Decisional Framework for Advance Care Planning

A Collaborative Project of:
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Good Health or Healthy Aging

Chronic Diagnosis

Advanced Chronic Diagnosis

Palliative Care

Hospice Care

Communication with Health Care Proxy and Physician
Update Documentation with changes and milestones

Advance Care Plan Continuum
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What is Good Health and Healthy Aging?:

This individual is typically a young to middle aged adult who may have an acute illness from time to time but no chronic conditions.

Important Definitions:

Quality of Life: Those preferences (features or factors) which contribute to positive and negative feelings of personal well-being.

- This step involves an introspective look at one's own lifestyle and values.
- Identify those preferences that are most important to you in experiencing what you feel allows you to achieve a high quality of life.
- This can involve conversations with others or by oneself.
- Exploration of what choices exist. Curative, life sustaining or comfort measures.
- Difficult/uncomfortable to talk about the subject.
- Where do you start?
- Untrained physicians/clinicians to be skilled and sensitive communicators.
- Patient difficulty accepting a poor prognosis.
- Difficulty understanding the limitations and complications of life-sustaining treatment.
- Disagreement among family members about goals of care.

Possible Considerations:

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What is Good Health and Healthy Aging:

This individual is typically a young to middle aged adult who may have an acute illness from time to time but no chronic conditions.

Important Definitions:

**Healthcare Proxy:** (a durable power of attorney for health care, medical power of attorney or healthcare agent) The document assigning a person or person(s) known as your proxy to act on your behalf to make health care decisions for you if you can not speak for yourself.

**Advance Directive:** a written statement or instruction that expresses a person’s wishes regarding medical treatment if they are unable to communicate them themselves.

Explanations of Activities Related to this step:

After initially identifying those values and preferences that are most important to you it often helps to expand this conversation to family and friends to further explore these concepts. These activities will also help you to narrow down who you want your proxy to be.

- Differing values among friends and family members; misunderstanding choices.
- Fear of hurting the feelings of someone close to you.

Possible Considerations:

Meet with family and friends to review and discuss preferences.
What is Good Health and Healthy Aging?:
This individual is typically a young to middle aged adult who may have an acute illness from time to time but no chronic conditions

Important Definitions:
- **Healthcare Proxy:** (a durable power of attorney for health care, medical power of attorney or healthcare agent) The document assigning a person or person(s) known as your proxy to act on your behalf to make health care decisions for you if you cannot speak for yourself.
- **Advance Directive:** a written statement or instruction that expresses a person's wishes regarding medical treatment if they are unable to communicate them themselves.

Explanation of Activities Related to this Step:
- Check the rules for health proxy in your state (i.e. age restrictions).
- Think about who will be able to ask questions of doctors and other providers without feeling intimidated. Someone that you trust.
- Speak with your intended proxy to make sure that they understand and accept this role and the responsibility.

Possible Considerations:
- Fear of offending a spouse or other close relative
- Unable to identify who you can trust to carry out your wishes

Name healthcare proxy. Document and discuss preferences.
What is Good Health and Healthy Aging:
This individual is typically a young to middle aged adult who may have an acute illness from time to time but no chronic conditions.

Important Definitions:
- **Primary Care Provider (PCP):** a health care practitioner who treats common medical problems.
- **Medical Record:** documents that include a single patient’s medical history and care across time within one particular health care provider’s jurisdiction or a medical system.

Explanation of Activities Related to this Step:
- Have a discussion with your PCP or provider, before a crisis occurs.
- Discuss treatments and procedures that may be important for you to understand before you complete your directives.
- Make sure your doctor is willing to follow your directives, they are not legally required to.
- Once the documents are finalized, PCP enter copy into your medical record.
- Your PCP may not feel comfortable having the conversation or it may be difficult.
- You may not feel that you understand the medical considerations clearly.

Possible Challenges:

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**What is Good Health and Healthy Aging?:**

This individual is typically a young to middle aged adult who may have an acute illness from time to time but no chronic conditions.

**Important Definitions:**

- **Milestone:** an event marking a significant change or development

**Explanation of Activities Related to this step:**

As you encounter certain life milestones, it is appropriate to review your advance care planning documents to see if there are any changes in what you originally preferred and/or your designated proxy. Some events are:

- marriage and divorce,
- a distance move,
- birth of a child,
- change in a Physician or other provider,
- a new serious medical condition,
- change of mind.

**Possible Considerations:**

- Forgetting the milestone
- Not communicating the changes to proxy or PCP
- Lost original documents or inconsistent documentation

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What is Chronic Illness?: An individual is typically identified in this stage when they have a condition or disease lasting 3 months or more, by the definition of the U.S. National Center for Health Statistics. These diseases are not usually preventable by vaccines or cured by medication, nor do they just disappear.

Important Definitions:

Healthcare Proxy: (a durable power of attorney for health care, medical power of attorney or healthcare agent) The document assigning a person or person(s) known as your proxy to act on your behalf to make health care decisions for you if you cannot speak for yourself.

Advance Directive: a written statement or instruction that expresses a person’s wishes regarding medical treatment if they are unable to communicate them themselves.

Explanation of Activities Related to this step:

After initially identifying those values and preferences that are most important to you it often helps to expand this conversation to family and friends to further explore these concepts. These activities will also help you to narrow down who you want your proxy to be.

Possible Considerations:

- Differing values among friends and family members.
- Fear of hurting the feelings of someone close to you.
What is Chronic Illness?:
An individual is typically identified in this stage when they have a condition or disease lasting 3 months or more, by the definition of the U.S. National Center for Health Statistics. These diseases are not usually preventable by vaccines or cured by medication, nor do they just disappear.

Important Definitions:
Healthcare Proxy: (see previous step)
Advance Directive: (see previous step)

Explanation of Activities Related to this step:
• Check the rules for health proxy in your state
• Think about who (usually one person) you can trust to honor your personal preferences, not necessarily your closest relative, who will be able to ask important questions
• Speak with your intended proxy to make sure that they understand and accept this role and the responsibility.

Possible Challenges:
• Fear of offending a spouse or other close relative
• Unable to identify who you can trust to carry out your wishes

Name healthcare proxy. Document and discuss preferences.
What is Chronic Illness?: An individual is typically identified in this stage when they have a condition or disease lasting 3 months or more, by the definition of the U.S. National Center for Health Statistics. These diseases are not usually preventable by vaccines or cured by medication, nor do they just disappear.

Important Definitions:

- **Primary Care Provider (PCP):** a health care practitioner who treats common medical problems.
- **Medical Record:** documents that include a single patient’s medical history and care across time within one particular health care provider’s jurisdiction or a medical system.

Explanation of Activities Related to this step:

Have a discussion with your PCP or provider, before a crisis occurs. Discuss treatments and procedures that may be important for you to understand before you complete your directives. Make sure your doctor is willing to follow your directives, they are not legally required to. Once the documents are finalized, be sure that your PCP has a copy entered into your medical record.

Possible:

This might be a difficult conversation to have with your PCP. Your PCP may not feel comfortable having the conversation. You may not feel that you understand the medical considerations clearly.
What is Chronic Illness?:
An individual is typically identified in this stage when they have a condition or disease lasting 3 months or more, by the definition of the U.S. National Center for Health Statistics. These diseases are not usually preventable by vaccines or cured by medication, nor do they just disappear.

Important Definitions:
Milestone: an event marking a significant change or development

Explanation of Activities Related to this step:
As you encounter certain life milestones, it is appropriate to review your advance care planning documents to see if there are any changes in what you originally preferred and/or your designated proxy. Some events are: marriage and divorce, a distance move, birth of a child, change in a Physician or other provider, a new serious medical condition, change of mind.

Possible Considerations:
Forgetting or lack of consistency with review at milestone.

Provide copy to proxy, PCP and maintain copy. Select milestone to review and update documents.

Milestone
Chronic Illness
Month 4-5
Timeline
## Advanced Chronic Diagnosis

### Month 1-2

**What is Advanced Chronic Diagnosis?:** This individual is one who is experiencing a long-term, medically complex condition. Typically, it involves chronic illness whose trajectory is unstable and fluctuating with a variable course of its illnesses over time.

### Important Definitions:

- **Healthcare Proxy:** (a durable power of attorney for health care, medical power of attorney or healthcare agent) The document assigning a person or person(s) known as your proxy to act on your behalf to make health care decisions for you if you can not speak for yourself.

- **Advance Directive:** a written statement or instruction that expresses a person's wishes regarding medical treatment if they are unable to communicate them themselves.

### Explanation of Activities Related to this step:

After initially identifying those values and preferences that are most important to you it often helps to expand this conversation to family and friends to further explore these concepts. These activities will also help you to narrow down who you want your proxy to be.

### Possible Consideration:

- Differing values among friends and family members.
- Fear of hurting the feelings of someone close to you.
What is Advanced Chronic Diagnosis:

This individual is one who is experiencing a long-term, medically complex condition. Typically, it involves chronic illness whose trajectory is unstable and fluctuating with a variable course of its illnesses over time.

Important Definitions:

Healthcare Proxy: (a durable power of attorney for health care, medical power of attorney or healthcare agent) The document assigning a person or person(s) known as your proxy to act on your behalf to make health care decisions for you if you can not speak for yourself.

Advance Directive: a written statement or instruction that expresses a person’s wishes regarding medical treatment if they are unable to communicate them themselves.

Explanation of Activities Related to this step:

• Check the rules for health proxy in your state (i)
• Think about who (usually one person) you can trust to honor your personal preferences, not necessarily your closest relative.
• Think about who will be able to ask questions of doctors and other providers without feeling intimidated.
• Speak with your intended proxy to make sure that they understand and accept this role and the responsibility.

Possible Considerations:

• Fear of offending a spouse or other close relative; Unable to identify who you can trust to carry out your wishes

Name healthcare proxy. Document and discuss preferences.
**What is Advanced Chronic Diagnosis:**

This individual is one who is experiencing a long-term, medically complex condition. Typically, it involves chronic illness whose trajectory is unstable and fluctuating with a variable course of its illnesses over time.

**Important Definitions:**

- **Primary Care Provider (PCP):** a health care practitioner who treats common medical problems.
- **Medical Record:** documents that include a single patient’s medical history and care across time within one particular health care provider's jurisdiction or a medical system.

**Explanation of Activities Related to this step:**

Have a discussion with your PCP or provider, before a crisis occurs. Discuss treatments and procedures that may be important for you to understand before you complete your directives. Make sure your doctor is willing to follow your directives, they are not legally required to. Once the documents are finalized, be sure that your PCP has a copy entered into your medical record.

**Possible Considerations:**

This might be a difficult conversation to have with your PCP. Your PCP may not feel comfortable having the conversation. You may not feel that you understand the medical considerations clearly.
What is Advanced Chronic Diagnosis?:

This individual is one who is experiencing a long-term, medically complex condition. Typically, it involves chronic illness whose trajectory is unstable and fluctuating with a variable course of its illnesses over time.

Important Definitions:

**Milestone:** An event marking a significant change or development

Explanation of Activities Related to this Step:

As you encounter certain life milestones, it is appropriate to review your advance care planning documents to see if there are any changes in what you originally preferred and/or your designated proxy. Some events are: marriage and divorce, a distance move, birth of a child, change in a Physician or other provider, a new serious medical condition, change of mind.

Possible Considerations:

Forgetting milestone or not updating the information.
What is Palliative Care?: The patient for whom palliative care is appropriate is one who, due to life-threatening illness, needs improvement in their quality of life. It is not the same as hospice and does not preclude any medical treatments for a patient.

Important Definitions:

Healthcare Proxy: (or a durable power of attorney for health care, medical power of attorney or healthcare agent) The document assigning a person or person(s) known as your proxy to act on your behalf to make health care decisions for you if you can not speak for yourself.

Advance Directive: a written statement or instruction that expresses a person’s wishes regarding medical treatment if they are unable to communicate them themselves.

Explanation of Activities Related to this step:

After initially identifying those values and preferences that are most important to you it often helps to expand this conversation to family and friends to further explore these concepts. These activities will also help you to narrow down who you want your proxy to be.

Possible Considerations:

- Differing values among friends and family members.
- Fear of hurting the feelings of someone close to you.

Meet with family and friends to review and discuss preferences.
What is Palliative Care?: The patient for whom palliative care is appropriate is one who, due to life-threatening illness, needs improvement in their quality of life. It is not the same as hospice and does not preclude any medical treatments for a patient.

Important Definitions:

- **Healthcare Proxy**: (a durable power of attorney for health care, medical power of attorney or healthcare agent) The **document** assigning a person or person(s) known as your proxy to **act on your behalf** to make health care decisions for you if you can not speak for yourself.

- **Advance Directive**: a written statement or instruction that expresses a person's wishes regarding medical treatment if they are unable to communicate them themselves.

Explanation of Activities Related to this step:

- Check the rules for health proxy in your state
- Think about who (usually one person) you can trust to honor your personal preferences, not necessarily your closest relative.; who will be able to ask questions of doctors and other providers without feeling intimidated.
- Speak with your intended proxy to make sure that they understand and accept this role and the responsibility.

Possible Challenges:

- Fear of offending a spouse or other close relative
- Unable to identify who you can trust to carry out your wishes
### What is Palliative Care?:

The patient for whom palliative care is appropriate is one who, due to life-threatening illness, needs improvement in their quality of life. It is not the same as hospice and does not preclude any medical treatments for a patient.

### Important Definitions:

- **Primary Care Provider (PCP):** A health care practitioner who treats common medical problems. This person is most often a doctor but may be a physician assistant or a nurse practitioner.

- **Medical Record:** Documents that include a single patient's medical history and care across time within one particular health care provider's jurisdiction or a medical system.

### Explanation of Activities Related to this step:

Have a discussion with your PCP or provider, before a crisis occurs. Discuss treatments and procedures that may be important for you to understand before you complete your directives. Make sure your doctor is willing to follow your directives, they are not legally required to. Once the documents are finalized, be sure that your PCP has a copy entered into your medical record.

### Possible Challenges:

This might be a difficult conversation to have with your PCP. Your PCP may not feel comfortable having the conversation. You may not feel that you understand the medical considerations clearly.
Palliative Care

Timeline

Month 4-5

What is Palliative Care?: The patient for whom palliative care is appropriate is one who, due to life-threatening illness, needs improvement in their quality of life. It is not the same as hospice and does not preclude any medical treatments for a patient.

Important Definitions:

Milestone: an event marking a significant change or development

Hospice care: End of Life care that includes medical, psychological, and spiritual support. Pain control and symptom management to allow a patient to be as alert and comfortable as possible are offered.

Explanation of Activities Related to this Step:

As you encounter certain life milestones, it is appropriate to review your advance care planning documents to see if there are any changes in what you originally preferred and/or your designated proxy. Some events are: marriage and divorce, a distance move, birth of a child, change in a Physician or other provider, a new serious medical condition, change of mind.

Possible Considerations:

Difficulty accepting the end of ones life. Depression due to a patient’s medical condition.
### What is Hospice?

The patient receiving hospice care services typically get basic medical care with a focus on pain and symptom control. Their medical condition has been determined to be terminal and is no longer treated or expected to improve.

### Important Definitions:

- **Healthcare Proxy**: (a durable power of attorney for health care, medical power of attorney or healthcare agent) The document assigning a person or person(s) known as your proxy to act on your behalf to make health care decisions for you if you cannot speak for yourself.

- **Advance Directive**: a written statement or instruction that expresses a person's wishes regarding medical treatment if they are unable to communicate them themselves.

### Explanation of Activities Related to this step:

After initially identifying those values and preferences that are most important to you it often helps to expand this conversation to family and friends to further explore these concepts. These activities will also help you to narrow down who you want your proxy to be.

### Possible Considerations:

- Differing values among friends and family members, fear of hurting the feelings of someone close to you.

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What is Hospice?:

The patient receiving hospice care services typically get basic medical care with a focus on pain and symptom control. Their medical condition has been determined to be terminal and is no longer treated or expected to improve.

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Advance Directive: a written statement or instruction that expresses a person's wishes regarding medical treatment if they are unable to communicate them themselves.

Explanation of Activities Related to this step:

- Check the rules for health proxy in your state
- Think about who (usually one person) you can trust to honor your personal preferences, not necessarily your closest relative.
- Think about who will be able to ask questions of doctors and other providers without feeling intimidated.
- Speak with your intended proxy to make sure that they understand and accept this role and the responsibility.

Possible Considerations:

- Fear of offending a spouse or other close relative; identify who you can trust to carry out your wishes
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Have a discussion with your PCP or provider before a crisis occurs. Discuss treatments and procedures that may be important for you to understand before you complete your directives. Make sure your doctor is willing to follow your directives, they are not legally required to. Once the documents are finalized, be sure that your PCP has a copy entered into your medical record.

Possible Challenges:

This might be a difficult conversation to have with your PCP. You may not feel that you understand the medical considerations clearly.

Review preferences with PCP or provider and ensure documentation in medical record.
Resources:

Good Health and or Healthy Aging

- http://www.gowish.org/
- http://www.agingwithdignity.org/five-wishes.php
- https://www.americanbar.org/content/dam/aba/administrative/law_aging/tool4.authcheckdam.pdf
- http://theconversationproject.org/
Resources:

Chronic Illness

http://www.gowish.org/
Caring Conversations;
http://theconversationproject.org/
http://www.advancecareplanning.ca/across-canada/the-top-ten-milestones-for-making-and(reviewing-your-advance-care-plan/)
http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3281
Resources:

http://www.gowish.org/
Caring Conversations:
http://theconversationproject.org/
http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3281