END OF LIFE

WHAT QUESTIONS SHOULD I AND MY FAMILY BE ASKING?

- Do I know what I want to accomplish before my end of life?
- Do I have clear goals and values communicated to my loved ones and doctor about my end of life?
- Is professional medical help accessible for routine and emergency needs?
- Do I have end of life symptoms that are controlled such as pain, feeling tired, shortness of breath, or loss of appetite?
- Do I prefer the quality of life more than the duration of life?
- Do I want more aggressive tests and treatments even at the expense of some suffering or time?
- Do I have specific fears about the end of life? If so, do my loved ones and healthcare team know about them?

WHAT ACTIONS CAN I TAKE FOR THIS AGENDA?

- Have a discussion with your loved ones and doctor about your values and wishes around your health and end of life
- Complete and look into important legal documents around the end of life such as a personal directive
- Think about and communicate your “goals of care” with your loved ones and healthcare team
- Consider asking for a palliative care team to see you around the end of life or if you have symptoms causing suffering
- Remember that you are the most important person regarding your health. Loved ones and the healthcare team should respect and value your wishes

WHAT DOES END OF LIFE MEAN?

- End of life means the stage in life where you are nearing death. There is no specific time before death we call the end of life

- End of life is a stage where we want to make sure that suffering is controlled, affairs are in order, and that our values are met
- End of life is a complex topic given differences in culture, religion, and personal values
- This agenda focuses on end of life importance, services to consider, and common questions that come closer to death

WHY IS IT IMPORTANT TO TALK ABOUT THE END OF LIFE?

- The sooner one talks about what to expect and do closer to their end of life the better
- Healthcare professionals can help with these complex end of life issues
- Prepare for your specific needs and apply the values you want
- This means some prefer more treatment than others
- Try to control any form of pain as much as possible
- Try to keep your function as best as it can be. This means to try and keep you doing the things you want to do independently
- Try to resolve long-standing conflicts with families or loved ones
- Try to satisfy final wishes

"END OF LIFE" IS A COMPLEX TOPIC WITH NO SPECIFIC TIME BEFORE DEATH

EVERYONE IS DIFFERENT ON WHAT THEY PREFER TO HAVE AT THEIR END OF LIFE WHEN IT COMES TO THEIR HEALTH

YOUR HEALTHCARE TEAM CAN HELP ACHIEVE YOUR IDEAL END OF LIFE WITH THE LEAST SUFFERING

WHAT ARE IMPORTANT SERVICES THAT CAN HELP DURING END OF LIFE?

- The following services may have different names or roles depending on where you are located
- Palliative care: A specialty in medicine that helps prevent and treat suffering. See below for more details
- Spiritual care: A specialty that focuses on the spiritual and/or religious needs of those that are ill and dealing with pain or grief. They are religion “neutral” meaning they do not pertain to a specific religion. They help patients of all faiths and beliefs
- Home care: A specialty that offers nursing services at your home. They can help with taking medications, baths, among other things
- Long-term care: A facility where those who need a full day's worth of nursing care go to. They have constant medical needs
- Hospice care: A facility or service where those who are sick at end of life go or get. They provide medical support to relieve pain and suffering

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PALLIATIVE CARE IS AN IMPORTANT SPECIALTY AT ALL STAGES OF ILLNESS BUT ESPECIALLY AT END OF LIFE

WHAT IS PALLIATIVE CARE?

- Palliative care is a specialty in medicine
- They focus on preventing and relieving suffering
- Suffering can be from physical issues of disease, but also emotional, psychological, and social issues
- They do not only focus on the end of life care
- They also focus on complex symptoms that cause suffering. They are experts in communication and look at how the disease affects you personally
- Common symptoms they are experts at dealing with are pain, shortness of breath, nausea, and feeling tired
- They help at any age regardless of the diagnosis
- There is good evidence that their involvement improves the quality of life and even duration of life in some cases

- Usually the earlier they are involved to help the better

A PALLIATIVE CARE PHYSICIAN SPECIALIZES IN PALLIATIVE CARE

THEY ARE EXPERTS AT TRYING TO RELIEVE SUFFERING, PROMOTE COMMUNICATION, AND HONOR YOUR HEALTHCARE VALUES

ARE THERE ANY IMPORTANT DOCUMENTS I SHOULD LOOK INTO THAT CAN HELP?

- The following terms and documents may have different names or roles depending on where you are
- Advance directives: A legal document that states your healthcare wishes and values. These are taken into account when you cannot communicate
- Personal directive: A person (agent) of your choice to make a healthcare decision on your behalf only when you cannot. This is usually a legal document that needs a witness and signature
- Power of attorney: A person (agent) of your choosing to make financial decisions on your behalf. This is usually a legal document that needs a witness and signature too
- Goals of care: A document or set of instructions that inform the healthcare team to what degree and focus of care you want. See below for more details
- Will: A legal document that expresses wishes as to how property is distributed after death. Some might confuse a will with the above documents
- It is important to remember that these are general terms and that depending on your location and healthcare, these might be different

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IT IS KEY TO LOOK INTO IMPORTANT LEGAL DOCUMENTS FOR YOUR END OF LIFE AND PREPARE THEM EARLY ON

COMPLETING A PERSONAL DIRECTIVE AND GOALS OF CARE CAN MAKE THINGS MUCH EASIER FOR YOU AND YOUR FAMILY

WHAT DOES "GOALS OF CARE" MEAN?

- Goals of care is a general term and may have other names depending on where you are
- Goals of care is usually a document or set of instructions that inform the healthcare team what degree and focus of care you want
- Important topics to discuss in goals of care are:

1. Chest compression if the heart stops (CPR)
2. Putting in a breathing tube through the mouth if the lungs stop (intubation)
3. Going to the intensive care unit (ICU) if the body gets very sick

- The reason we talk about these points early on is to know what you want before doing them
- Different people have different goals of care depending on their personal values and stage in illness and health
- Goals of care might be different for you depending on your culture, religion, and personal values
- Given said differences in personal values, some might want more aggressive treatment no matter what. Others might prefer to let nature take its course and not go for aggressive treatments
- Make it clear to the healthcare team and loved ones your preference for quality of life or duration of life
- If one prefers the quality of life more, they may not wish to have the healthcare team be aggressive with treatments. This is to avoid getting more bloodwork, tests, or procedures. These can be experienced as a form of suffering too
- If one prefers duration of life more despite those experiences, then they may want to pursue more aggressive treatments
- You should be able to change your goals of care at any time. Talk to your family and doctor for more information on your preferences

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GOALS OF CARE IS A GENERAL TERM THAT FOCUSES ON WHAT PREFERENCES YOU HAVE WHEN IT COMES TO YOUR HEALTH

IMPORTANT TOPICS IN GOALS OF CARE ARE CHEST COMPRESSIONS, BREATHING TUBES, AND GOING TO THE ICU

ALWAYS BALANCE THE RISKS AND BENEFITS OF YOUR HEALTHCARE CHOICES TO MAKE AN INFORMED DECISION

WHAT IS "COMFORT CARE"? WHAT DO "PALLIATIVE GOALS" MEAN?

- The term "comfort care" and "palliative goals" may differ depending on where you are
- Generally, comfort care means focusing on the patient's comfort and letting the disease or illness take its natural course
- Comfort care focuses on reducing suffering as much as possible
- This means controlling pain, shortness of breath, nausea, and so on
- The focus shifts from curing or treating the disease actively as it may not be possible. This may also be the case given the person's wishes
- It also means trying to avoid aggressive tests and procedures as much as possible. Even basic bloodwork can be seen as an "aggressive" test especially when the goal is for comfort
- Talk to your healthcare team and family to express what comfort care means to you
- Be vocal with your healthcare team and family if you have had enough of all the medical treatments you are getting to start this discussion

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WHAT ARE COMMON FEARS OLDER ADULTS HAVE AROUND THE END OF LIFE?

- Losing their independence
- Becoming a burden
- Choking or suffocating
- Fearing that the pain will not be relieved
- Fearing they will be overly sedated
- Suffering from indignity
- Dying alone or without anyone caring

COMFORT CARE MEANS FOCUSING ON RELIEVING PAIN AND SUFFERING AS THE MAIN GOAL OF TREATMENT

THIS MEANS THE GOAL IS NO LONGER TO PROLONG LIFE RATHER TO IMPROVE QUALITY

WHAT ARE COMMON THINGS LOVED ONES CAN DO TO REDUCE FEARS AT END OF LIFE FOR OLDER ADULTS?

- Always ask permission to do something
- Respect freedom of choice and encourage older adults to make choices they want
- Recognize and respect the patient's values and choices that guide the decision-making process
- Encourage an open dialogue by inviting questions and opinions
- Allow private time with family and visitors as often as possible
- Leave as much control to the older adult and what they wish for regarding their health

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WHERE SHOULD I BE AROUND MY END OF LIFE?

- This is a difficult question that depends on the person’s values
- The easiest answer is ideally where one prefers to be at their end of life
- Most people prefer to be at home surrounded by their loved ones and family. Sometimes that can be difficult
- Ideally, planning that if you were to get sick, family and the healthcare team know whether to take you to the hospital or not
- Usually, if one has difficulty controlling symptoms or forms of pain, it is better to go to the hospital

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TALK TO YOUR HEALTHCARE TEAM AND FAMILY IF YOU ARE EXHAUSTED FROM ALL THE MEDICAL TREATMENTS

BE VOCAL ABOUT WHAT YOUR WORRIES ARE AROUND THE END OF LIFE SO YOUR HEALTHCARE TEAM AND FAMILY CAN HELP

CAN MY DOCTOR KNOW HOW LONG I HAVE TO LIVE?

- This is a difficult question and it depends on the patient's health and disease state
- Doctors mostly have an educated guess as to how long you have to live
- There is a better estimation for those with cancer compared to those who have other long-term (chronic) diseases
- Doctors usually have a "moderate" estimate of how long one has to live but it is still an educated assumption
- Talk to your doctor about this and what applies to your specific condition

WHAT SHOULD THE HEALTH SYSTEM DO TO MAKE SURE I HAVE A GOOD END OF LIFE CARE?

- Respect older adults with their values and preferences
- Simplify open and timely discussion of decisions related to treatment
- Help complete important legal documents as mentioned above
- Encourage loved ones in their supportive roles
- Respect older adults for the need for control and independence
- Respond to signs of burnout in family caregivers
- Recognize and respect the important differences in cultures and religions
- Ask for a palliative care team to help if needed
- Ask for a spiritual care team to help if needed
- Ask for an official interpreter to translate if needed

KNOWING HOW LONG YOU HAVE TO LIVE IS A COMPLEX TOPIC. IT IS USUALLY AN EDUCATED GUESS BY YOUR DOCTOR

THE HEALTH TEAM SHOULD RESPECT YOUR WISHES, PROMOTE INDEPENDENCE AND DIGNITY, AND ENCOURAGE COMMUNICATION

References

1. Robert L Kane et al. Essentials of Clinical Geriatrics 8th edition (2018) Jeffrey B. Halter et al.
2. Hazzard's Geriatric Medicine and Gerontology 7th edition (2016)
3. Jayna Holroyd-Leduc et al. Evidence Based Geriatric Medicine (2012)
4. Melissa Wayne et al (2019) Late Stage and End of Life Care. Help Guid
5. Michael J. MacLean, et al (2000) A Guide to End-of-Life Care for Seniors. Canadian Association of Retired Persons. Age Wise Inc
6. Kapo J, Morrison LJ, Liao S. Palliative care for the older adult. J Palliat Med 2007; 10:185.
7. Wijk H, Grimby A. Needs of elderly patients in palliative care. Am J Hosp Palliat Care 2008; 25:106.