Decisional Framework for Advance Care Planning

A Collaborative Project of:





DISCLAIMER; NOT A SUBSTITUTE FOR PROFESSIONAL HEALTHCARE, OR FOR MEDICAL OR LEGAL ADVICE: We do not endorse any products or websites. Third Party Links contained are for reference and as example of concepts described.

Communication with Health Care Proxy and Physician Update Documentation with changes and milestones		Good Health or Healthy Aging	Chronic Diagnosis	Advanced Chronic Diagnosis	Palliative Care	Hospice Care
	$\langle [$			•	•	

Advance Care Plan Continuum

© Planetree and CTCPS

Milestone ueline	Good Health and or Healthy Aging	Chronic Illness	Advanced Chronic Diagnosis	Palliative Care	Hospice
E Month 1-2	Identify that choice exist and what preferences are important to the individual	Meet with family and friends to review and discuss preferences	Meet with family and friends to review and discuss preferences	Meet with family and friends to review and discuss preferences	Meet with family and friends to review and discuss preferences
Month 2-3	Meet with family and friends to review and discuss preferences	Name healthcare proxy. Document and discuss preferences.	Name healthcare proxy. Document and discuss preferences.	Name/confirm/update healthcare proxy. Discuss/update preferences. Create documentation.	Name/confirm/update healthcare proxy. Discuss/update preferences. Create documentation.
Month 3-4	Name healthcare proxy. Document and discuss preferences.	Review preferences with PCP or provider and ensure documentation in medical record.	Review preferences with PCP or provider and ensure documentation in medical record.	Review preferences with PCP or provider and ensure documentation in medical record.	Review preferences with PCP or provider and ensure documentation in medical record.
Month 4-5	Review preferences with PCP or provider and ensure documentation in medical record.	Provide copy to proxy, PCP and maintain copy. Select milestone to review, update documents.	Select milestone to update, provide copy to proxy and maintain copy.	Select milestone to update, provide copy to proxy and maintain copy.	
Month 5-6	Provide copy to proxy, PCP and maintain copy. Select milestone to review, update documents.				

© Planetree and CTCPS, 2017

What is Good Health and Healthy Aging?:

Important Definitions:

Explanation of Activities Related to this Step:

Possible Considerations:

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

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 ones 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.



© Planetree and CTCPS, 2017

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

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.

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.



Important Definitions:

Explanation of Activities Related to this step:

Possible Considerations:

© Planetree and CTCPS, 2017

	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
Milestone Good Health and/or Healthy Aging Name healthcare	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.
Month 3-4 proxy. Document and discuss preferences.	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



	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
Milestone Good Health and/or Healthy Aging Provide copy to proxy, PCP and maintain copy. Select milestone to review and update documents.	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 Last original documents or inconsistant

• Lost original documents or inconsistent documentation

Possible Considerations:

	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.
Milestone General Chronic Illness Month 1-2 Milestone Chronic Illness Meet with family and friends to review and discuss preferences	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 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.
Milestone Chronic Illness	Important Definitions:	Healthcare Proxy: (see previous step) Advance Directive: (see previous step
Month 2-3	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

	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.
Milestone Chronic Illness	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.
Month 3-4 Review preferences with PCP or provider and ensure documentation in medical record.	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.
© Planetree and CTCPS, 2017	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.



Possible Considerations:

Forgetting or lack of consistency with review at milestone.

	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.
Milestone Milestone Month 1-2 Advanced Chronic Diagnosis Meet with family and friends to review and discuss preferences	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.
discuss preferences	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.



imeline

	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.
Milestone Advanced Chronic Diagnosis	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.
Month 3-4 Chronic Diagnosis Review preferences with PCP or provider and ensure documentation in medical record.	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.
© Planetree and CTCPS, 2017	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.



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.
Palliative Care Meet with family and friends to review and discuss preferences	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.

Milestone

Month 1-2

Timeline

	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.
Milestone Palliative Care Name/confirm/update healthcare proxy.	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.
Month 2-3	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.
Planetree and CTCPS, 2017	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.
Milestone Palliative Care	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.
Month 3-4 Review preferences with PCP or provider and ensure documentation in medical record.	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.
© Planetree and CTCPS, 2017	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.

	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.
Palliative Care	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.
Select milestone to update, provide copy to proxy and maintain copy.	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

Milestone Palliative Care Select milestone to update, provide copy to proxy and maintain copy.

	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.
Milestone Hospice Month 1-2	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 Considerations:	 Differing values among friends and family members, fear of hurting the feelings of

someone close to you.

	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.
Hospice Name/confirm/update healthcare proxy.	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.
Discuss/update preferences. Create documentation.	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

Milestone

Month 2-3

Timeline

	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.
Milestone Hospice Review preferences with PCP or provider	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.
Month 3-4 and ensure documentation in medical record.	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. You may not feel that you understand the medical considerations clearly.

Resources:

Good Health and or Healthy Aging

- http://www.gowish.org/;
- <u>https://mydirectives.com/en/how-it-works/;</u>
- <u>http://www.agingwithdignity.org/five-wishes.php;</u>
- https://www.americanbar.org/content/dam/aba/administrative/law_aging/tool4.authcheckdam.pdf;
- <u>https://www.practicalbioethics.org/files/caring-conversations/caring-conversations.zip;</u>
- <u>http://theconversationproject.org/;</u>
- <u>http://www.advancecareplanning.ca/across-canada/the-top-ten-milestones-for-making-and-reviewing-your-advance-care-plan/</u>

Resources:

Chronic Illness

http://www.gowish.org/; Caring Conversations; http://theconversationproject.org/ http://theconversationproject.org/wp-content/uploads/2017/03/ConversationProject-ProxyKit-English.pdf; http://www.nolo.com/legal-encyclopedia/choosing-health-care-agent-29939.html; http://www.advancecareplanning.ca/across-canada/the-top-ten-milestones-for-making-and-reviewing-youradvance-care-plan/ http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3281 https://www.nia.nih.gov/health/discussing-financial-and-life-changes-your-doctor

Resources:

Advanced Chronic Diagnosis

http://www.gowish.org/; Caring Conversations; http://theconversationproject.org/ http://theconversationproject.org/wpcontent/uploads/2017/03/ConversationProject-ProxyKit-English.pdf; http://www.nolo.com/legal-encyclopedia/choosing-health-care-agent-29939.html; http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3281 https://www.nia.nih.gov/health/discussing-financial-and-life-changes-your-doctor http://www.advancecareplanning.ca/across-canada/the-top ten-milestones-for-making-and-reviewing-youradvance-care plan/

Resources:		
Palliative Care	Hospice	

http://www.gowish.org/; Caring Conversations;

http://theconversationproject.org/

http://theconversationproject.org/wp-content/uploads/2017/03/ConversationProject-ProxyKit-English.pdf; http://www.nolo.com/legal-encyclopedia/choosing-health-care-agent-29939.html;

http://bit.ly/2tqzEKY

http://bit.ly/2gTLprG

http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3281

https://www.nia.nih.gov/health/discussing-financial-and-life-changes-your-doctor

http://www.advancecareplanning.ca/across-canada/the-top-ten-milestones-for-making-and-reviewing-your-

advance-care-plan/

http://theconversationproject.org/wp-content/uploads/2017/03/ConversationProject-ProxyKit-English.pdf; http://www.nolo.com/legal-encyclopedia/choosing-health-care-agent-29939.html;

http://bit.ly/2tqzEKY

http://bit.ly/2gTLprG

http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3281

https://www.nia.nih.gov/health/discussing-financial-and-life-changes-your-doctor