Elder Care Common Sense

As of April 18, 2017

Introduction

Being over 65 is considered being in the last **third** of life. As this population segment increases, many of us will be lucky enough to experience it, either first hand, with parents or with friends. This brochure/web page attempts to share some of the wisdom and experience from and with parishioners of St Michael's. It makes no pretense to be the definitive document on things to think about for Elder Care. Nor is this intended as an override of one's own experience, intuition, common sense, or other expertise gathered.

This information was compiled by St Michael's parishioners and shared at Senior Ministry forums with input from SAGE (Service and Advocacy for GLBT Elders). More information is available on other Websites, in books, and at primary sources. We do not cite external resources as they are easy enough to find, and more options evolve all the time. We suggest you use the internet wisely – especially regarding medical information - and that you seek professional advice in legal, financial, medical and spiritual matters.

Additional information as well as notification of errors, omissions or needed updates can be sent to the St Michael's Office, to the attention of the Senior Ministry.

Getting Your House in Order

- **Material & Sentimental Objects** – You can't take them with you. Besides what you use every day, you can continually clean out closets, cupboards and drawers, sorting out what to give away, sell or throw away. If items are earmarked for people after you are gone, put their names **on** them, in case the separate list cannot easily be located.
- **Documents Checklist** – Make it easy for someone to step into your administrative shoes. Make a single notebook with all information needed to access financial, legal and personal information pertinent to your estate. Store this securely, but it needs to be easy to find or people need to know where it is or have a copy. If a partner to whom you were not married is to be recognized as a spouse would be, it is especially important that you spell out the duties and benefits for this person.
    - Select an **Executor** for your estate and those who have various powers of attorney (POA – see below).
    - List **personal information**, date of birth, legal name, Social Security number, military service information, next of kin to be notified, sources of income, insurance policies, regular payments, automated billing, mortgages, loans, real property, passwords to computers and online accounts.
    - Lists all **bank accounts and credit cards**.

- Prepare a **Living Will**. Make sure Advance Directives are on file at home, with people who have power of attorney for health care, and with your regular doctors and medical systems.
- **Powers of Attorney (POA).** There is more than one kind, each requiring a legal document. General POA is broad authority to act on your behalf in financial transactions, such as paying bills or real estate. POA for Health Care is authority to make medical decisions if you are unconscious, mentally incompetent or otherwise unable. There are also Special POA and Durable POA that you may wish to specify.
- **Will**, include a list of intended gifts from your estate (e.g. who gets the piano?)
- Put **burial or cremation** intentions or plans in place.
- Make a **list of checks** you would like to have written as gifts, thank-you or compensation for services rendered to you.
- Are there **trust** documents and a preferred **legal firm**?

- **Funeral Desires**
  - **Service** – Get a form from the Church office and on it identify the hymns and readings you would like at your memorial service.
    - Talk to musicians in advance if you would like special music at your funeral.
    - Write a short biography to print in the bulletin – less than 500 words.
    - Select a picture for your service.
  - **Obituary**. You don't have to put an obit in the newspaper, but if you want to and there's something specific you would like it to say or not, now's the time to draft one.

Doctors, Hospitalization, Medicare & Insurance

- **Choosing Providers**
  - Find a **primary care doctor** you like, and system that you can work with – they are not all the same and company policies change over time.
    - Your primary should be your intermediary with specialists, but this communication cannot be assumed. You need to ensure that specialists are informed as your medical situation evolves.
    - Make sure your primary has privileges in the hospital you are likely to go to.
  - You can change or 'fire' your doctors if you aren't getting what you need in the relationship.
- **Role of a Patient Advocate**
  - When you are ill, you may not have the clarity to grasp the complexities of changing medical situations. Having someone who knows and can speak up for your wishes, who knows your general health condition, who can remain calm and polite under stress, who can take notes and help clarify situations and ideally who may have Power of Attorney (POA) for Health Care, can be very valuable as you navigate encounters with medical systems. See the note above on types of POA.
  - If you don't have close family available, identify someone and make sure they are available to accompany you on a planned medical journey. You may need to name them in your Living Will as POA for Health Care.
- **Preparing to go to the Hospital – scheduled or unscheduled**
  - Have a list of your meds, dosage, and frequencies of taking them.
  - Have a list of what meds or food NOT to take, what you are allergic to or have had bad reactions to.
  - Bring a list of your doctors and their phone numbers.
  - Bring a container for valuables that you can hand to someone for safe-keeping.
  - Bring someone who has power of attorney for health care for you.
  - Bring a written health history – these are easier and quicker for a doctor to read than for you or a loved one to recall under stress. Include dates, diagnoses, treatments, outcomes.

- **In the Hospital during a scheduled stay**
  - As situations evolve, plans of action can change. Make sure you & your POA for Health Care understand the options and planned courses of action in order to manage everyone's expectations.
  - Consider keeping a dated log at the time of conditions, plans, actions and reactions as you are being treated. Afterward these complicated situations can all become a blur.
  - As medications are prescribed, ask about interaction with other meds. A pharmacist has expertise in this arena.
  - The patient's advocate or POA, may need to monitor that all needed meds are administered, as some may not be for the condition for which the patient is currently being treated.
  - If something feels wrong, question it – you/your PoA are part of the team in your treatment. You may have information the medical staff need to make a better decision.
  - You are permitted to get a second opinion.
  - Be nice to the staff; they like to and want to help. They are working hard and doing the best they can.
  - Procedural errors are likely to happen at shift changes. Help staff do the right thing for the patient.
- **Rocky Roads and Bad Outcomes**
  - As patient conditions evolve, directives and DNR (Do Not Resuscitate) or DNI (Do Not Intubate) orders can be changed. Some days you want to die, others you don't.
  - Know that bad outcomes can result for reasons that are nobody's fault. The patient and POA are part of the medical team determining and providing care, so being supportive, helpful and attentive can help caregivers and institutions avoid negligence or errors in care.
- **Billing**
  - Keep your insurance company's provider guide and statement of coverage with your household records.
  - Keep the Explanation of Benefits (EoB) that come with bills, reading carefully the Patient Responsibility columns.
  - Never pay a bill you think is wrong – you will never get it back.
  - Your insurance broker should be able to explain what should be covered and, in the event of denial of a legitimate claim, advocate on your behalf.

Care at Home

- **Things to Think About : Limits of Home Care**
  - Aging in place and dying at home are often spoken of as desirable and the first choices of many elders. There may be ways to help make this happen.
    - Family or trusted, close friends, and neighbors may help make this happen, if available.
    - Home Care agencies can supplement or provide daily care needs as part of or instead of sharing living space.
    - Agencies can also provide respite for primary caregivers, without moving the elder.
  - Caregiver jobs tend to attract people, mostly women, sometimes in transition, who can only work part time, who may not have other professional skills, or students. Caregiver pay is much less than what you are billed. Consider paying familiar neighbors, friends or family members at a higher rate than the agency pays for part of the care. Staff turnover and personal compatibility from agencies may also be of concern.
  - There are many providers in this arena. The web provides information about services and rate options. Recommendations regarding quality of care from someone's experience are helpful.
  - Providers have different rate plans for daily length of services and elder needs.
  - If one-on-one care is needed around the clock, it can be very expensive over time.

- **Types of Care**
    - **Companion Care, unskilled nursing** – privately paid for by the hour at various rates depending on the length of time and individual needs. These people can help with meals, activities of daily living, outings, light housekeeping and the like.
    - **Home Health Care** – is skilled care, prescribed by a doctor as part of a recovery plan that may include Physical Therapy and bi-weekly nurse visits. A nurse or aide can assist with bathing. This is usually covered by Medicare, but doesn't cover daily unskilled care needs.

Care in Residential Facilities
Assisted Living, Memory Care, Nursing Care, Rehabilitation

- **Things to Think About**
    - Can you get better (physically healthier), or just stronger?
    - What change is triggering this situation, and what is the likely trajectory (of needs, costs, time)? How long and in which likely conditions will this facility serve the resident well? Is the change needed for the long term?
    - Does your caregiver need short-term respite care?
    - There are trade-offs with different options, especially if one can't afford "the best" care available. Can everyone accept the risks and trade-offs?
    - This is a regulated and profitable industry, related to the medical world. You are entering an institutional system in which:
        - Your freedoms will be limited by law and institutional policy. How the facility provides care will be somewhat similar or the same for all or most residents, less personal, and maybe safer.
        - Caregiver salaries are low, resulting in low education levels of hands-on staff, a perhaps higher-than-expected rate of errors in care, and sometimes high staff turnover rates. Quality of care may vary a lot from caregiver to caregiver.
        - Lawyers and law firms are well-paid to protect institutional providers - not you, the customer.
    - If there is more than one provider or set of conditions, medical, palliative and care needs are complicated and will never become simpler. Is it realistic to think that a facility with multiple caregivers can best provide this level of care?
- **Choosing Providers**
    - **Marketing vs policy & procedure information**
        - See it before you believe it. Marketing staff are not care-giving staff. A beautiful lobby is not where the resident lives. Take a tour, talk to residents, confirm that what is being sold is what is delivered (ratio of caregivers and nurses to residents, etc.).
        - When there are multiple providers, ensure that care can be seamless for the resident, e.g. Home Health Care or Physical Therapy in Assisted Living, Hospice in Memory or Nursing Care, etc.
        - Does the institution have an anti-bullying policy and a non-discrimination policy? Are they committed to creating a safe environment for all, including LGBTQ residents and family members and other marginalized people?
    - **Signing & Committing**
        - Litigation / Arbitration clauses define how disputes or breaches of contract will be settled. Make sure you understand and agree with your rights and approach to resolution if services are not delivered as advertised or paid for, or if there is negligence or breach of contract or errors in procedures that result in bad outcomes.

Consider the resources required for legal handling of disputes – these institutions have extensive legal capacity.
        - Determine how easy it is to access care logs for the resident.
        - Read everything yourself, and have a friend, advocate or lawyer read the documents ***before signing***.
        - X-out what doesn't apply to your situations.
        - Get all your questions answered in writing.
        - Never sign a blank form.
        - Get copies of fully executed (signed by both parties) documents.
    - **Breaking a Contract**
        - Is there a way out if things don't work out or it's not a good fit, fault aside?
- **Types of Providers**
    - **Independent Senior and Assisted Living**. This is where meals, utilities, laundry, cleaning and assistance with activities of daily living (eating, bathing, dressing, toileting, transferring (walking) and continence) are sometimes included in the rental. Additional care, such as medications or walking assistance, is sometimes billed separately according to level of need.
    - **Nursing**. Skilled care is prescribed by a physician and is paid for by Medicare. Facilities meet federal guidelines.
    - **Rehabilitation**. Physical and Occupational Therapies are prescribed by a physician and are paid for by Medicare. Rehab can be residential, part of assisted living, or part of home health care.
    - **Memory Care**
        - Alzheimer's Association is an authority for appropriate care for people with dementia or Alzheimer's.
        - Facilities that provide memory care may have areas that provide different levels of care according to patient needs. Safety is a primary concern.
- **When Care Providers Overlap**
    - With Hospice: Since both providers (Facility and Hospice) are being paid (by the Resident and Medicare) to provide services, there should be no worry about receiving services. But make sure all services are covered by one entity or the other – such as bathing, wound care, etc. There should be no gaps in care; duplications are more desirable.
- **During One's Stay**
    - Put the resident's name on all belongings.
    - Review the Care Log for the resident.
    - Confirm that routine procedures are followed for the resident:
        - Meds, eating, drinking, hygiene, etc.
    - Visit the facility at odd hours to observe and affirm that promised levels of care are being delivered. If not, help the facility caregivers provide the needed care, and also let management know of your concerns.

Hospice and Advance Medical Directives

- **Things to Think About**
    - EVERYONE should have Advance Directives on file with their medical provider and caregivers.
    - One does not need to be in Hospice to have a DNR or DNI order.
    - Enrolling in Hospice indicates that
        - You have a terminal illness and will not be cured.
        - Death may likely be less than 6-months away.
        - Medical treatment is palliative to relieve pain, rather than intended to treat an illness or prolong life, under the oversight of your Doctor, and/or a hospice physician. This care should maintain your quality of life and alleviate suffering. Pain control is of

primary concern. If you are dying of cancer, you may or may not wish to continue your heart medication, when you are in Hospice. Oxygen may make you more comfortable, but won't cure you – you can have it when you are in Hospice.

- **Choosing Providers**
  - Hospice is covered by Medicare. Patients are in the care of nurses under the oversight of (palliative care) Physicians.
  - Care is prescribed by Physicians and governed by federal guidelines, but not all Hospice organizations deliver the same quality of care. Get recommendations from friends.
  - Institutional Hospice options in Albuquerque are rare, and may require a person to be actively dying and bed-ridden, or only allow short-term respite care. Many hospice patients, who are not in hospitals or nursing facilities, are in their places of residence (home, assisted living, memory care…). Social hospice options are not currently available in Albuquerque.