friend, neighbor, or paid and unpaid help. A caregiver is a professional or nonprofessional provider of care to a person with a chronic illness or debilitating disease. Someone is a caregiver if s/he helps a family member or friend who is ill, disabled or frail by providing the assistance he or she needs, such as bathing, making meals, assisting to toilet, ambulate, etc.

Bereavement Resources: Adults

(See section on children and adolescents for additional information)

Area Churches: Check with local churches for grief support groups.

Catholic Family Services: Offers a variety of non-denominational grief programs that are professionally directed and conducted to facilitate the journey of grieving and the moving toward to readjustment. 523 N. Duluth Ave, Sioux Falls, SD 57104-2714. (605) 988-3775

Compassionate Friends: A national self-help support organization which assists families in positive resolution of grief following the death of a child. Monthly meetings. (605) 361-5645. www.compassionatefriends.org

Hospice Support Groups: Contact one of the area hospice programs to inquire about their bereavements services and programs.

Community, Family & Caregiver Resources:

There are many technologies available for help in managing the many responsibilities of caregiving. Resources for setting up a caregiver team include:

- Lance Armstrong Foundation Survivor Notebook free at www.laf.org
- LotsaHelping Hands - www.lotsahelpinghands.com
- Red Toe Nail - www.redtoenail.org
- Patient Partner Project - www.thepatientpartnerproject.org
- Caring Bridge - www.caringbridge.org
- Share the Care - www.sharethecare.org

Community Organizations:

American Cancer Society: Offers: Financial Assistance Grant – Transportation, Child Care, and Home Care. The Patient Navigator Program provides guidance for cancer patients, survivors and caregivers to help them navigate the cancer experience.

- Cancer Survivors Network
- Reach to Recovery
- Look Good, Feel Better
- Durable Medical Equipment, 1-800-227-2345. www.cancer.org

Cancer Care: A national non-profit organization that provides free, professional support services for anyone affected by cancer. Offers:

- Financial Assistance Grant
- Transportation, Child Care
- Home Care
- Online/Telephone Support Groups for many diagnoses
- Helping Hand Resource guide for People with Cancer 1-800-813-4673, www.cancercare.org

Help!Line Center: The Center help persons find answers about community information, financial assistance, suicide prevention, child care, support groups, counseling, volunteer opportunities, mentoring, donation information, crisis intervention, food, clothing, shelter, and/or substance abuse. 1000 West Avenue North, Suite 310, Sioux Falls, SD 57104-1314. (605) 339-4357 or dial 211, www.helplinecenter.org

Complementary and Alternative Medicine (CAM):

Complementary and alternative medicine refers to a group of diverse medical and health care systems, practices, and products that are not considered to be part of conventional medicine. Examples include: yoga, healing touch, reiki, acupuncture, reflexology, biofeedback, herbal medicine and nutritional supplements. Complementary medicine refers to treatments used in conjunction with conventional medicine. Alternative Medicine refers to treatments used in place of conventional medicine. While some scientific evidence exists to support their use, the list of changes as research proves their efficacy for the diseases or medical conditions for which they are used.

Avera Cancer Institute Educational Programs: The following classes and educational sessions are held at Avera Cancer Institute (ACI), 1000 E. 21st St. For further information about these or other educational offerings at ACI call (605) 322-3000 or 1-800-657-4377.

A Time to Heal: A free 12-week education and support program for women who have completed breast cancer treatment. Time and location will vary.

Hand Massage: Location varies.

Look Good...Feel Better: A class for women to help woman deal with the outward side effects of chemotherapy and radiation on hair and skin.

Nutrition: Teaches how to maximize your nutrition and discover ways to manage side effects of treatments.

Yoga: A free therapeutic class for cancer patients and their caregivers. For more information contact:

Sanford Oncology Educational Classes: For information about these or other educational offerings call (605) 328-8000

Cancer Connections: Available for all cancer patients. Presentations on music and art therapy, dealing with the blues, scarves, make-up and skin care.

Cancer Kickers Support Group: Available for cancer patients coping with daily issues surrounding a cancer diagnosis.

Cancer Wellness: Available for all cancer patients and focuses on consultation with an exercise professional.

Journey of Healing Arts: This arts program is available for all cancer patients and families. A professional artist works with patients to explore ways to relieve stress and pain through the use of the arts.

Journey of Healing Reflections: Reflections on survivorship. Evening program offered intermittently.

Survivorship Clinic: Available for Breast Cancer Patients. The clinic identifies areas of need, psychosocial stress, weight, diet, and future cancer screenings.

Yoga: Available for all cancer patients at the clinic. Call for the times and days of the classes.

Home Health Care:

Home Health Care: Home health care is often provided to persons who are recovering from an acute illness, injury or surgery. It is also available for persons who have long term chronic health conditions or a permanent disability. A variety of cares can be provided to persons in the home setting. The type of service provided is based upon medical needs as well as individual preferences. There are several home health care agencies that provide care in the Sioux Falls area. The agencies may be part of a hospital system or privately owned. Many of the agencies are Medicare certified which means that Medicare, Medicaid and private insurance may pay for the services they provide. Agencies that are not Medicare certified typically are fee for service and individuals choose the type of services they wish to receive and privately pay for them. Services may be provided by licensed professionals as well as unlicensed persons. A physician order is usually required if any type of personal care such as bathing is provided in the home.

The types of services provided by home health include:

- Nursing
- Physical Therapy
- Occupational Therapy
- Speech Therapy
- Medical Social Work
- Home Health Aide
- Homemaking Services.

Refer to the yellow pages for a listing of home care agencies which provide services in the Sioux Falls area.

Home Medical Equipment & Supplies:

Avera Living Well Center - Avera Home Medical Equipment:

2400 S Minnesota Ave, Sioux Falls, SD 57117. (605) 322-1881

Kriesers: 2200 W. 46th St. Sioux Falls, SD 57105. (605) 336-1155

H.M.E. Exchange: 3505 N. Cliff Avenue, Sioux Falls, SD 57104. (605) 271-4639

PSI Health Care Inc: 2211 W. 49th St. Sioux Falls, SD 57105. (605) 336-1005

Sanford Home Medical Equipment: 2710 West 12th Street, Sioux Falls, SD 57104.
(605) 328-4438

Veterans Administration Medical Center: Enrolled veterans may obtain needed equipment through the VA Prosthetics Dept. (605) 336-3230

Diaper Assistance: Up to 40% discount on name brand diapers for babies and adults.
1-800-342-7377. www.1800diapers.com

Senior Mobility Program: Provides electric wheelchairs to senior citizens and permanently disabled at no cost to qualifying persons. 1-800-451-0971

Wishes on Wheels: Makes available Electric Powered Wheelchairs to seniors (65 and older) and permanently disabled. Must be able to safely operate a joystick controller on armrest and understand basic instructions. Program usually provides wheelchair at no charge or out of pocket expense for persons who meet criteria. Physician approval required. 1-800-823-5220.
www.threewishes2.com

Home & Medication Monitoring Systems for Home Alone Elderly & Disabled:

There are many types of systems available to help persons remain independent in their home. Costs vary as well as availability. Typically, expect to pay an installation fee and then monthly charge. Medical alert call systems can be purchased or rented from Home Medical Equipment Suppliers, local stores and online. Some local phone companies may offer these systems at reduced prices for eligible persons.

ADT Companion Service: The personal help button transmits an alarm signal to an ADT monitoring specialist who can respond to the situation via two-way voice intercom and call for assistance if needed. 1-800-209-7599. www.aarp.org/adtkompanion

Department of Social Services: Eligible persons may receive financial assistance with a monthly fee for an emergency device from the South Dakota State Department of Social Services-Adult Services and Aging. (605) 367-5400.

Jitterbug: Can be used as an emergency cell phone - senior friendly. www.jitterbug.com

Midcontinent Communications: 1-800-888-1300

Philips Lifeline: The Lifeline Personal Help Button connects patients to a trained Personal Response Associate who can send help quickly - 24 hours a day, seven days a week. 1-800-543-3546. www.lifelinesys.com

Prairie Freedom Center: Assists with programs, funding and adaptive devices such as ramps, wheelchairs, and lifeline to assist people with disabilities and remain at home. Contact the Center for a complete list of their services, eligibility criteria and application. 301 S. Garfield, Suite 9, Sioux Falls, SD 57104. (605) 367-5630, 1-800-947-3770. www.pfcil.org

Quest Communications: 1-800-244-1111.

Rescue Alert: Personal emergency response systems give you the independence to live like you are used to. Rescue Alert's medical alert systems provide peace of mind for you and those who care about you the most - anytime, 24 hours a day. 1-800-688-9576. www.rescuealert.com

Ready Response: 1-866-310-9061. www.walgreens.com (search for "Ready Response")

Sanford USD Medical Center LifeLine: 24-hour emergency response system (help button is worn in event of an emergency). (605) 328-4420.

Home Monitors:

Attentivecare: An Internet-based caregiver support system that enables family and friends to provide informal care for their loved ones from anywhere in the world.
1-888-317-7702. www.caregivertech.com

AT&T Home Monitoring System: This system uses cameras, door, and window sensors to monitor the activity in the home. The system sends email, text message, or cell phone alerts when activity suggests cause for concern. 1-888-333-6651. www.atrm.com

Beamer TV: Beamer TV Videophone works with your television, home phone and home phone line, to instantly add video to your phone calls. Call your family and friends, and see them on your television screen. 1-877-963-8383. www.vialtastore.com/beamertv.htm

QuickCam: 1-800-231-7717
www.logitech.com/index.cfm/webcam_communications/video_security_systems/&cl=us,en

Quiet Care Home Health Security System: Monitors the regular routine of a loved one using a variety of sensors. Individual on the other end is alerted when there is a change in behavior.
1-877-822-2468. www.quietcare.com

Medication Monitors:

My Med Schedule: Creates printable medication lists, with pictures of the medication and times to take them. Also you can be notified to take your pills by email or text message. Free Service.
www.mymedschedule.com

Lending Libraries:

Choice Magazine Listening (CML): Records memorable writing from 100 leading magazines for blind, visually impaired, physically disabled, or dyslexic subscribers. Subscribers to this free service receive eight hours of unabridged articles, fiction, and poetry read and recorded onto four-track cassette tapes. The Library of Congress provides subscribers with a four-track cassette player free of charge. More information and an application for this service and for the four-track player are online. 1-888-724-6423. www.choicemagazinelisting.org

Our Saviors' Lutheran Church: Our Savior's maintains an extensive library of books, tapes, DVDs, pamphlets and educational material related to end of life issues. 909 W. 33rd St. Sioux Falls, SD. (605) 336-2942

Wegner Health Source Information Center: Provides quality information service to its partners and their constituents by maintaining and delivering relevant information that supports healthcare, education and research. 1400 W. 22. St., Suite 100, Sioux Falls, SD 57105.
(605) 357-1400, 1-800-521-2987. www.wegner@usd.edu

Siouxland Libraries: Provides library services to citizens of all ages in Sioux Falls and Minnehaha County. www.siouxlandlib.org

Sioux Falls: Locations:

Main Branch Library, 200 N. Dakota Ave, Sioux Falls, SD 57117-7403
(605) 367-8720

Caille Branch Library, 4100 Carnegie Circle, Sioux Falls, SD 57106
(605) 367-8144

Oak View Branch Library, 3700 E. 3rd St. Sioux Falls, SD 57103
(605) 367-8060

Ronning Branch Library, 3100 E. 49th St. Sioux Falls, SD 57103
(605) 367-8140

County Branches:

Baltic Branch Library, 213 St. Olaf Ave., Baltic, SD 57003
(605) 529-5415

Brandon Branch Library, 305 S. Splitrock Blvd, Brandon, SD 57005
(605) 582-2390

Colton Branch Library, 325 E. 4th St. Colton, SD 57018
(605) 446-3519

Garretson Branch Library, 649 Main Ave., Garretson, SD 57030
(605) 594-6619

Hartford Branch Library, 705 E. 2nd Hartford, SD 57033
(605) 528-3223

Humboldt Branch Library, E. 3rd & N. Main Ave., Humboldt, SD 57035
(605) 363-3361

Valley Springs Branch Library, 401 Broadway Ave, Valley Springs, SD 57068
(605) 757-6264

Lodging:

Joe's House: Housing resource for cancer patients and their families who must leave home for cancer treatment. 1-877-563-7468. www.joeshouse.org

National Association of Hospital Hospitality House: Association of more than 150 non profit organizations located throughout the U.S. that provide lodging services to families and their loved ones who are receiving medical treatment far from their home. 1-800-542-9730. www.nahhh.org

Ronald McDonald House Charities of South Dakota: Founded with a mission to provide aid and support to seriously ill children and their families as they receive treatment at health care facilities. The Ronald McDonald homes provide a "home away from home."

- **Ronald McDonald House:** Currently located at 2001 S. Norton Avenue, Sioux Falls, SD 57105. The new Ronald McDonald House will be built approximately one block north of the new Sanford Children's Hospital. This home will provide 18 bedrooms. 825 S. Lake Ave, Sioux Falls, SD 57105. (605) 336-6398.

- **Walsh Family Village:** Ronald McDonald House: Located on the Avera McKennan Campus this home provides eight bedrooms. 808 E. 24th St, Sioux Falls, SD 57105. (605) 322-3550

The Room in the Inn Program-Holiday Program: Tharaldson Lodging Company offers free rooms at locations nationwide. This program is available to people who have friends or family hospitalized over the holidays.

Participating hotels in South Dakota:

- Comfort Inn: 3216 S. Carolyn Ave, Sioux Falls, SD 57106 (605) 361-2822
- Comfort Suites: 3208 S. Carolyn Ave, Sioux Falls, SD 57106 (605) 362-9711
- Fairfield Inn: 4501 W. Empire Pl, Sioux Falls, SD (605) 361-2211
- Residence Inn: 4509 W. Empire Pl, Sioux Falls, SD (605) 361-2202

Walsh Family Village: Includes the Nano Nagle Inn and Casa de Carlitos, and Ronald McDonald House which provide homes for out of town patients and their families at Avera McKennan who are not able to afford traditional housing options. Located on the Avera McKennan Campus, 808 E. 24th St, Sioux Falls, SD 57105. (605) 322-3550

The **Casa de Carlitos Welcome Centein** includes community spaces such as gathering areas and a meditation room, as well as two guest rooms for children who come to Avera McKennan for charity treatment through the Los Cabos Children's Foundation and other guests with special needs.

The **Nano Nagel Inn** is a guest house with eight rooms for patients and their families. The inspiration for this Inn is the story of Nano Nagel, who lived in Ireland in the mid-1700's, caring for the aged, sick and poor. Nano Nagel was among the founders of the Presentation Sisters, who along with the Benedictine Sisters sponsor Avera.

The Ronald McDonald House for the families of pediatric patients. See additional information under Ronald McDonald House.

Life Chronicle Organizations/Materials:

Many hospice, home care and non-profit organizations have life story questionnaires that families can use to document their loved ones memories for posterity and future generations.

Life Chronicles: A non-profit corporation that produces video recordings that capture a person's life story and memories. Donations encouraged for the production costs. 1-866-998-5433. www.lifechronicles.org

Memoirs Inc: A service that works with individuals to publish their life story in a hardcover book. (651) 698-1158. www.memoirsinc.com

Senior Advantage: Provides a booklet "Just a Few Memories to Share" free of charge to hospice programs. Senior Advantage Consultants, 5062 135th Ave. Clear Lake, MN 55319 1-800-367-5307. sac5062@frontiernet.net

National, State and Local Resources:

Ageing Love: Provides area seniors and caregivers information regarding local services and resources including area nursing homes and assisted living facilities. In addition, provides information about protecting assets, healthy aging and making final arrangements.
www.aginglove.com

American Association of Retired Persons (AARP): This site offers resources for caregivers on grief and loss including checklists for steps to take after the death of a loved one.
www.aarp.org/families/grief_loss

Caring Bridges: Free personal websites that connect patients, family and friends during a serious medical condition, treatment and recovery. www.CaringBridge.org

Caring Connections: Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer and community engagement initiative to improve care at the end of life. 1-800-658-8898. www.caringinfo.org

Caregiving Info: www.caregiving.com

Family Caregiver Alliance (FCA), National Center on Caregiving: FCA has developed a wide array of services and publications based on caregiver needs and offers programs at local, state, and national levels. Often described as a “one-stop shopping center for caregivers,” FCA programs and services include: tips and advice for caregivers, information on caregiving and long-term care for policy makers, health and service providers, media, program developers, funding agencies and families. 1-800-445-8106. www.caregiver.org

Gerontological Society of America (GSA): A non-profit professional organization with more than 5000 members in the field of aging. GSA provides researchers, educators, practitioners, and policy makers with opportunities to understand, advance, integrate, and use basic and applied research on aging to improve the quality of life as people age. www.geron.org

Lotsa Helping Hands: Program offers a simple, immediate way for friends, family, colleagues, and neighbors to assist loved ones in need. It’s an easy-to-use, private group calendar, specifically designed for organizing helpers, where everyone can pitch in with meals delivery, rides, and other tasks necessary for life to run smoothly during times of medical crisis, end-of-life caring, or family caregiver exhaustion. It’s also a place to keep these “circles of community” informed with status updates, photo galleries, message boards, and more. www.lotsahelpinghands.com

My Med Schedule: Creates printable medication lists, with pictures of the medication and times to take them. The service can notify individuals by email, or text message, and remind them to take their medications. Free Service. www.mymedschedule.com

National Family Caregivers Association (NFCA): Educates, supports, empowers and speaks up for the more than 50 million Americans who care for loved ones with a chronic illness or disability or the frailties of old age. NFCA reaches across the boundaries of diagnoses, relationships and life stages to help transform family caregivers' lives by removing barriers to health and well being. 1-800-896-3650. www.thefamilycaregiver.org

Share The Caregiving, Inc: Seeks to inform and educate healthcare providers, corporations, communities, clergy, universities, and individuals about Share The Care™, a model that details how ordinary people can create and operate a unique extended family-type support system to care for a friend or loved one, whether for a month or for years. They also provide links among caregivers and providers to evolve and continually develop the model through evidence-based evaluations and feedback from caregivers and providers. (646) 467-8097. www.sharethecare.org

The Eldercare Locator: Public service of the Administration on Aging, finds resources for older adults in any U.S. community. This service links those who need assistance with state and local area agencies on aging and community-based organizations that serve older adults and their caregivers. The Eldercare Locator assists with finding services such as meals, home care or transportation, or services to help when a caregiver needs training and education or a well-deserved break from caregiving responsibilities. 1-800-677-1116. www.eldercare.gov

The National Alliance for Caregiving: The Alliance was created to conduct research, do policy analysis, develop national programs and increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance's mission is to be the objective national resource on family caregiving with the goal of improving the quality of life for families and care recipients. (301) 718-8444. www.caregiving.org

The Thoughtful Caregiver: Wisdom and encouragement for caregivers in the form of writings and photography. www.thoughtful-caregiver.com

Willowgreen: Provides information, inspiration and support through books, tapes, CDs, DVDs, and photography for people in transition, dealing with grief, aging, care giving and illness. www.willowgreen.com

Respite Services:

Called to Care: Respite for caregivers in their homes. This is an outreach ministry of Bethany Lutheran Home with support from the ELCA Foundation and Lutheran Services for the Elderly Endowment. Called to Care volunteers are members from congregations trained to provide help to members of their congregation. For general information call: (605) 582-8622

Participating churches are:

East Side Lutheran, (605) 336-3597

Our Saviors' Lutheran, (605) 336-2942

Salem Lutheran, (605) 247-3353

First Lutheran, (605) 336-3734

Nathanael Lutheran, (Alcester), (605) 934-2351

St. Marks' Lutheran, (605) 338-2351

Caregiver Respite: Department of Social Services, Adult Services and Aging (DSS-ASA): The Caregiver Relief Program provides Caregivers with a temporary period of relief so they can run errands, rest, spend time with friends, or go on vacation. During this time, the person selected by the family can choose to have an individual go to the home to provide care. There are two programs available.

- *Regular Respite:* Open to any age person, but there are income/asset limits.
- *Caregiver Program:* Open to those 60 & older. No income limit.

Both programs require an evaluation by a Case Manager from the DSS-ASA. Contact the DSS-ASA to inquire about specific financial amounts available. 811 E. 10th St. Sioux Falls, SD 57105. (605) 367-5400.

Veterans: Respite Programs available through the VA. Also see Section XI: Veterans' Resources.

Senior Directory:

Senior Directory: The Senior Directory is published annually as a guide with information for older adults with listings of area assisted living, nursing homes, senior day centers, home health agencies, etc. Contact the Helpline "211" for copies. www.211sd.org

Spiritual Care:

Faith Community Nurses/Parish Nurses: A faith community nurse is a registered nurse committed to the healing mission of the faith community working to help congregational members find support in crisis or with day to day struggles. They work directly with the ministry team to assist parishioners in the search for wellness and improved quality of life. As a faith community staff member, a faith community nurse brings healthcare and related services to the church family in a number of ways. Faith community nurses are: health counselors, health educators, advocates for the parishioner, liaisons to the community, referral sources, and serve to integrate faith and health. Contact your local church to inquire about services available. For more information on Faith Community Nurses/Parish Nurse Programs contact:

- Sanford Parish Nurse Program: (605) 336-2942
- Avera McKennan Parish Nurse Program: (605) 322-4706

Prayer Shawls: Many regional faith communities provide prayer shawls for people going through crisis or changes in their environment. Call your local church, place of faith or a Hospice organization to inquire about prayer shawls.

Support Groups:

Many Nursing Homes, Adult Day Programs and specific disease related non-profit organizations offer caregiver support groups. Check with the following local organizations for more information:

- Alzheimer's Association www.alz.org
- Parkinson Association www.parkinsonsd.org/
- MS Society www.volunteermatch.org/search/org

Bone Marrow Transplant Support Group: Avera Cancer Institute (ACI): Group for individuals, and their caregivers, that have gone through or may be undergoing a transplant. Free. Time and location will vary. Contact the Avera Cancer Institute for more information. 1000, E. 21st St. Sioux Falls, SD 57105. (605) 322-3000 or 1-800-657-4377

Local Organizations:

Help!Line Center: The Center help persons find answers about community information, financial assistance, suicide prevention, child care, support groups, counseling, volunteer opportunities, mentoring, donation information, crisis intervention, food, clothing, shelter, and/or substance abuse. 1000 West Avenue North, Suite 310, Sioux Falls, SD 57104-1314. (605) 339-4357. www.helplinecenter.org

Sources of Information:

Who Cares: Provided by the Federal Trade Commission (FTC) this site provides reliable information about health care products and services. www.ftc.gov/whocares

Section VII:

Cultural Diversity Resources & Information

Cultural Diversity Resources:

Working with diverse cultures can be rewarding and challenging. South Dakota and Sioux Falls continue to undergo significant demographic changes. The complexities associated with cultural diversity in South Dakota affects all aspects of the provision of health and end of life care. It is important to endeavor to provide culturally competent services to individuals and families. While race and ethnicity have been associated with cultural diversity; it is important to note that diversity may also refer to the socio-cultural experience of persons of different ages, gender, sexual orientation, religious and spiritual beliefs, social class, geography, language, physical, and mental abilities.

Hospice Liaison for Jehovah's Witnesses: Works specifically with the issues of what medical treatments are allowed for Jehovah Witness congregants. Offers a 24 hour emergency line out of St. Louis, MO and will offer recommendations in regards to how to work with this population. (314) 440-1115.

Lutheran Social Services (LSS) of South Dakota Refugee and Immigration Center: LSS provides interpreters, case management, interim cash assistance, reception and placement services, match grant program, community orientation classes, and employment services during the first eight months in the United States. 1609 West 11th Street, Sioux Falls, SD 57104. (605) 339-4601. www.lsssd.org

Multi-Cultural Center: 515 N. Main Ave, Sioux Falls, SD 57104. (605) 367-0008.

Presentation Sisters Hispanic Ministry (Cominando Juntos): Sioux Falls, SD. Monday-Friday 9:30-5:00 p.m. Offers Spanish interpreter services, assistance with competing forms, help arrange and transport Hispanic clients to appointments with agencies. 617 E. 7th St. Sioux Falls, SD 57103. (605) 274-3735.

Urban Indian Health: Transportation for medical and dental care, medical services, chronic disease management, mental health services, eye glass program, nutritional counseling, Diabetic Foot Care Program and substance abuse services. 320 S. 3rd Ave, Suite B, Sioux Falls, SD 57104. (605) 339-0420. www.sduih.org

Bureau of Indian Affairs (BIA), Branch of Social Services:

Bureau of Indian Affairs (BIA), Branch of Social Services: Maintains information about the nine tribes in South Dakota including contact information. Services provided include general

assistance, burial assistance, emergency assistance, and Managing Individual Indian Money (IIM) accounts for minors and adults that have been classified as adults in need of financial assistance, contract monitoring of tribal programs involved in the social services field and referrals from other agencies. The BIA assists families who are at or below poverty level and have exhausted all other resources. www.state.sd.us/oia/answers.asp

Burial Assistance: The BIA can provide burial assistance when there is an absence of other resources and eligibility requirements are met. Relatives of a deceased Native American Indian may apply for assistance by submitting an application to the social services office of the BIA.

- Applications must be submitted within 30 days following a death
- Eligibility is based on income level and includes, but is not limited to: SSI, veterans' death benefits, social security, and IIM accounts
- Determination of need is on a case by case basis using the BIA payment standard

Eligibility requirements for burial assistance program:

- Enrolled member of a federally recognized Indian tribe
- Be a resident of the service area for the past 6 months
- Be under the poverty level for income as defined by the State of South Dakota (2008= \$899.00 or less)

Transportation Assistance: Transportation costs directly associated with burials are normally a part of the established burial rate. If there is an additional transportation cost added by the provider due to extenuating circumstances the social services worker may approve those charges if the following is met:

- The charges are reasonable and equitable
- The deceased was an eligible indigent Indian who was socially, culturally, and economically affiliated with his or her tribe
- The deceased resided in the service area for at least the last 6 consecutive months of his/her life

Additional financial assistance may be available from the individual tribes for costs associated with wakes.

Tribal Resources-American Indian Reservations in South Dakota:

Cheyenne River Sioux Tribe: (605) 964-4155

BIA: (605) 964-6611

Reservation: Cheyenne River Reservation; Dewey and Ziebach Counties

Division: Teton

Bands: Minnecoujou, Two Kettle (Oohenunpa), Sans Arc (Itazipco) and Blackfoot (Si Sapa)

Tribal Headquarters: Eagle Butte, SD

Traditional Language: Lakota

Crow Creek Sioux Tribe: (605) 245-2221

BIA: (605) 245-2311

Reservation: Crow Creek Reservation; Buffalo, Hyde, and Hughes Counties

Division: Santee, Yankton
Bands: Mdewakanton (People of Spirit Lake), Ihanktonwan (People of the End)
Tribal Headquarters: Ft. Thompson, SD
Traditional Language: Dakota

Flandreau-Santee Sioux Tribe: (605) 997-3891
Reservation: Flandreau Reservation; in Moody County
Division: Santee
Bands: Mdewakanton, Wahpekute
Tribal Headquarters: Flandreau, SD
Traditional Language: Dakota

Lower Brule Sioux Tribe: (605) 473-5561
BIA: (605) 473-5512
Reservation: Lower Brule Reservation; Lyman and Stanley Counties
Division: Teton
Bands: Sicangu (Brule or Burnt Thigh)
Tribal Headquarters: Lower Brule, SD
Traditional Language: Lakota

Oglala Sioux Tribe: (605) 747-2381
BIA: (605) 867-5125
Reservation: Pine Ridge Reservation; Shannon and Jackson County
Tribal Headquarters: Pine Ridge, SD
Traditional Language: Lakota

Rosebud Sioux Tribe: (605) 747-2381
BIA: (605) 747-2224
Reservation: Rosebud Reservation; Todd, Mellette and Tripp Counties
Division: Teton
Band: Sicangu (Brule or Burnt Thigh)
Tribal Headquarters: Rosebud, SD
Traditional Language: Lakota

Sisseton-Wahpeton Oyate: (605) 698-7676
BIA: (605) 698-7676
Reservation: Former Lake Traverse; parts of Marshall, Day, Codington, Grant and Roberts Counties
Division: Santee
Bands: Sisseton (People of the Marsh), Wahpeton (People on Lake Traverse)
Tribal Headquarters: Agency Village, SD
Traditional Language: Dakota

Standing Rock Sioux Tribe: (701) 854-7202
Reservation: Standing Rock Reservation, Corson County SD
Division: Yanktonais, Teton

Bands: Hunkpapa, Blackfeet, Tanktonais and Cutheads
Tribal Headquarters: Ft. Yates, ND
Traditional Language: Dakota and Lakota

Yankton Sioux Tribe: (605) 384-3804

BIA: (605) 384-3651

Reservation: Diminished Yankton Reservation; part of Charles Mix County

Division: Yankton

Bands: Ihanktonwan

Tribal Headquarters: Marty, SD

Traditional Language: Dakota

Interpreting Services:

A to Z World Languages: Foreign language interpreting for medical, legal and business appointments. 24 –hour service, seven days a week. 408 S. 2nd Avenue, Sioux Falls, SD 57104. (605) 275-6565

Web Resources:

Caring Connections: A program of the National Hospice and Palliative Care Organization (NHPCO): A national consumer engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation. Provides resources to help professionals reach out and assist diverse populations such as African American, Chinese and Latino. 1-800-658-8898. www.caringinfo.org

Hospice Minnesota: Provides multicultural resources for end-of-life on their website including information about cultural competency, Hmong, Somali, Native American, Latino, Jewish, and African American. www.mnhospice.org/displaycommon.cfm?an=1&subarticlenbr=192

National Center of Cultural and Linguistic Competency at Georgetown University: Provides a self assessment for healthcare providers that can assist in identifying areas in which they might improve the quality of their services to culturally diverse populations. www.gucchd.georgetown.edu/nccc/

Educational Materials:

Ethnic Variations in Dying and Grief: Diversity in Universality, Edited by Donald P. Irish, Kathleen F. Lundquist and Vivian Jenkins Nelson; Taylor and Francis Publisher, 1900 Frost Road, Suite 101, Bristol, PA. 1993.

How Different Religions View Death and Afterlife, Edited by Christopher Jay Johnson and Marsha McGee, The Charles Press Publisher, Philadelphia, PA. 1998.

Searight H, Gafford J. *Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians*. *American Family Physicians*; 2005; 71:515-521.

Section VIII:

Financial

Bereavement Airline Fares:

Information can be obtained through these websites:

www.cheapoair.com

www.LowFares.com

www.BookingBuddy.com

www.smarter.com

www.flying.myapplications.info

County Welfare Assistance:

Counties provide assistance with rent, food, utility bills, laundry, clothing, transportation, burials, non-food items, dental bills, medical bills, and hospital bills.

Lake County Welfare: 200 E. Center St., Madison, SD 57042. (605) 256-7619.

Lyon County, Iowa: www.lyoncountyiowa.com

Minnehaha & Lincoln County Human Services: 521 N. Main Avenue Suite 201, Sioux Falls, SD 57104. (605) 367-4214. www.lincolncountysd.org, www.minnehahacounty.org

Rock County, Iowa: 2 Roundwind Road, Luverne, MN 56156. (507) 283-5070.
www.co.rock.mn.us

Department of Social Services:

Adult Services and Aging: Information and Referral can provide information and direction to services in the community. Services include: case management, caregiver relief/respice, caregiver training, homemaker, nursing, personal care, and supplemental services. 811 E. 10th St. Sioux Falls, SD 57105. (605) 367-5400. www.dss.sd.gov or www.dss.sd.gov/elderlyservices or www.state.sd.us/social or www.sd.connect.sd.gov

Economic Assistance: Applications for food stamps, Medicaid, temporary assistance to needy families (TANF), long-term nursing home care, assisted living care, and medical savings program (help with Medicare premium and co-payments). 811 E. 10th St, Sioux Falls, SD 57105. (605) 367-5444. www.dss.sd.gov

Medical Services: Answers questions regarding medical bills and medical services. 700 Governors Drive, Pierre, SD 57501. (605) 773-3495.

Energy Assistance:

Low Income Energy Assistance & Weatherization: Assistance with heating bills and weatherization. There is an application process. 206 W. Missouri Ave, Pierre, SD 57501-4517. 1-800-233-8503.

National, State and Local Resources:

Avera McKennan Financial Counseling: Provides assistance with insurance and medical bills. A financial counselor can help clients sort through bills and assist in filing insurance claim forms. There is no charge for an initial consultation with the financial counselor, and for a nominal charge of \$75 per year (\$60 per year for members of PrestigePLUS) the financial counselor will completely manage clients' medical billing file and will contact Medicare and/or an insurance company on the clients' behalf. (605) 322-6444.

Brain Tumor Society Financial Assistance Program (BTS): Created to provide supplementary financial assistance to people experiencing financial need. This program is for specific non-medical costs related to a primary brain tumor diagnosis. Grants are available for up to \$2000 per family, per year. 123 Watertown Street, Suite 3H, Watertown, MA 02472. 1-800-770-8287. www.tbts.org

Cancer Fund of America: A non-profit set up to help cancer patients, hospice and other healthcare providers by way of sending products free of charge. They provide liquid nutritional supplies, personal care items, etc. 2901 Breezewood Lane, Knoxville, TN 37921. 1-800-578-5284. www.cfoa.org

Children's Miracle Network: Helps children with medical needs. This includes travel expenses and lodging for families traveling to receive medical care for a child, and medical equipment to be used in the home. Located at Sanford USD Medical Center, 1305 W. 18th St, Sioux Falls, SD 57105. (605) 333-3232

Community Outreach: Provides financial assistance and advocacy for emergency needs of individuals living in the Sioux Empire. An assessment of the family is completed. Services include housing, legal aid, medical services, employment, education, financial assistance, rental assistance, utility assistance, and vouchers for food and gasoline. Walk-ins accepted Monday through Friday from 9 AM to 4 PM; or by appointment Monday through Friday 1 PM to 4 PM. 431 N. Cliff Avenue, Sioux Falls, SD 57105. (605) 331-3935. www.thecommunityoutreach.org

Hospice Education Institute–Small Gift Program: Provides assistance to needy hospice patients and families. Hospice professionals contact the Small Gift Program which makes immediate gifts to hospice patients and families for non-medical needs, as identified by local hospice staff members. These gifts are made within one working day, and after the request is reviewed and approved, a check is on its way. The nature of the non-medical assistance is limited only by the needs of patient and family, and the ingenuity of the hospice caregiver. (207) 255-8800. www.hospiceworld.org

Leukemia and Lymphoma Society: Offers a variety of services and programs in support of people with Leukemia, Lymphoma, Hodgkin's disease and Myeloma. They offer \$500 in financial assistance annually for transportation and medication costs. 1-800-955-4572. www.lls.org

Patient Advocate Foundation: Colorectal Transportation Assistance Fund Provides \$200 financial assistance for transportation costs associated with treatment of colorectal cancer. 1-866-657-8634.

Social Security Administration (SSA): 2400 W. 49th St. Oxbow Ctr. 1, Sioux Falls, SD 57103. (605) 330-4334, 1-800-772-1213 (National Number)

- Social Security checks are issued for the month prior.
- To retain a check for the prior month the deceased person must have been alive through the last day of that month. That is to say, that if a person dies on June 30th, the June SS check received in July must be returned.

Veteran Service Officer (VSO): Each county has local VSO available to assist veterans with applying for financial assistance. See website to identify local VSO. www.nacvso.org/cvso.asp

Misplaced Life Insurance Policies:

American Council of Life Insurers: Provides consumer information on search tips for locating misplaced life insurance policies. www.acli.com

MIB Solutions: A trade association group that will search its policyholder database for missing policy. Nominal fee for the service. www.mib.com

Prescriptions Assistance Programs:

Some prescription manufacturing companies offer free or low-cost prescriptions to low-income individuals who meet eligibility guidelines. Prescriptions Assistance programs typically require application made through a physicians' office, hospice or home care program. Some programs allow individuals to apply online and provide the name of the name, address and phone number of the physician. Income guidelines vary by company and medication. Proof of income may be required. Application process can take 30-60 days for approval. Contact your physician or social worker for more information on these programs.

American Medical Pharmaceutical Outlet II, Inc: Discount or low cost prescription program. 1-888-956-5802. www.medshelp4u.com

Healthwell Foundation: Monday-Friday 9am to 5pm Eastern Time. This foundation provides financial assistance to patients with specific illnesses cover out of pocket costs such as prescription co-pays, deductibles, and insurance premiums. 1-800-675-8416. www.healthwellfoundation

NeedyMeds: www.needymeds.com (“Click on Patient Assistance Programs”)

Pharmaceutical Research and Manufacturers of America: www.phrma.org

Patient Access Network Foundation: Assists insured people with out of pocket costs of treatment for specific conditions. 1-866-316-7263. www.patientaccessnetwork.org

Patient Advocate: Assists people with specific life threatening or debilitating diseases to assure access to care, maintenance of employment, and assists them to remain financially stable through a variety of resources. 1-800-532-5274. www.patientadvocate.org

South Dakota Medication Assistance: 1-866-854-5465. www.rxaccess.sd.gov

Co-Pay Assistance Foundations:

Assist with co-pays for medications based on diagnosis

Chronic Disease Foundation: 1-877-968-7233. www.cdfund.org

Healthwell Foundation: 1-800-675-8416. www.healthwellfoundation.org

National Organization for Rare Disorders (NORD): 1-800-634-7207. www.rarediseases.org

Patient Access Network: 1-866-316-7263. www.patientaccessnetwork.org

Patient Advocate Foundation: 1-866-512-3861. www.copays.org

Patient Services, Inc: 1-800-366-7741. www.uneedpsi.org

Psychosocial Support:

Cancer Care: Free professional support services for people affected by cancer. Counseling, telephone and internet support groups provided free of charge. 1-800-813-4673. www.cancercare.org

Lance Armstrong Foundation: Variety of support services available from the moment of diagnosis. 1-866-235-7205. www.laf.org

Sensational in Survival: A nonprofit organization created to provide financial assistance to those who have breast cancer. 1-585-586-5680. www.sensationalinsurvival.org

Wellness Community: Dedicated to providing emotional support, education and hope for people who are affected by cancer. Online support is available. New online support group for people living with metastatic cancer. 1-888-793-9355. www.thewellnesscommunity.org

Publications for Cancer Survivors and Caregivers:

CURE Magazine: Cancer Updated, Research and Education is a quarterly magazine that combines the science and humanity of cancer for those who have to deal with it on a daily basis. CURE provides scientific information in an easy to understand language. This is a free subscription to cancer survivors and caregivers. Can register online for single subscription or bulk copies for office or cancer center. 1-800-210-2873. www.cure.com

Women and Cancer: Offers all women a trusted resource covering prevention, management and wellness issues related to cancer while fostering community and inspiring hope. There is a free subscription to cancer survivors and caregivers for one year. Can register online for single subscription or bulk copies for office or cancer center for a fee. www.cancerconsultants.com

Coping with Cancer: Coping with Cancer is a consumer magazine for people whose lives have been touched by cancer. Now in its 20th year of providing knowledge, hope, and inspiration, its readers include cancer survivors, families, caregivers, health care teams, and support group leaders. Waiting room program of 25 copies for shipping charge of \$14.00. (615) 790-2400. www.copingmag.com

Livestrong Survivorship Notebook: The Livestrong Survivorship Notebook is designed to organize and guide your cancer experience. It is a notebook so you can take it with you to healthcare appointments and other important meetings. They are offered free of charge from the Lance Armstrong Foundation as an easy way for cancer survivors and their caregivers to access and keep important information organized. Shipping and handling charges will be extra. www.livestrong.org

Telephone Support Lines:

Resources for support to match cancer survivors and caregivers with others experiencing the same diagnosis.

Cancer Survivors Network-American Cancer Society: www.cancer.org

Cancer Hope Network: 1-877-467-3638. www.cancerhopenetwork.org

Connections: National Brain Tumor Foundation. 1-800-934-2873. www.braintumor.org

First Connection (Peer to Peer) Program-Leukemia and Lymphoma Society:

1-888-220-4440 ext 110. www.lls.org

MD Anderson Support Line for Patients and Caregivers: 1-800-345-6324.

www.mdanderson.com

RA Bloch Foundation Cancer Hotline: 1-800-433-0464. www.blochcancer.org

Y-Me Match Program for Patients and Caregivers: 1-800-221-2141. www.y-me.org

Web Resources:

www.helpingpatients.org

www.sdconnect.sd.gov

Section IX:

Legal

What are Advance Directives?

Advance directives are written instructions regarding a patient's medical care preferences. Anyone 18 years old or older is encouraged to develop an advance directive. It can be very helpful for patients with a life-limiting or terminal illness to have a conversation and develop their advance directive with their family and health care providers. For some patients this may be a difficult conversation. But most of us like to be in charge of our lives and the health care we receive. Completing an advance directive can help the patient to remain in charge of the care they want (or do not want) at end of life.

Types of Advance Directives:

There are 3 types of advance directives: Living Will, Durable Power of Attorney for Health Care and Comfort One. These forms do not have to be completed by an attorney, however, they do need to be signed, witnessed and possibly notarized.

Living Will: Directs what treatment to provide or withhold when a patient is terminally ill and death is imminent or if the patient is permanently unconscious. It only becomes effective when a person is not able to speak for one's self. Often this legal document gives input to medical treatments such as: mechanical breathing (respirator or ventilators), tube feedings, and resuscitation.

- Initially passed 1991, 2007 Senate Bill 75 is an Act to revise certain provisions regarding living wills, 34-12D.
- "Terminal condition," an incurable and irreversible condition such that, in accordance with accepted medical standards, death is imminent if life-sustaining treatment is not administered, or a coma or other condition of permanent unconsciousness that, in accordance with accepted medical standards, will last indefinitely without significant improvement and in which the individual is unable to communicate verbally or non verbally, demonstrates no purposeful movement or motor ability, and is unable to interact purposefully with environmental stimulation
- 34-12D-5. A living will declaration becomes operative when the declarant is determined by the attending physician to be in a terminal condition, death is imminent, and the declarant is no longer able to communicate decisions about medical care.

Five Wishes: This is a kind of living will that includes medical wishes but also personal, emotional and spiritual wishes of the seriously ill patient. The patient also identifies who should make health care decisions for him/her if s/he can't do so. A copy of Five Wishes may be obtained for a nominal fee. Five Wishes is available in Spanish also. Aging with Dignity, PO Box 1661, Tallahassee, FL 32302-1661. 1-850-681-2010. www.agingwithdignity.org

A Durable Power of Attorney for Health Care (DPOA): Appoints someone to speak for a patient when the patient is no longer able to direct his/her care. This could include an illness, accident or terminal condition. This is different than a financial power of attorney form since it focuses only on health care decisions. Most South Dakota hospitals and clinics have access to a form that may be used by patients to identify a DPOA and their health care wishes. In addition, persons may consult with an attorney for assistance.

Comfort ONE: Available in South Dakota Comfort ONE provides quick identification of patients who choose not to receive resuscitation treatment by emergency personnel. The patient wears a special bracelet or has a document that states these requests and that the emergency team should only provide comfort measures. There is a specific form that must be signed by the physician, nurse practitioner or physician assistant. The patient can purchase a Comfort ONE bracelet for a fee of approximately \$30.00. Some hospice programs offer a bracelet loan program to clients unable to afford the cost of the bracelet. In addition, these programs will accept donated bracelets that are then re-registered to new owners. The bracelet and Comfort ONE forms may be obtained by medical providers from the South Dakota Emergency Medical Services: Office of Emergency Medical Services, 118 West Capital, Pierre, SD 57501-2000. (605) 773-4031.
www.state.sd.us/dps/EMS/EMT_Information/dnr_form_request.htm

Living Wills and Durable Power of Attorney for Health Care each have limitations. There is no way the patient and health care provider can plan ahead for every situation. But having a conversation about the patient’s values and advance directive will help give the family and the health care provider greater insight into what the patient would want in medical situations.

Advance Directive	Purpose	Advantages	Disadvantages
Living Will	Lists patient’s feelings on certain medical treatments and interventions	Gives patient’s doctors and family an idea of the EOL care preferred if patient can’t speak.	Used as a guide, but is limited to imminently terminal or permanently unconscious patients
Durable Power of Attorney for Health Care	Appoints who patient wants to make medical decisions about treatments if patient can’t speak.	The health care providers know who patient wants to make decisions.	May or may not expressly tell what decisions the DPOA should make.
Comfort One	Informs the Emergency Medical Services that the patient only wants comfort measures if 911 is activated.	Allows the EMS to forgo resuscitation efforts and focus on comfort care. Honors the patient’s wishes for DNR status.	The form or bracelet must be with the patient to be honored by EMS.

Choosing a Decision-Maker:

Patients should be encouraged to carefully choose and authorize a person to act as the Durable Power of Attorney for Health Care. This person doesn't necessarily have to be a family member. Some patients want to have the Financial Power of Attorney be a different person from the Durable Power of Attorney for Healthcare.

If a patient does not identify a Durable Power of Attorney for Health Care, then the health care provider relies upon the "South Dakota Health Care Consent Act" to determine who should be the patient's decision maker when the patient is unable to do so. This law states:

In the absence of a durable power of attorney for health care or the appointment of a guardian of the person, or if neither the attorney in fact nor guardian is available to consent, a health care decision for an incapacitated person may be made by the following persons or members of the incapacitated person's family who are available to consent, in the order stated:

- (1) The spouse, if not legally separated;
- (2) An adult child;
- (3) A parent;
- (4) An adult sibling;
- (5) A grandparent or an adult grandchild;
- (6) An adult aunt or uncle, adult cousin, or an adult niece or nephew;
- (7) Close friend.*

* "Close friend," any adult who has provided significant care and exhibited concern for the patient, and has maintained regular contact with the patient so as to be familiar with the patient's activities, health, and religious or moral beliefs.

Source: *SL 1990, ch 222, § 1; SL 2007, ch 192, § 1.*

"However, any person may, before a judicial adjudication of incompetence or incapacity, disqualify any member of the person's family from making a health care decision for the person. The disqualification shall appear in a document signed by the person or may be made by a notation in the person's medical record, if made at the person's direction. Any member of the incapacitated person's family may delegate the authority to make a health care decision to another family member in the same or succeeding class. The delegation shall be signed and may specify conditions on the authority delegated.

Any person authorized to make a health care decision for an incapacitated person shall be guided by the express wishes of the incapacitated person, if known, and shall otherwise act in good faith, in the incapacitated person's best interest, and may not arbitrarily refuse consent. Whenever making any health care decision for the incapacitated person, the person available to consent shall consider the recommendation of the attending physician, the decision the incapacitated person would have made if the incapacitated person then had decisional capacity, if known, and the decision that would be in the best interest of the incapacitated person."

Source: *SL 1990, ch 222, § 3; SL 2007, ch 192, § 2.*

www.legis.state.sd.us/sessions/2007/bills/SB74enr.htm

Treatment Definitions:

It is helpful for patients and families to understand medical terminology before completing Advance Directives. It is important that the health care provider educates the patient and family on the likelihood of success for these medical interventions based upon the status of the patient's life-limiting or terminal illness. These interventions can all be helpful in temporary situations in which the patient is expected to recover. In end of life situations, these interventions may only prolong the dying process. Many patient situations will fall somewhere in between help and hindrance where the chances for recovery are unknown. These gray areas are difficult to plan for but the conversations can be helpful in guiding the medical care over time. Discussions about withholding or withdrawing treatment that are life sustaining should be based upon:

- Medical indications
- Analysis of the treatment's benefits and burdens according to the patient's goals of treatment
- Patient's determination of quality of life that may result from the treatment
- Patient's wishes

There is no ethical distinction between forgoing treatment and withdrawing treatment. Although making a decision to forgo a treatment may be much easier psychologically than making a decision to withdraw it, ethically the decisions are equivalent.

(American Academy of Hospice and Palliative Medicine

Porter Storey, MD and Carol F. Knight, Ed.M

UNIPAC Six: Ethical and Legal Decision Making When Caring for the Terminally Ill)

Resuscitation: This is the utilization of Cardiopulmonary Resuscitation (CPR) to restart the heart when it has stopped beating. This can be a beneficial intervention for younger, healthier patients. But it is not as effective in older adults and the terminally ill as it may only temporarily prolong life.

Code Status: Depending upon the patient's wishes, it may be important to discuss the formal designation of a Do Not Resuscitate (DNR), or allow natural death (AND) order. Many patients believe that once their Living Will is formalized, that a DNR is in place. It is important to share that a formal medical order must be written by the physician when the patient enters a facility such as hospital, hospice, assisted living, or nursing home. A DNR order means that the patient wants to allow the natural dying process and not have interventions of CPR.

Mechanical Ventilation: This is a machine that takes over the breathing for the patient. It can temporarily take over breathing while the doctors treat an illness affecting lungs; however, it can't reverse the disease or illness.

Artificial Hydration and Nutrition: This refers to a method of delivering a chemically balanced mix of nutrients and fluids when a patient is not able to eat or drink. The patient may receive fluids through a tube inserted directly into his or her stomach, a tube put through the nose and throat to the stomach or a needle in a vein. For a temporary condition, it alleviates hunger and

confusion from dehydration. For terminally ill, it may not extend life but prolongs the dying process.

34-12D-12: Providing treatment, artificial nutrition, and hydration--Responsibilities of health care provider. If an individual's declaration contains a directive to provide treatment or artificial nutrition and hydration under any circumstances, any health care provider who has responsibility for the treatment and care of the individual must provide the directed treatment or artificial nutrition and hydration in those circumstances so long as it is technically feasible. A health care provider who objects to providing such treatment may instead transfer the individual to a health care provider willing to honor the declaration, but must continue to provide the treatment or care until the transfer is effectuated. *Source: SL 1991, ch 273, § 11A; SL 2007, ch 193, § 7.*

59-7-2.7: Comfort care required--Conditions for withdrawal of artificial nutrition or hydration. The attorney-in-fact or agent may not authorize the withholding or withdrawal of comfort care from the principal. The attorney-in-fact or agent may authorize that artificial nutrition or hydration be withheld or withdrawn if one or more of the following exist:

- (1) Artificial nutrition or hydration is not needed for comfort care or the relief of pain and the attending physician reasonably believes that the principal's death is imminent; or
- (2) Artificial nutrition or hydration cannot be physically assimilated by the principal; or
- (3) The burden of providing artificial nutrition or hydration outweighs its benefit, provided that the determination of burden refers to the provision of artificial nutrition or hydration itself and not to the quality of the continued life of the principal; or
- (4) There is clear and convincing evidence that the principal expressed the desire that artificial nutrition or hydration be withheld, or refused artificial nutrition or hydration prior to the loss of decisional capacity; or
- (5) The principal expressed in the document creating the power of attorney that artificial nutrition or hydration be withheld; or
- (6) The principal expressly authorized, in the writing creating the power of attorney, the attorney-in-fact or agent to direct the withholding of artificial nutrition or hydration.

Source: SL 1990, ch 412, § 4; SL 2007, ch 296, § 2.

Dialysis: Removes waste from the patient's blood and manages fluid levels if the kidneys don't function.

Legal Assistance:

East River Legal Services: Provides civil (not criminal) legal services to low income individuals. 335 N. Main Avenue 2nd Floor, Sioux Falls, SD. (605) 336-9230.

Guardianship:

Establishment of guardianship requires the involvement of an attorney.

Educational Materials:

Caring Connections: 1-800-658-8898. www.caringinfo.org

Section X:

Special Topics

Body Donation:

The Sanford School of Medicine (SSOM) of the University of South Dakota: The SSOM accepts voluntary donation of bodies for their medical and allied health program. Information and consent forms can be obtained from the school in Vermillion, SD. (605) 677-5141.
www.usd.edu/med/biomed/bodydonation.cfm

- Donors are provided with an identification card to be carried at all times
- Persons of advanced age are acceptable
- The Uniform Anatomical Gift Law prohibits medical schools from purchasing human bodies
- At the time of death, families should inform their funeral director of the intent for donation and request the funeral director contact the school prior to the initial preparation of the body
- The donor body is embalmed prior to the being sent to the school
- Family can proceed with a customary or traditional type of funeral with a body and casket.
- Autopsied bodies are not accepted, although the eyes can be donated to an eye bank
- With the exception of eye donation, the school does not accept bodies in which organs have been removed
- There is a charge for transportation of the body to the school
- Families have two options for the final disposition. 1. At no cost the remains may be buried anonymously in an unmarked plot maintained by the SSOM. 2. If the family wishes to have the remains returned, they can make arrangements with a funeral home. In that event the remains are reduced to ash. The ashes are returned in a sealed container for a nominal fee
- A bequest can be canceled or revoked at any time

BioGift Anatomical, Inc: 1-866-670-1799. www.biogift.org

Organ and Tissue Donation:

Facts about Donation:

- One organ and tissue donor can save up to 60 lives!
- Organs that can be donated include heart, lung, liver, kidneys, pancreas and intestine
Tissues that can be donated include heart valves, bone, connective tissue, skin, veins and corneas
- Organs are allocated regionally and nationally based on medical criteria such as severity of illness, length of time waiting and blood- and tissue-typing
- All major religions support donation
- An open casket funeral is still an option after donation

- There is no cost to the donor or donor family for donation; LifeSource assumes all costs for donation and passes it on to the recipient's health insurance company.
- Being an organ and tissue donor will not affect the quality of medical care received at the hospital.

How to Register:

South Dakotans over the age of 18 can register to be an organ and tissue donor by checking the box on their driver's license or state identification card application or renewal form. This is a legal agreement to having organs and recovered for transplant after death. If persons are under the age of 18 they can register to be an organ and tissue donor on their driver's license or state identification card, however, their parent or guardian will make the final decision about donation at the time of death.

LifeSource: A non-profit organization dedicated to saving lives through organ and tissue donation in the Upper Midwest. 1-888-536-6283, www.Life-Source.org or www.DonateLifeSD.org

South Dakota Lions Eye Bank: Coordinates the procurement, processing, and distribution of eye tissues. In addition, they offer full tissue procurement services throughout South Dakota and the surrounding region. 1321 W. 22nd St. Sioux Falls, SD 57105. 1-800-245-7846, (605) 373-1008. www.sharingthegift.org

- Costs associated with eye procurement are absorbed by the eye bank placing the tissue.
- Donation is performed within hours of death, typically within 12 hours, so funeral arrangements can proceed without interruption or delay.
- Donation will not affect the donor's appearance. Funeral arrangements, including viewings, may proceed as planned.

After Death Issues:

Deceased Do Not Mail List: To cancel commercial mail addressed to the deceased. Register the deceased person's information for \$1 online at www.preference.the-dma.org/cgi/ddnc.php or write DMA at P.O. Box 1270, Carmel, NY 10512. Include the name, date of death, your name, relationship, and contact information. The fee is to discourage fraud.

Financial Assistance with Funerals and Burial:

County Welfare: Each county differs in the amount and type of assistance they can provide to financially needy families. Persons in need should contact their County Welfare Office after the death to determine eligibility. 521 N. Main Avenue Suite 201, Sioux Falls, SD 57104. (605) 367-4214. www.lincolncountysd.org, or www.minnehahacounty.org

Minnehaha County Funeral Assistance: Provides financial assistance to qualifying persons with the following: 2008 allowable assistance. Funeral - \$2,100, Cremation- 54% or more, open & close grave - \$275.00. Amounts are subject to change.

Native Americans: See Section VII Cultural Diversity Resources and Information for additional information on funeral and burial assistance.

Veterans: See Section XI Veterans' Resources for additional information on funeral and burial assistance.

Funeral General Information:

Some funeral homes in the Sioux Falls area give professional services free of charge for infants and children up to a certain age. Check with the funeral home of choice to determine services available. Some funeral homes do provide memory books and DVDs of pictures for memorial services. Some funeral homes in town give educational tours.

The National Funeral Directors Association: Provides information for consumers related to arranging funerals, making tributes, preplanning, cremation, understanding grief, types of losses, and explaining death to children. www.nfda.org www.nfda.org/consumerresources.php

Cremation Association of America: Provides guidelines for consumers to help choose a cremation provider. www.cremationassociation.org

Funeral Consumers Alliance: A non profit organization that provides consumer guidelines for choosing meaningful, dignified and affordable funerals. www.funerals.org

International Cemetery, Cremation, and Funeral Association: Provides straight answers to real questions about funeral and cemetery arrangements, cremation, grief and other issues related to end of life. www.icfa.org

Educational Materials on Funeral Customs:

Funeral Customs the World Over, Habenstein and Lamers, 4th edition (1994)

International Handbook of Funeral Customs, (1998), ISBN: 0-313-30443-2

Wish Granting Organizations for Adults:
(Also, see children and adolescence Section V)

Crossing the Finish Line: Offers a one-week excursion for adults between the ages of 18 and 50 that have been diagnosed with cancer. (610) 260-0552. www.crossingthefinishline.org

Disney World Compassion Program: Provides free passes to Disney World parks and attractions. (407) 828-9928

Dream Foundation: Grants wishes to terminally ill adults with one year or less to live who would not otherwise be able to financially fulfill the dream. Grants wishes to adults ages 18-65 and who have life expectancy of one year or less and whose finances are limited to the extent they are unable to fulfill dreams for themselves. Additional restrictions apply so check with your social worker or the web site to determine if the request is realistic. (805) 564-2131. www.dreamfoundation.org or e-mail address: steven@dreamfoundation.org

Fairygodmother Foundation: Their mission is to make wishes come true for adults facing a terminal illness. (773) 388-1160. info@fairygodmother.org www.fairygodmother.org

United Special Sportsman Alliance: A non-profit Christian organization that coordinates with other organizations granting terminally ill and disabled sportsmen and women an outdoors adventure of their dreams. (715) 884-2256 or 1- 800-518-8019. biotec@tds.net
www.deerfood.com/ussa.htm

Additional information on Wish Granting Organizations can be found at:
www.dmoz.org/Society/Philanthropy/Organizations/Cheer_and_Support/Wish_Fulfillment/
Provides a comprehensive list of organizations that grant wishes.

Section XI:

Veterans' Resources

General Resources:

Eligibility: To determine eligibility for Veterans' Benefits in South Dakota contact your local VSO (see website for assistance) www.nacvso.org/cvso.asp or the regional office located on a VAMC campus. 1-800-827-1000. Some of the benefits may include Non-Service Connected Pension, Aid and Attendance, and Homebound Assistance. To obtain a full list of services available, contact your CVSO, Regional Office (see previous contact information) or primary care out-patient social worker at 605-336-3230, extensions 5911 or 6758.

Respite Program: Veterans who have established health care with VA are eligible for inpatient and outpatient respite services. Please contact Community Health Nurse Coordinator at (605) 336-3230, Ext 6354 or 6544 for more information.

End of life care can be provided in an inpatient setting at the VAMC or in nursing homes which have VA contracts. Each case will be evaluated individually.

Veterans Death Benefits:

Veterans may be eligible for:

- Burial and funeral expense allowance
- Government headstone or marker at no charge
- American flag to drape on casket which is given to next of kin, close friend, or associate

For further information contact the Applicant Assistance Division 1-800-697-6947, Veterans Administration at 1-800-827-1000 or local Veteran Service Officer (VSO) for eligibility information regarding these benefits.

Section XII:

Appendix

Caregiver Tips:

The trauma of a chronic, cancer or terminal diagnosis and treatment, and end of life care will often rearrange family roles, responsibilities, and relationships. Navigating those new, evolving relationships takes communication, patience and support.

Tips for families who care for the patient:

- Figure out exactly what the person needs during and after treatment.
 - Discuss expected duties and division of daily tasks
- Be an advocate for the patient:
 - Become the second set of ears
 - Educate yourself about important information and treatments
- Keep a notebook or journal to stay organized.
 - Make a list of questions for MD visits.
 - Lance Armstrong Foundation Survivor Notebook free at www.laf.org

End of Life Discussions with Culturally Diverse Clients:

In working with a culturally diverse person or family the following questions are an example of how one can gain important information about how culture impacts an individuals understanding of health, serious illness, and end of life care.

- *How would this situation/problem/issue be handled in your... homeland/family/church?*
- *How much do you want to know about his/her condition?*
- *Who should or will make medical decisions?*
- *Are there family members we should speak to and ones we should not to speak to?*
- *Are there religious and spiritual issues that may impact their decision making process or care?*

When considering therapeutic options, physicians should consider that members of many cultural groups prefer that family members, rather than patients make treatment decisions. Direct discussion of advance directives and therapeutic support levels may be undesirable in situations in which they are viewed as potentially harmful to patients' well being.

Reasons for Nondisclosure Include:

- *Discussion of serious illness may be viewed as being disrespectful or impolite.*
- *Open discussion of serious illness is viewed as provoking unnecessary patient depression or anxiety.*
- *Direct disclosure may eliminate patient and family hope of recovery.*

- *Speaking the name of a serious, life-threatening condition, even in a hypothetical sense, makes death and terminal illness a reality.*

Reference: Searight H. Gafford J. *Effect of Culture on End-of-Life Decision Making*. AAHPM bulletin. 2005; 6-:1-4.

Tips for Talking to Patients/Families about End of Life Care and Hospice:

When surveyed, most patients report that they expect the physician or nurse to bring up the topic of end-of-life care and hospice. This discussion is perhaps easiest to bring up soon after a terminal diagnosis is made. When discussing treatment options, a statement such as, “While we will work hard and hope for the best possible outcome for you as you deal with this illness, sometimes things don’t go well. If we get to that point, the introduction of hospice, a method of care that focuses intensely on the comfort and dignity of the patient and support for the family, is often helpful. If I think we are reaching that point I will tell you and we can discuss hospice further.”

If, in fact, treatment fails to achieve remission or cure, or seems to be yielding very marginal benefit, the physician or nurse can say, “It seems to me that our treatments are causing as much burden as benefit. Some patients at this point want to know more about hospice care. Are you feeling like this would be a good time to discuss hospice further?”

Many times the answer to this question will be “Yes.” At that point it is helpful to ask the patient who else, if anyone, s/he would like to be involved in the conversation. Set aside time for a meeting when all parties can attend. At the meeting ask everyone (starting with the patient) about their current understanding of what is happening, and what questions they have. After the patient and others have reported their impressions and questions, review the case from a medical perspective and discuss options. Emphasize that the goal of hospice is to preserve as much comfort and dignity as possible, and to support the patient’s loved ones. Explain or provide written material listing the facts about hospice mentioned above. If there is a choice of hospice providers available, the choices should be listed and the patient allowed time to make an informed choice among the possible hospice providers.

The approach described above will generally permit the patient and/or family time to think about the possibility of hospice care and the choice of providers in a thoughtful and unhurried manner.

If you are able to maintain the doctor-patient or nurse-patient relationship after hospice care starts, be sure the patient knows that. If you are unable to continue providing care for the patient in the hospice setting, reassure the patient and family that you will help them obtain a new physician and care team who are skilled in hospice care. It is very important that the patient and family do not feel abandoned at this important transition of care.

How to Prepare for a Patient/Family Meeting to Discuss End of Life Issues:

1st Step: Why Have a Patient/Family Meeting?

- To share information
- To set goals
- To make decisions

2nd Step: Pre-meeting Planning

- Review medical history/treatment options/prognostic information
- Coordinate medical opinions between consultants/primary MD
- Obtain patient and family psychosocial data from care team members. Although the patient is the unit of treatment, the family is the unit of understanding
- Determine what care team staff (palliative/hospice) should be present at the meeting
- Reflect on the outcome that you are hoping to achieve with the meeting. Is the outcome realistic
- Check your emotions
- How you feel will be expressed as what you say
- Review Advance Care Planning documents
- Is there a Power of Attorney (DPOA)
- Is the patient able to make decisions

3rd Step: Environment: Choose a proper environment

- Quiet, comfortable, chairs in a circle
- Kleenex on the table
- Invite participants to sit down
- Turn off beepers/phones

4th Step: Introductions

- All team members should introduce self and role
- All participants should introduce self and relationship to patient
- Explain purpose of meeting
- Establish ground rules that all can talk and that there should be no interruptions
- Build the relationship
- Ask the patient/family to tell you something about the patient. The goal is to “come to know” the patient as a person
- Hobbies, activities, values

5th Step: Establish Common Knowledge Base

Make no assumptions. Determine what the patient/family already knows. Allow each to provide input.

- “What do you understand about your condition?”
- “What have the doctors told you about your condition?”

6th Step: Medical Review

Present medical information succinctly sharing the current condition, expected course, prognosis and clarify and misconceptions without use of medical jargon.

7th Step: Reactions and Questions

- Allow silence, give patient/family time to react and ask questions
- Acknowledge and validate reactions
- When the family is not accepting of a terminal diagnosis, going over the medical facts is not helpful, instead, deal with the emotions

8th Step: Decision Making

If the goal is to establish a decision:

- Present the options
- Discuss risks and benefits
- Make a recommendation
- Sensitivity to cultural needs
- Pay attention to nonverbal behaviors

When patient can speak for him/herself ask:

- “What treatment are you considering?”
- “What support would you like?”
- “If you were so sick, that you were unable to speak with me, who would the doctors talk with regarding decisions that need to be made about your health care?”

Invite discussion:

When the patient can't speak for him/herself:

- Ask the family, “What would _____ choose if he/she were sitting with us today?”
- Make a recommendation such as, “Based upon your mother’s medical condition and what you have told me, I would recommend that we discontinue the dialysis, keep her comfortable, and allow her to die peacefully.”

Avoid stating the following:

- “There is nothing more we can do.” *This may be true if the goal is to cure but there is much that can be done to ensure comfort.*
- “Would you like us to do everything possible?” *This is a broad statement and family may assume that this will provide a cure or restore function.*
- “What would you like us to do for your mother?” *This can put guilt on the family. And most families want you to restore their loved one’s health. So it is always best to frame it from the perspective of “What would your mom tell us to do?”*
- “I think we should stop aggressive therapy.” *This implies that something is being taken away from the person, which may cause family to be defensive. Often it is better to state, “I think it’s time to focus on comfort measures.”*
- “If your heart stops, would you like us to restart it?” *Need to impart accurate information to the patient/family. Discuss the realistic outcomes of CPR. Most people assume that if you restart the heart that the function/mental alertness will be present.*

Often using the terminology of “Allowing Natural Death” or “Dying Naturally” is helpful.

9th Step: When There is No Consensus

- Acceptance of dying is a process, it occurs at different times for different family members
- A sudden illness at any age, or illness in a young person, makes acceptance of dying more difficult for everyone.
- Prior family conflicts, especially concerning alcohol, drugs, or abusive relationships, make decision-making a challenge.
- Ensure that everyone in the family has the same medical information. Consistency is very important; the information must be clear and unambiguous.
- Ensure that a relationship of trust exists between the doctor and family. Without trust, there can be no basis for shared decision-making.
- Time is an ally. Schedule a follow-up meeting.
- Establish a time-limited trial.
- “Let’s continue this aggressive support for another 72 hours and if there is no improvement, let’s meet again and re-discuss the options.”

Consider other options such as:

- The Palliative Care Team
- The Ethics Team
- Personal Minister or Chaplain

10th Step: Conclusion

- Summarize areas of consensus and disagreement
- Caution against unexpected outcomes—the dying patient doesn’t always die
- Provide continuity
- Document in the medical record
- Discuss results with other allied professionals not present
- Provide reassurance, support and hope but be realistic

References:

Buckman, R. *How to Break Bad News: A Guide for Health Care Professionals*. Baltimore: Johns Hopkins University Press. 1992.

Diem SJ. Lantos JD. Tulsky JA. *Cardiopulmonary Resuscitation on Television. Miracles and Misinformation*. New England Journal of Medicine. 1996; 334 (24): 1578-82.

Fast Facts #23 and #24 J Pall Med 1999; 2: 339-340.

Junkerman, Charles and Schiedermayer, David. *Practical Ethics for Students, Interns and Residents*, 2nd Ed. University Publishing Group ISBN 1-55572-054-4. Presentation by Dr. David Weismann 2005.

Checklist for Getting Your Affairs in Order:

- _____ Gather your important papers and documents related to:
 - property
 - investments
 - income
 - insurance
 - taxes
 - checking and saving accounts
 - credit cards
 - home and car titles, registrations

- _____ Include information on your;
 - physicians and medications
 - education
 - military and employment records
 - social security number
 - birth, citizenship, adoption, marriage, divorce and death certificates

- _____ Keep the important papers in one location. If the important papers are kept in a bank deposit box, always keep a list of the stored documents/information at home.

- _____ Tell family, significant others, Power of Attorneys or a trusted family friend where you keep your important documents.

- _____ In advance, give consent for your physician or lawyer to speak to your caregiver/s. This can be accomplished by verbal or written consent.

- _____ Communicate your wishes about EOL treatment to your physician, family members and significant others. Complete an Advance Directive and provide a copy of the document to your physician, family members, attorney and/or trusted friend.

Checklist for Steps to Take After the Death of a Loved One:

- _____ Collect important papers and documents. Some of the items you may need are:
 - birth, marriage, and death certificates
 - social security card for dependent children, spouse and the deceased
 - recent federal tax returns
 - military records-discharge certificate
 - will
 - bank account, stocks, bonds, real estate and personal property records

- _____ Request additional copies of the death certificate from the funeral director to notify insurance companies, banks, creditor, and other various organizations.

- _____ Notify in writing all insurance companies of the death to determine how to claim policy benefits; and keep copies of all correspondence.

- _____ Notify all creditors in writing and keep copies of correspondence. Inquire if loans are insured.

- _____ Contact the Social Security office to determine if the survivor or deceased's children are eligible for additional or new benefits. Two types of benefits are possible if the deceased paid into Social Security for at least 40 quarters:
 1. *Death Benefit:* \$255.00 is paid for burial expenses to the eligible spouse or dependent children.
 2. *Survivor's Benefit:* Benefits amounts are dependent upon the age and relationship of the survivors. Eligibility is based on:
 - Spouse age 60 and older
 - Disabled surviving spouse age 50 and older
 - Spouse age 60 and under who care for dependent children age 16 and under or are disabled
 - Children of the deceased under the age of 18 or who are disabled

- _____ For Veterans, contact the nearest Veterans Administration office to apply for benefits. Discharge papers are necessary. If a copy cannot be located contact: National Personnel Records Center, 9700 Page Boulevard, St. Louis, MO 63132-5200. Note on the correspondence the branch in which the person served.

- _____ Contact former employer to determine if the deceased is due a final paycheck, vacation, sick leave, annuity or pension plan. In addition, inquire if the survivor or deceased's children are entitled to continued health insurance coverage.

- _____ Begin probate process

If a person dies without a will, state law determines how the deceased assets and property are distributed. Contact the probate court in the state where the deceased lived to determine the process.

Web Resources:

www.aarp.org/families/grief_loss/

www.hospicefoundation.org/

Funeral Preplanning:

Funeral Preplanning involves arranging and paying for the types of services desired at a funeral or memorial service in advance. Paying for services in advance relieves the financial burden on family members at the time of death. Different finance options are available. For example, money can be set up in an irrevocable funeral trust so that the money is protected. An irrevocable funeral trust is not considered an asset and will not disrupt SSI and Medicaid benefits.

Questions to ask about prearrangements and what to look for in a funeral home:

What does the facility look like?

- Is it clean?
- Is the staff warm and friendly?
- Will it accommodate your family needs?
- Is there a luncheon room available?

Financial Questions

- What type of financing is available?
- Is it taxed -1099?
- Does interest accrued on the prepayment go to you or the funeral home?
- Does the excess go back to the family or to the funeral home?

What happens if you move or change funeral homes?

- Is there a transfer or administration fee?

Are there additional costs?

- Luncheon room costs, package costs, surcharges, prayer service charges, etc.

Books about Grief and Loss:

Bade, John McCullough. *Will I Sing Again? Listening for the Melody of Grace in the Silence of Illness and Loss*. Augsburg Books. 2003.

This is a beautiful book of poems, scripture and personal comment written by a pastor who was diagnosed with Parkinson's disease.

Bolton, Martha. *Saying Goodbye When You Don't Want To*. Gospel Light Pubns. 2002.

Uses personal experiences, poetry, and scripture verses to provide advice on how to cope with all kinds of loss in one's life, including death, moving, the end of a friendship, and other difficult situations.

Bowen, Deborah E., Stickler, Susan L.A. *Good Friend for Bad Times*. Augsburg Books. 2004.

A book written by two grief counselors filled with practical suggestions for how to help a friend or loved one through grief at various times following the loss.

Bozarth-Campbell. *Alla, Life is Goodbye, Life is Hello: Grieving Well Through All Kinds of Loss*. Hazelden. 1994.

Guidance through all kinds of grief. Encouragement to thoroughly experience the grief and when the time comes, to move on to acceptance.

Davidson, Glen W. *Understanding Mourning*. Augsburg Books. 1984.

Helpful guidelines for healthy mourning and returning to a reorganized life.

Detrich, Richard Lewis. *How to Recover from Grief*. Judson Pr. 1996.

This book provides the tools for understanding and will help combat the fear and confusion that often accompany grieving.

Dobson, James Dr. *When God Doesn't Make Sense*. Tyndale House Publishers. 1995.

This book is an address to those who have been left confused and disillusioned by life's difficulties.

Graham, Billy. *Facing Death and the Life After*. Word Books. 1987.

Discusses death and grief from a Christian perspective. He discusses death, preparing for death, coping through grief, and what happens after death, to name a few chapters. The discussion is illustrated by stories of people who have experienced all kinds of death, including that of children.

Heavilin, Marilyn Willett. *Roses in December*. Harvest House Publishers. 2006.

Helps you understand the grieving process, support family members, give insight into sibling grief, and maintain your marriage during this difficult time.

Herhold, Bob. *On Our Way Home – Courage and Faith for the Final Journey*. Cowley Publications. 2006.

This is a little book of stories about individuals who have faced death, each in their own way. Through the author's eyes we receive many perceptions of death and faith.

- Hickman, Martha Whitmore. *Healing After Loss*. HarperCollins Publishers. 1998.
This is a book of daily meditations that were written after Hickman lost her daughter many years ago. She understands that grief is long lived. Although this book is not Bible based, it contains helpful, practical suggestions for dealing with many different issues faced by people who have experienced the loss of a loved one and comes recommended by those who have used it. Because of its format, daily readings for a year, it is suggested that individuals who would like to use it have their own personal copy.
- James, John. *The Grief Recovery Handbook*. HarperPerennial. 1988.
How to work through various kinds of loss to create a richer, fuller life for yourself and those around you.
- Linn, Dennis and Matthew. *Healing the Greatest Hurt*. Paulist Press. 1985.
A book about death and the great amount of unresolved grief in our society from suicide, abortion, miscarriage and stillbirth.
- Linn, Erin. *I Know Just How You Feel...Avoiding the Clichés of Grief*. Pubs Mark. 1986.
Answers to the questions, “What can I say to them?” and “Why did they say that to me?” and explores the uncomfortable feelings no matter what side of the fence you are on.
- Marta, Suzy Yehl. *Healing the Hurt, Restoring the Hope*. SawRobin Press. 2003.
Even if children or teenagers you love appear to be doing “just fine” after a loss, the truth is, they may be suffering in silence. They may not even know they need your help. Now with the trusted guidance of founder and president Suzy Yehl Marta, you will discover the most effective advice, stories, and techniques from Rainbows’ worldwide grief programs.
- McLeod, Beth Witrogen. *Caregiving: The Spiritual Journey of Love, Loss, and Renewal*. John Wiley & Sons, Incorporated. 1999.
A personal, practical account that validates caregivers and highlights spiritual growth. Beth recounts her journey of caring for and losing her parents and her husband within a few years while she was in middle adulthood.
- Metzgar, Margaret. *Time to Mourn, A Time to Dance*. AAL Qualitylife Resources. 2000.
A book about all kinds of loss. It includes stories, examples, scripture and beautiful photographs of nature.
- Meyer, Joyce. *Help Me – I’m Alone: Trusting God in Times of Loneliness and Grief*. Harrison House Inc. 1998.
- Miller, James E. *Seasons of Grief and Healing*. Augsburg Books. 2000.
A beautifully written little book which is a general guide to grieving. Contains suggested activities for aiding the healing process.

- Newfeld, Elsie. *Dancing in the Dark*. Herald Press. 1990.
An illumination of the grieving process so that the pathways of healing become a little safer. This is based upon the author's experience of losing her adult brother.
- Nouwen, Henri, J. M. *Our Greatest Gift*. HarperCollins. 1995.
Author's personal look at human mortality as he shares his own experience with aging, loss, grief and fear.
- Osmont, Kelly. *More than Surviving: Caring for Yourself While You Grieve*. Centering Corp. 2001.
Focusing your energies on staying healthy while going through the process of painful grieving can be a very healing thing to do.
- Shellenberger, Susie. *Help My Friend's In Trouble!: Supporting Your Friends Who Struggle with Family Problems, Sexual Crises, Food Addictions, Self-esteem, Depression, Grief and Loss*. Servant Pubns. 2000.
Discusses how to make and keep friends and how to help. She deals with some of the difficult issues young people face, including depression, sex, illness, homosexuality and violence.
- Sittser, Gerald L. *A Grace Disguised, How the Soul Grows Through Loss*. Zondervan. 1998.
A moving meditation on the losses we all suffer and grace that can transform us.
- Smith, Harold Ivan. *A Decembered Grief: Living with Loss While Others Are Celebrating*. Beacon Hill Press of Kansas City. 1999.
How can you celebrate the Christmas holidays while you are grieving?
- Stearns, Ann Kaiser. *Living Through Personal Crisis*. Ballantine Books. 1984
National bestseller recommended by Ann Landers, explains how grief, as agonizing as it may be, is a natural response to life's tragedies that helps us along through anger and isolation to a lasting healing process.
- Wangerin, Walter, Jr. *Mourning Into Dancing*. Zondervan. 1996.
Grief-filled losses or "little deaths" help us recognize that life is found in our relationships: with ourselves, our world, other people and our Creator. Beautifully written, very thought provoking.
- Westberg, Granger E. *Good Grief: A Faith-based Guide to Understanding and Healing*. Augsburg Books. 2004.
This book describes what happens to us whenever we lose someone or something important.
- Whitson, Stephanie Grace. *How to Help a Grieving Friend*. NavPress. 2005.
A small book full of practical suggestions for how to help someone who is grieving. An answer to the question, "What can I do?"

Loss of Spouse:

Didion, Joan. *The Year of Magical Thinking*. Vintage Books. 2007

The author describes her daughter's serious illness, her husband's sudden death and another serious illness suffered by her daughter. The book describes her journey.

Tagliaferre, Lewis, Harbaugh, Gary. *Recovery from Loss*. Center for Applications of Psychological Type. 2001.

One of the authors was inspired to write this after the loss of his wife. Response to grief is related in part to Myers-Briggs personality types. Discusses the journey through grief from isolation to recovery. Many examples from the author's own experience.

Miscarriage or Loss of a Infant or Toddler:

Hayford, Jack. *I'll Hold You in Heaven*. Gospel Light Pubns. 2003.

This pastor offers biblically based answers to some of the many questions that parents who have lost a child through miscarriage, stillbirth, abortion or early infant death.

Hinton, Clara. *Silent Grief*. New Leaf Press. 2004.

Several stories of miscarriages, stillbirths and child deaths. Feelings of isolation and grief are described. The author's purpose is to demonstrate that parents who have this experience are not alone and that there is hope after the grief.

Keaggy, Bernadette. *Losing You Too Soon*. Harvest House. 2002.

Finding hope after miscarriage or the loss of a baby. This is the true story of the author's multiple miscarriages interspersed with suggestions for ways to remember the lost babies and stories from other parents.

Rank, Maureen. *Free to Grieve*. Bethany House Publishers. 1985.

Maureen Rank, a survivor of multiple miscarriages, offers guidance to the hurting and helps women look to the future, recognizing that grief is justified, is necessary, and is individual and that it will end. Based on sound research as well as personal experience, it explores treatment options for physical and emotional healing.

Multiple Losses:

Schocket, Sandra Klamkin. *My Life Closed Twice*. Published by Sandra Klamkin Schocket. 2004.

Sandra tells her story of losing her husband and son within 2 days. She shares in detail the tasks that needed to be done and the journey she undertakes for survival.

Teens and Grief:

Grollman, Earl A. *Straight Talk About Death for Teenagers: How to Cope with Losing Someone You Love*. Beacon Press. 1993.

This book describes the various ways people mourn and grieve, thus validating personal experience of the reader. The table of contents describes each chapter, making it easy to find the information in the book which is most relevant to the reader.

Wolfelt, Alan D. *Healing Your Grieving Heart for Teens*. Companion Press. 2001.

This book contains 100 practical ideas for understanding and expressing grief for teenagers. The book is written in easy to read, bullet format.

Children and Grief:

Brown, Laurie Krazy. *When Dinosaurs Die: A Guide to Understanding Death*. Little, Brown and Company. 1996.

Explains in simple language the feelings people may have regarding the death of a loved one and the ways to honor the memory of someone who has died.

Buscaglia, Leo. *The Fall of Freddie the Leaf*. Distributed H. Holt. 1982.

As Freddie experiences the changing seasons along with his companion leaves, he learns about the delicate balance between life and death.

Goble, Paul. *Beyond the Ridge*. Bradbury Press. 1989.

At her death, an elderly Plains Indian woman experiences the afterlife believed in by her people, while surviving family members prepare her body according to their custom.

Hanson, Warren. *The Next Place*. Walden House Press. 1997.

An inspirational journey of light and hope to a place where earthly hurts are left behind.

Johnson, Joy and Marvin. *Tell Me Papa: Answers to questions children ask about death and dying (revised edition)*. Centering Corporation. 2005.

Children want their questions answered out of love and caring, not out of necessity. This book helps share the truths of life and death.

Mellonie, Bryan and Ingpen, Robert. *Lifetimes: The Beautiful Way to Explain Death to Children*. Bantam Books. 1983.

A pet, a friend, or a relative dies and it must be explained to a child. This sensitive book is a useful tool in explaining to children that death is a part of life and that eventually all living things reach the end of their own special lifetime.

Portnoy, Mindy Avra. *Where Do People Go When They Die?* KAR-BEN Publishing, Inc. 2004.

Children ask different adults and themselves about death and receive a wide variety of answers. Includes an afterward and suggestions for parents.

- Owens, Connie S. *My Heart Is Sad*. Warner Press. 2005
An illustrated book about a young boy (second grader) whose grandmother dies. The story talks about heaven, explains a little about the funeral and reaffirms that it is OK to be sad and that eventually you will feel better.
- Schweibert, Pat. *Tear Soup- a recipe for healing after loss*. Grief Watch Publishing. 1999.
Grandy has suffered a big loss in her life and so she is cooking up her own unique batch of “tear soup.”
- Stiles, Norman. *I'll Miss You, Mr. Hooper*. Random House/Children's TV Workshop. 1984.
Big Bird and the rest of the Sesame Street gang try to come to terms with Mr. Hooper's death.

Death of a Parent:

- Al-Chokhacy, Elissa. *How Can I Help Papa?* Works of Hope Publishing. 2002.
A child's journey through loss and healing.
- Clifton, Lucille. *Everett Anderson's Goodbye*. Henry Holt and Company. 1983.
Everett has a difficult time coming to terms with his grief after his father dies.
- DiSunno, Rebecca. *Jeremy Goes to Camp Good Grief*. East End Hospice Publication. 2004.
After his mom dies, Jeremy goes to camp for a week to be with other kids who have experienced a loss and to explore his difficult new feelings in a safe environment.
- Dennison, Amy. *Our Dad Died*. Free Spirit Publishing. 2003.
The true story of three kids whose lives changed with the death of their father.
- Krement, Jill. *How it Feels When a Parent Dies*. Knopf. 1981.
Eighteen vignettes written by kids ages 7-18 sharing their feelings about their parent's death.
- Madenski, Melissa. *Some of the Pieces*. Little, Brown and Company. 1991.
A year after the death of their father, two children and their mother try to come to terms with their loss.
- Munsch, Robert. *Love You Forever*. Willowdale, Ontario Firefly Book. 1996.
A parent's love endures over time and through generations.
- Parkinson, Carolyn Stearns. *Mommy's In the Hospital Again*. Solace Publishing. 1996.
Six-year-old Eric's mother is hospitalized and must miss his first day of school and birthday party.
- Powell, Sandy E. and Graef, Renee. *Geranium Morning*. Carolrhoda Books. 1990.
Two friends learn to deal with death of parents-one by accident and one by illness.

Scrivani, Mark. *I Heard Your Daddy Died (revised 2001)*. Centering Corporation. 1996.
A simple and helpful tool for family members and caregivers to read to the child who has lost a parent. The book encourages discussion and lets the child know that all feelings are normal.

Scrivani, Mark. *I Heard Your Mommy Died*. Centering Corporation. 1994.
Helps children cope with the death of a mother by examining the feelings they experience and the changes in their lives.

Vigna, Judith. *Saying Goodbye To Daddy*. Albert Whitman and Company. 1991.
A gentle story about a child's grief and the healing after a father's death.

Death of a Grandparent:

DePaola, Tomie. *Nana Upstairs and Nana Downstairs*. Puffin Books. 1998.
A small boy enjoys his relationship with his grandmother and his great-grandmother, but he learns to face their inevitable death.

Barron, T.A. *Where is Grandpa?* Philomel Books. 2000.
As a family reminisces after his beloved grandfather's death, a boy realizes that his grandfather is still with him in all the special places they shared.

Fox, Mem. *Sophie*. San Diego: Harcourt Brace and Company. 1994.
As Sophie grows bigger and her grandfather gets smaller, they continue to love each other very much.

Haynes, Max. *Grandmother's Gone to Live in the Stars*. Albert Whitman and Company. 2000.
In the moments after Grandmother has passed away, her spirit is at peace as she says goodbye to her sleeping family and her home.

Howe, James. *Kaddish for Grandpa in Jesus' Name Amen*. Atheneum Books for Young Readers. 2004.
Five-year-old Emily tries to understand her grandfather's death by exploring the Christian and Jewish rituals that her family practices during and after his funeral.

Lewis, Beverly. *What is Heaven Like?* Bethany House Publishers. 2006
A young boy and his sister, missing their recently departed grandfather, ponder heaven.

Mathis, Melissa Bay. *Granddad Bill's Song*. Philomel Books. 1994.
A boy asks others how they felt when his grandfather died and then shares his own feelings.

Miles, Miska. *Annie and the Old One*. Little, Brown and Company. 1971.
A Navajo Girl unravels a day's weaving on a rug whose completion she believes will mean the death of her grandmother.

Scheller, Melanie. *My Grandfather's Hat*. MacMillan Publishing Company. 1992.

A boy recalls his special relationship with his grandfather by playing with his grandfather's old hat.

Death of a Friend:

Adams, John. *The Dragonfly Door*. Feather Books Inc. 2007.

Two insect friends, water nymphs Lea and Nym, play together in the marsh. While sleeping, Nym discovers that his friend, Lea, has died and gone to a new world as a dragonfly.

Bahr, Mary. *If Nathan Were Here*. Eerdmans's Books for Young Readers. 2000.

A young boy grieves the loss of his best friend and thinks about how things would be if he were still alive.

Bunting, Eve. *Rudi's Pond*. Clarion Books. 1999.

When a sick boy dies, his friends and classmates remember him by building a schoolyard pond in his memory.

Cohn, Janice. *I Had A Friend Named Peter*. W. Morrow. 1987.

When Betsy learns about the death of her friend, her parents and kindergarten teacher answer questions about dying, funeral and the burial process.

Varley, Susan. *Badger's Parting Gifts*. Anderson Press. 1989

Badger's friends are sad when he dies, but they treasure the legacies he left them.

Death of a Pet:

Clark, Emma Chichester. *Up in Heaven*. Random House. 2003.

A tender and hopeful story, just right for any child who has ever lost a beloved pet.

Harris, Robie. *Goodbye Mousie*. Margaret K McElderry Books. 2001.

A boy grieves for his dead pet Mousie, helps to bury him and begins to come to terms with his loss.

Rogers, Fred. *When a Pet Dies*. G.P. Putnam's Sons. 1988.

Explores the feelings of frustration, sadness and loneliness that a youngster may feel when a pet dies.

Viorst, Judith. *The Tenth Good Thing About Barney*. Aladdin Paperbacks. 1971.

In an attempt to overcome his grief, a boy tries to think of the ten best things about his dead cat.

Other Readings:

Cramer, Kathy. *If I Could be Sick for You for Just One Day*. TRISTAN Publishing. 2005.

A book about giving the gift we wish we could give to take away the aches and pains of a loved one when they are sick.

Jordan, Mary Kate. *Losing Uncle Tim*. Whitman Niles. 1989.

A poignant story of how a boy copes with his uncle's death from AIDS.

White Pel Marjorie. *I Don't Have an Uncle Phil Anymore*. Magination Press. 1998.

Told through the eyes of a child, the story describes many traditions and social rituals associated with death and addresses a wide range of feelings and questions.



*This directory was funded by a grant from The Wellmark Foundation.
Our sincere thanks for support of this collaborative public awareness endeavor!*



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