

BUILDING AN INTENTIONAL & EMPOWERED CARE PLAN

Farrah N Daly, MD MBA

EvenBeam Neuropalliative Care, LLC

CULTIVATING AN INTENTIONAL & EMPOWERED CARE PATH

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INTRODUCTION

- Neurologist
- Palliative Care Physician
- Vice President of International Neuropalliative Care Society
- 18 years working in late stage neurologic illness
- Vice President of International Neuropalliative Care Society
- 2nd degree family caregiver 2012-2014



RISKS OF AN UNINTENTIONAL PATH

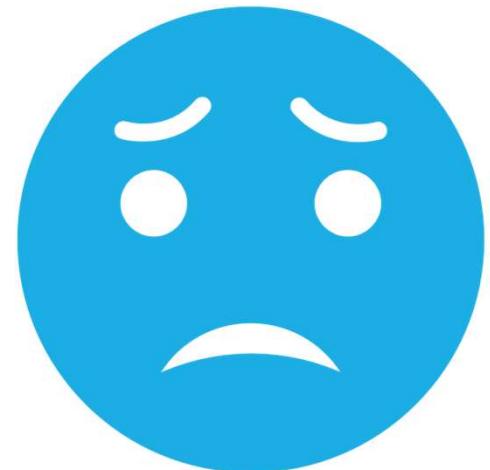
Care not consistent with values

Getting stuck in the diagnostic process

Unaddressed emotional needs hitting a wall in the medical system

Spending time, money, and energy on one issue while a different issue runs wild

Unaddressed caregiver stress leading to burnout and crisis



INTENTIONAL AND EMPOWERED



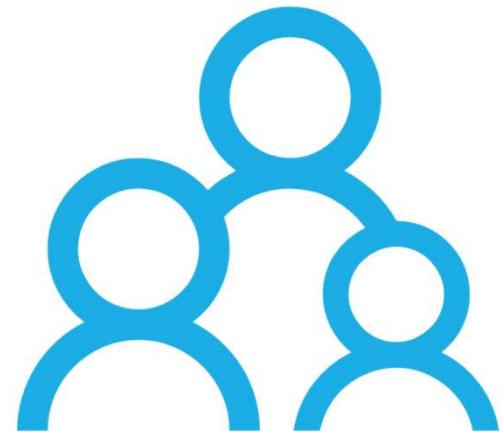
Intentional = done on purpose,
deliberate



Empowered = stronger and more
confident, with authority to take action

BENEFITS OF AN INTENTIONAL PATH

- Care consistent with values and priorities
- Clear idea of the purpose of different tests and appointments
- Intentional decision to spend time on the things that are of value to you
- A team involved to address medical and emotional needs in coordination
- A balanced approach to life adaptations over time
- Sustainable caregiving in a way that is authentic to the relationship



Welcome to

The Waiting Room REVOLUTION



Program



Map Project



Book & Workbook



Podcast

www.waitingroomrevolution.com

What Matters to Me
A Workbook for People with Serious Illness

ARIADNE LABS

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PATIENTS AND FAMILIES: 7 Keys for Navigating a Life-Changing Diagnosis

Walk Two Roads

Balance staying positive while also seeking honest, accurate information. This helps you stay hopeful and grounded in reality.



ASK YOURSELF

What you are hoping for and what you need to plan for just in case?

Zoom Out

Every illness has a known pattern to it. Understanding this storyline gives you a birds-eye and long view of where you are at in your illness.



ASK YOUR PROVIDER

What will my illness look like over time? What can I expect along the way?

Know Your Style

Your unique way of being will have as much impact on your illness experience as the illness itself. Harness information about your style to gain more control.



REFLECT

What are your tendencies when facing stressful situations and how those might play out in your illness?

Customize Your Order

Ideally you want to tailor your care to match your values. Share what's important to you to ensure that your care matches who you are as a unique person.



ASK YOURSELF

What do you want people to know about you? What do you value most?

Anticipate Ripple Effects

Your inner crew (e.g. family and caregivers) will have a parallel illness journey. Their lives will be affected in multiple ways.



CONSIDER

What support do you need from your inner crew? Encourage them to get information and support too.

Connect the Dots

You and your inner crew need to play a central role in co-ordinating information. This enhances continuity and safety, especially at transition points



ASK YOURSELF

Who in your crew will be the manager of your illness journey?

Invite Yourself

Initiate conversations with your healthcare team. Don't assume no news is good news. Passive, polite patients are encouraged to be respectfully assertive.



ASK QUESTIONS

Seek information so you can understand how to plan, prepare, and make decisions.

The Waiting Room REVOLUTION



For more tools and resources visit

waitingroomrevolution.com

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BALANCING TODAY & TOMORROW

Value Present Well-being

Focusing on enjoying life today

Prepare for the Future

Setting clear goals and planning ahead.



TODAY

&

TOMORROW

- **Beginning Stage**

- Clarify underlying cause (testing)
- Consider second opinions
- Explore involvement in research
- Improve diet, exercise, and social connections

- **Middle Stage**

- Seek and engage additional support for care
- Collaborate with physical, occupational, and speech therapists
- Seek and engage a counselor

- **Late Stage**

- Adapt to limited mobility
- Obtain assistance with hands-on care
- Evaluate professional care versus home care options

- **End Stage**

- Arrange and engage hospice services
- Access grief support resources

TODAY

&

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BEGINNING STAGE SIGNS

- Repetition of questions/stories
- Difficulty processing complex information
- Confuse times/places
- Forget recent events & conversations
- Gets lost easily
- Mild personality changes
- Social withdrawal

MIDDLE STAGE SIGNS

- Forget information, meals, medication
- Wandering
- For some, resistance to personal care
- For some, agitation, anxiety, delusions, aggression, hallucinations

LATE STAGE SIGNS

- Can't recognize familiar people
- Loss of expression & emotion
- Changes in mobility
- Loss of bladder/bowel control
- Difficulty communicating

END STAGE SIGNS

- Loss of interest in food
- Difficulty swallowing
- Weight loss
- Fatigue, long periods of sleep, unresponsive

TODAY

&

TOMORROW

- **Beginning Stage**

- Clarify underlying cause (testing)
- Consider second opinions
- Explore involvement in research
- Improve diet, exercise, and social connections
- **Take some trips, do important things**
- **Build a support team, find a counselor**

- **Middle Stage**

- **Put support team into action**

- Collaborate with physical, occupational, and speech therapists

- **Work with your counselor**

- **Get familiar with home care and professional care resources**

- **Late Stage**

- Adapt to limited mobility
- Obtain assistance with hands-on care

- **Act on plan for professional or home care**

- **Check local hospice resources, feel confident that you know when to engage**

- **End Stage**

- **Engage hospice services**

- **Access grief support resources**

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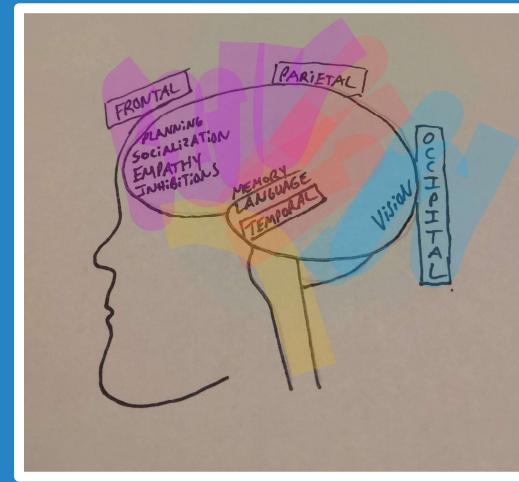
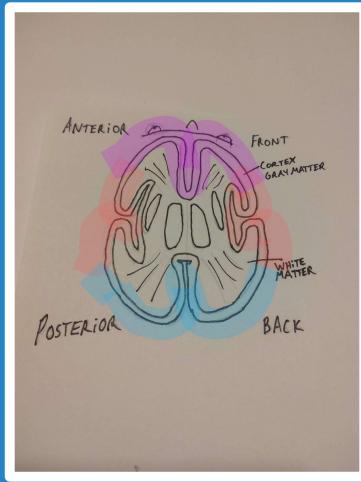
ASK YOUR PROVIDER

What will my illness look like over time?
What can I expect along the way?

www.waitingroomrevolution.com

IN THE RECIPE FOR EMPOWERMENT,
KNOWLEDGE IS A KEY INGREDIENT.





DEMENTIA

memory loss + dysfunction in at least 1 other cognitive domain

CAUSES OF DEMENTIA

Infections

Ex. HIV, syphilis

Structural Abnormalities

Ex. Brain tumors, Enlarged fluid spaces

Vascular problems

Ex. Large strokes or small accumulated strokes

Nutritional and Genetic Factors

Ex. Vitamin B12 deficiency, Huntington's disease

Degenerative Diseases

Ex. Alzheimer's, Parkinson's disease, Frontotemporal Dementia, Posterior Cortical Atrophy



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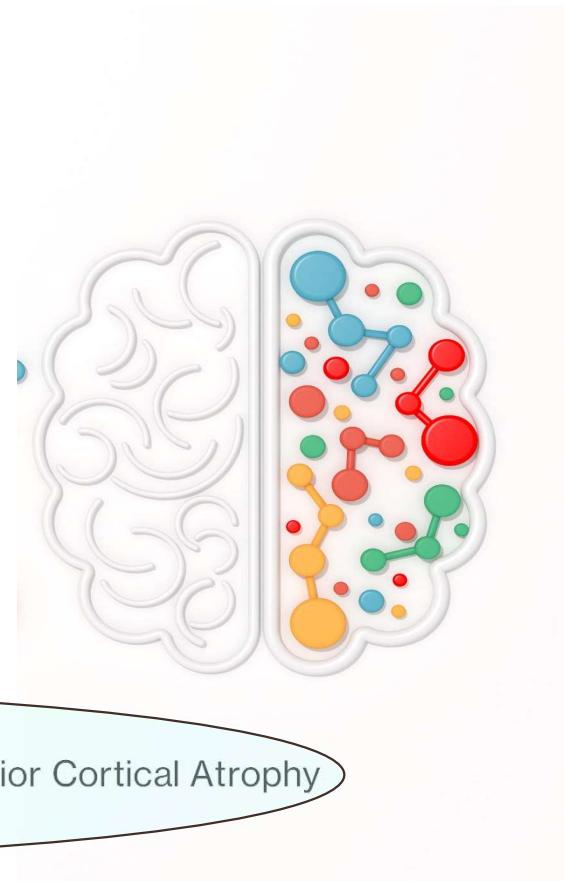
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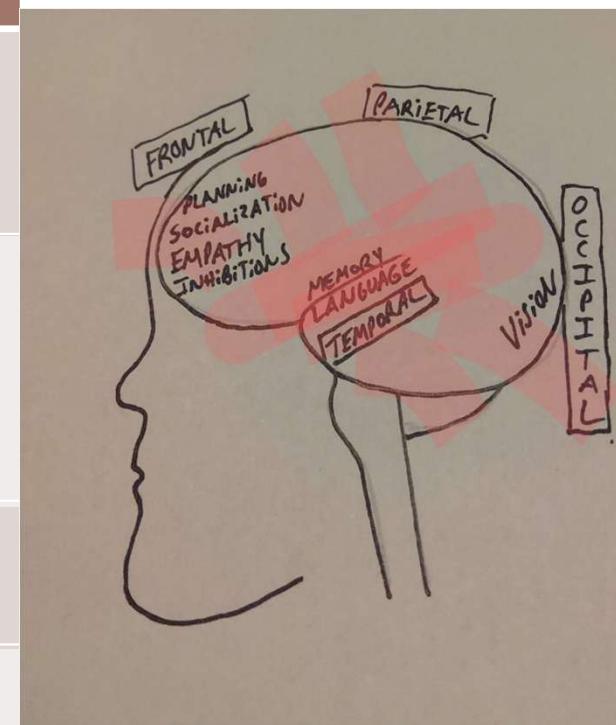
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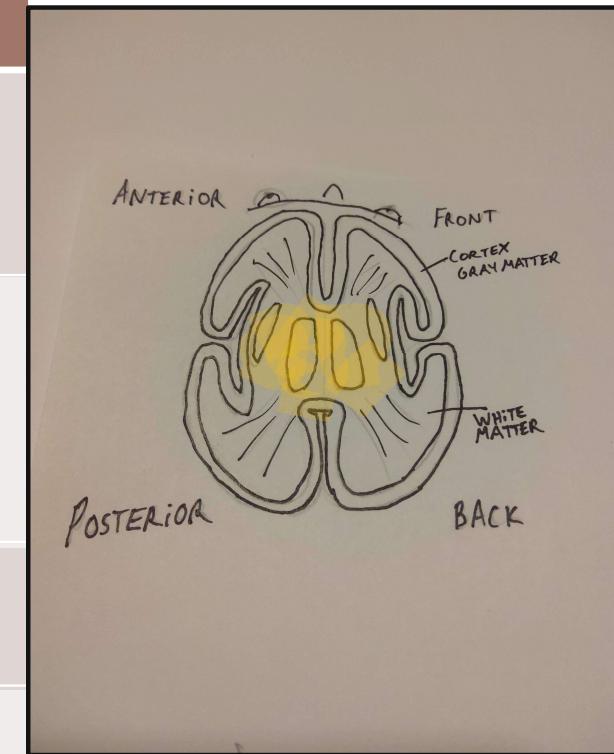
COMPARING MAJOR DEMENTIAS

Dementia type	Starting Location	Early Symptoms	Safety Concerns
Alzheimers	Hippocampus	Memory loss Trouble with locations/space	Wandering
Frontotemporal	Frontal lobe Temporal lobs	Behavior and personality change Language	Impulsive Disinhibitions Poor judgement
Posterior Cortical	Occipital Lobe	Impaired visual processing	Blindness Fear



COMPARING MAJOR DEMENTIAS

Dementia type	Starting Location	Early Symptoms	Safety Concerns
Lewy Body	Central White matter and basal ganglia	Hallucinations Fluctuations Movement	Falls
Parkinsons related	Basal Ganglia and central white matter	Movement Hallucinations Freezing	Falls Impulsivity
Vascular	Throughout	Varies	Abrupt change in function



PROGRESSION TOWARD A COMMON PATHWAY

Independent Origins

Early symptoms of the illness are related to the part of the brain that is most affected

Pathway Integration

As more of the brain is involved, the symptoms can become more similar over time

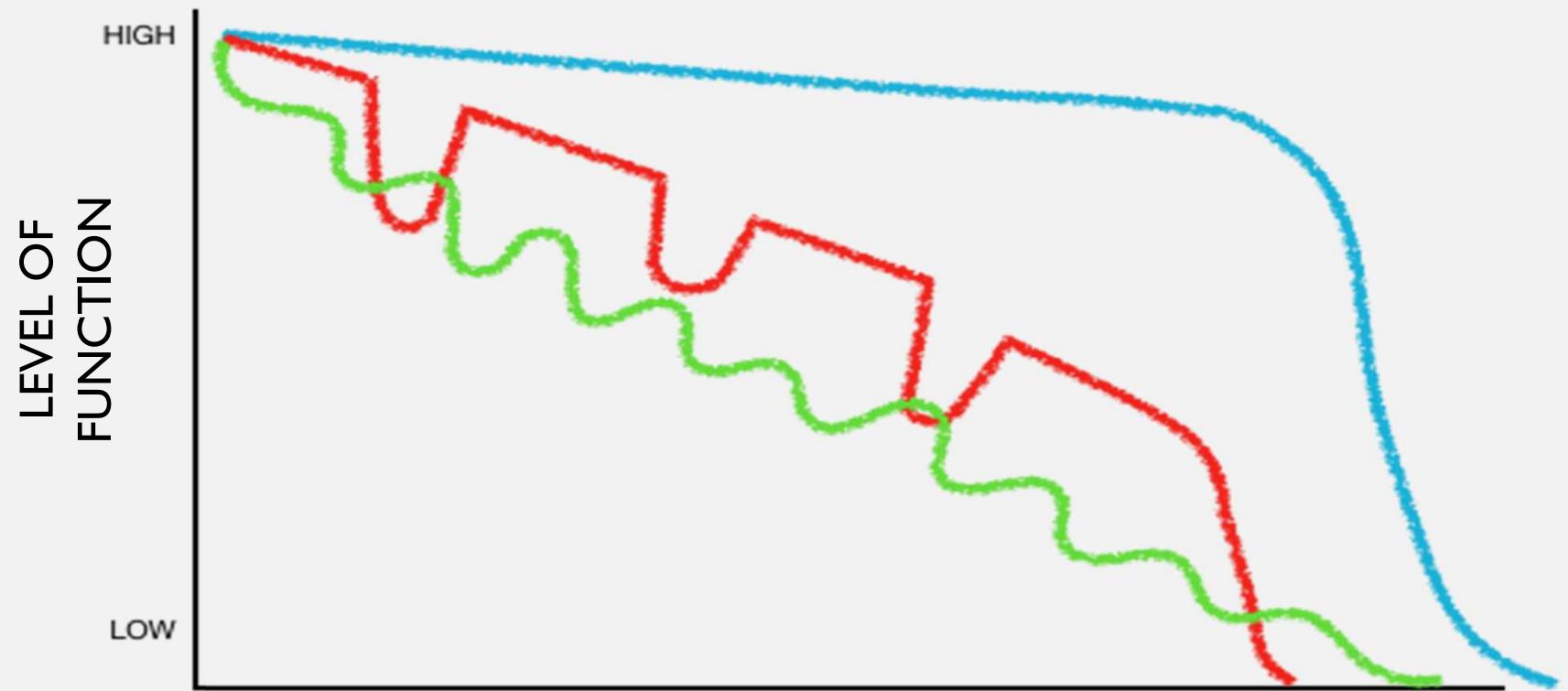
Unified Outcome

All types progress to affecting basic functions such as talking, walking, using the bathroom



WHAT WILL MY MEDICAL JOURNEY LOOK LIKE?

- There is no single path or trajectory that someone's health will take



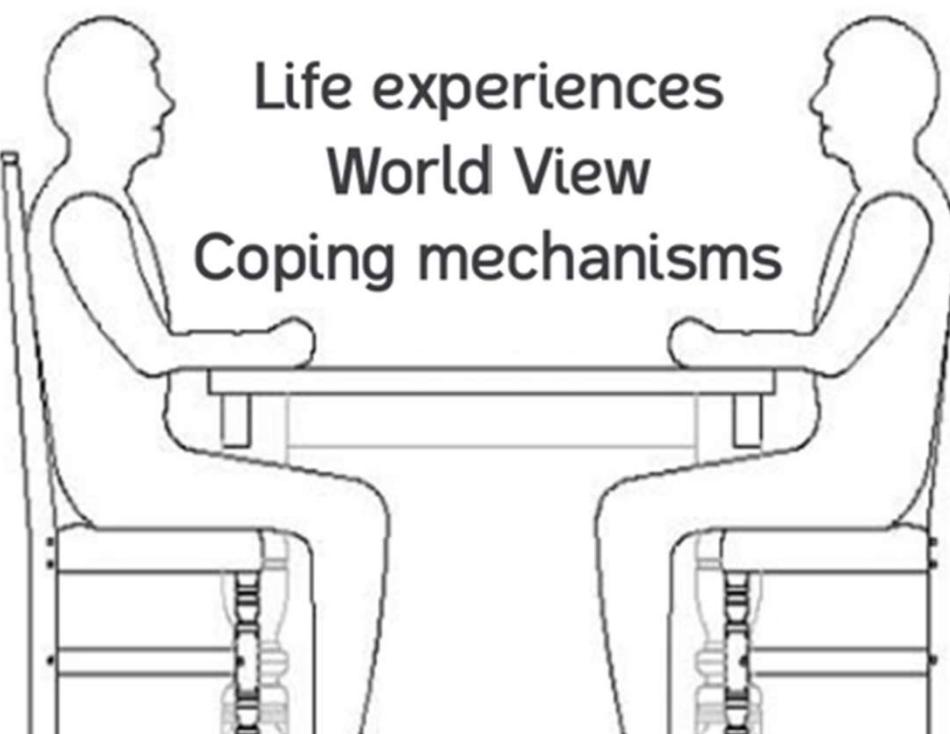
Know Your Style

Your unique way of being will have as much impact on your illness experience as the illness itself. Harness information about your style to gain more control.



REFLECT

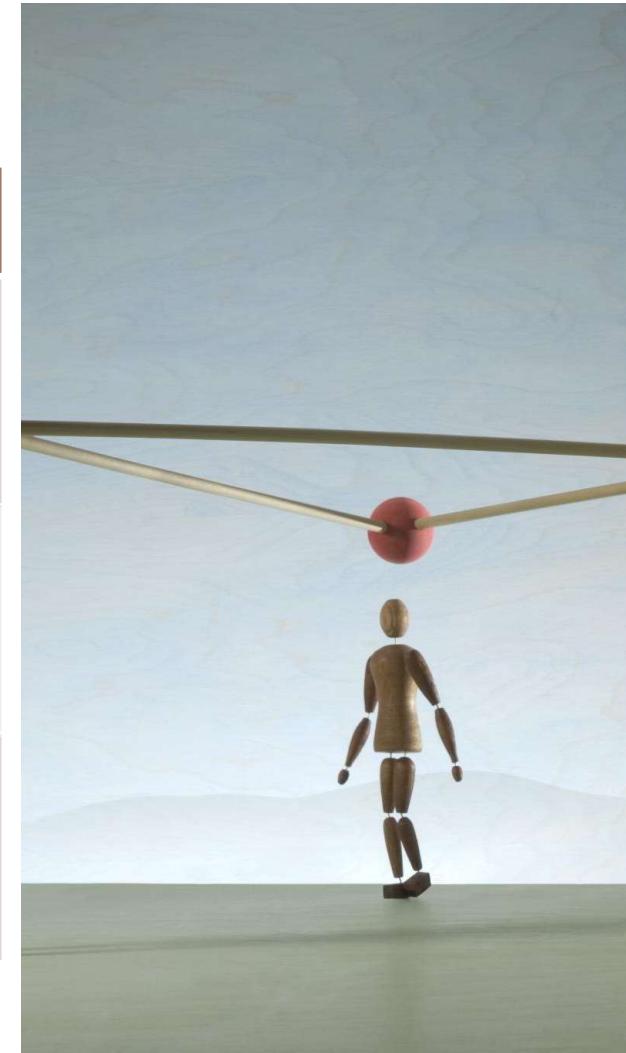
What are your tendencies when facing stressful situations and how those might play out in your illness?



Life experiences
World View
Coping mechanisms

KNOW YOUR STYLE

Adaptability	I adapt easily to change	I create strong routines and have a hard time with change	I get overwhelmed but can change with support
Dealing with stress or sadness	I lean into sources of support & face it directly	I prefer to distract myself with other things, let the future take care of itself	I have a tendency to shut down
Socialization	I have strong social connections and bring new people in easily	I prefer to keep to myself	I like company but don't have much connection now



[Home](#) > [Serious Illness Care](#) > [Resources](#) > [Tools & Downloads](#)

What Matters to Me Workbook

What Matters to Me

A Workbook for People with Serious Illness

 November 16, 2021  1 min

Developed in collaboration with The Conversation Project, the What Matters to Me Workbook is designed to help people with a serious illness get ready to talk to their health care team about what is most important to them.

[DOWNLOAD THE WORKBOOK \(ENGLISH\)](#)[DOWNLOAD THE WORKBOOK \(CHINESE\)](#)[DOWNLOAD THE WORKBOOK \(SPANISH\)](#)[DOWNLOAD THE WORKBOOK \(PORTUGUESE\)](#)

the conversation project

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› As a patient, I'd like to know...

.....

Only the basics about my condition and my treatment

All the details about my condition and my treatment

› When there is a medical decision to be made, I would like...

.....

My health care team to make all the decisions

To have a say in decisions whenever possible

› What are your concerns about medical treatments?

.....

I worry that I won't get enough care

I worry that I'll get too much care

› How much medical treatment are you willing to go through for the possibility of gaining more time?

.....

Nothing: I don't want any more medical treatments

Everything: I want to try any medical treatments possible

› If your health situation worsens, where do you want to be?

.....

I strongly prefer to be in a health care facility

I strongly prefer to be at home, if possible

› When it comes to sharing information about my illness with others...

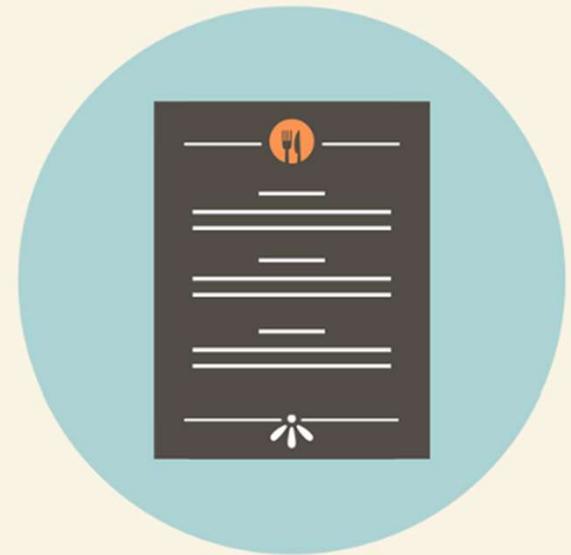
.....

I don't want those close to me to know all the details

I do want those close to me to know all the details

Customize Your Order

Ideally you want to tailor your care to match your values. Share what's important to you to ensure that your care matches who you are as a unique person.



ASK YOURSELF

What do you want people to know about you?
What do you value most?



WE KNOW HOW TO CUSTOMIZE

📦 Bread Bonanza:

- ◆ Soft & fluffy White
- ◆ Nutty & wholesome Wheat
- ◆ Heart-healthy Multigrain

🧀 Cheese Choices:

- ◆ Sharp & creamy Cheddar
- ◆ Smooth & nutty Swiss
- ◆ Melty & rich Provolone

🥩 Meat Marvels:

- ◆ Tender Turkey
- ◆ Classic Ham
- ◆ Juicy Roast Beef

🌿 Tasty Toppings:

- ◆ Crisp Lettuce
- ◆ Juicy Tomato
- ◆ Tangy Onions

쓱 Saucy Selections:

- ◆ A variety of flavorful sauces to jazz up your sandwich!



YOU ALREADY
HAVE AN
ADVANCE CARE
PLAN, BUT IS IT
CUSTOMIZED
FOR YOU?

GENERIC (STATE APPOINTED) DECISIONMAKER

- Guardian or Committee (appointed by a Court)
- Spouse (unless divorce action filed)
- Adult children (equal authority to all those in the class)
- Parents (equal authority to all those in the class)
- Adult siblings (equal authority to all those in the class)
- Any other blood relative in descending order (equal authority to all those in the class)
- Non-family member for non-end-of-life decisions

Virginia Code § 32.1-2986

ADVANCE CARE PLANNING

1: Surrogate decisionmaker / proxy

Who makes decisions for you when you can not?

Do you have a custom decisionmaker or a generic decisionmaker?

2: Description of **your general or specific ideas about care** in the future. This is guidance for your surrogate decisionmaker.

VIRGINIA

Advance Directive

Planning for Important Health Care Decisions

CaringInfo
1731 King St., Suite 100, Alexandria, VA 22314
www.caringinfo.org
800/658-8898

CARINGINFO

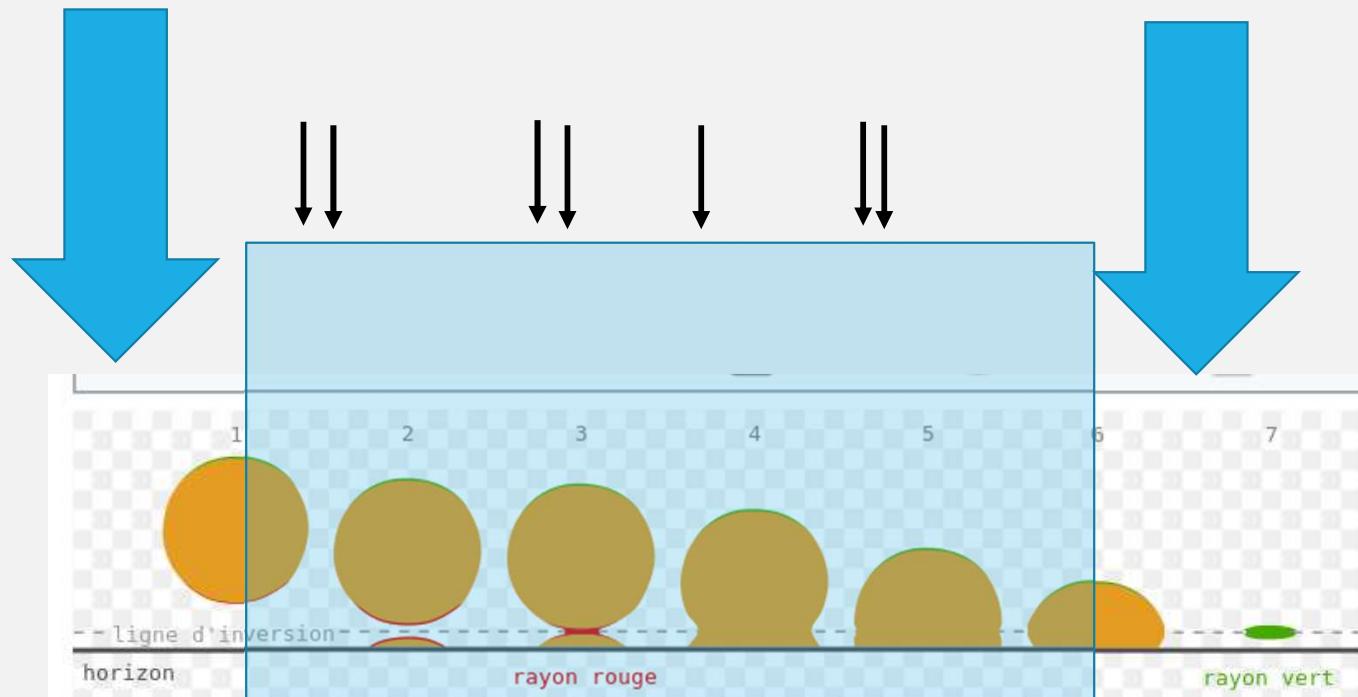
A. Instructions If I have a Terminal Condition

I provide the following instructions in the event my attending physician determines that my death is imminent (very close) and medical treatment will not help me recover:

B. Instructions if I am in a Persistent Vegetative State

I provide the following instructions if my condition makes me unaware of myself or my surroundings or unable to interact with others, and it is reasonably certain that I will never recover this awareness or ability even with medical treatment:

Basic Advance Care Plan leaves a big gap!



https://commons.wikimedia.org/wiki/File:Inferior_mirage_phases_of_sunset-fr.svg

MEDICAL ACP – BASIC / BETTER / BEST

- Basic – write down some of your values and wishes on a state-specific ACP form.
- Better – consider your own health and think about most likely future problems. Write down expanded ideas.
- Best – all of the above, plus conversations with your decisionmaker

WHAT DRIVES YOUR
PREFERENCES FOR
HEALTH CARE?

Values

Priorities

Surrounding situation

Other people's needs

Likes/dislikes related to body

Prior trauma

QUESTION THAT IS
OFTEN ASKED:

DO YOU WANT . . .

- Better questions are:
- What are your hopes?
- What are your worries?
- What is the hardest part of your day?
- What is the best part of your day?
- What is your biggest fear?



WHY IS ADVANCE CARE PLANNING IMPORTANT?

A person is more likely to have care consistent with their wishes if ACP has been discussed with a physician (Mack, 2010)

Less stress, anxiety, and depression in surviving relatives (Detering 2010)

Less emotional distress at the end of life (Vandeboort 2014)

Family members of people with dementia predicted different choices up to 1/3 of the time (Dening, 2016)

THE 5 C'S OF CAPACITY

Context

- Capacity refers to specific issues, e.g. complex finances vs. assigning power of attorney

Condition

- Anosognosia

Choices

- Understand what choices they have

Consequences

- Understand the consequences of their choices

Consistency

- Consistent answers over time

Use

“Teach Back” to ensure patient understanding

Anticipate Ripple Effects

Your inner crew (e.g. family and caregivers) will have a parallel illness journey. Their lives will be affected in multiple ways.



CONSIDER

What support do you need from your inner crew?
Encourage them to get information and support too.



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IMPACT OF DEMENTIA: CAREGIVER

- Distress
- Anxiety and depression
- Physical Exhaustion
- Medical health / chronic stress
- Social isolation



RESOURCES AND STRATEGIES FOR CAREGIVER WELL-BEING

Educational Resources

Providing caregivers with education improves their skills and confidence in patient care.

Support Groups

Support groups offer emotional encouragement and a sense of community for caregivers.

Respite Care Services

Respite care provides caregivers with necessary breaks to reduce stress and burnout.

Counseling and Mental Health

Counseling supports caregiver mental health and promotes resilience.



CAREGIVER RESOURCES

Training and Online Support

The Conversation Project

- Guide to being a healthcare proxy
- Guide for caregivers of people with dementia

Family Caregiver Alliance

Virginia Caregiver Coalition

Local Education and Support Services

- Insight Memory Care Center
- Memory Café

1:1 support

- Counseling with expertise in grief and/or caregiving
- Dementia consultants or coaches (local or online)
- Aging Life Care Managers

Advocacy opportunities

- International Neuropalliative Care Society

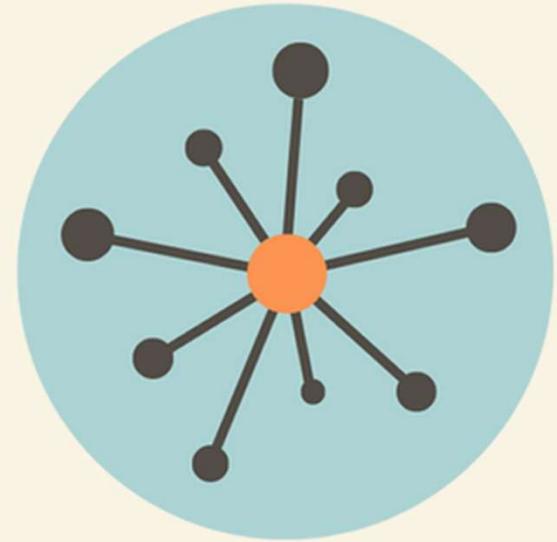


TOP 3 TIPS:

1. Build a team before you need it
2. Embrace the idea that your health is just as important
3. Know that there is not one “right” way to be a caregiver

Connect the Dots

You and your inner crew need to play a central role in co-ordinating information. This enhances continuity and safety, especially at transition points



ASK YOURSELF

Who in your crew will be the manager of your illness journey?

Circle of Support

Who are the important people in your life that you can turn to for support?

Use this list to start identifying your existing network and supports. We will use this list later to help develop our care plan.

Family

-
-
-

Friends/ Neighbors

-
-
-

System Supports

(Healthcare, Physicians)

-
-

Community Resources

-
-

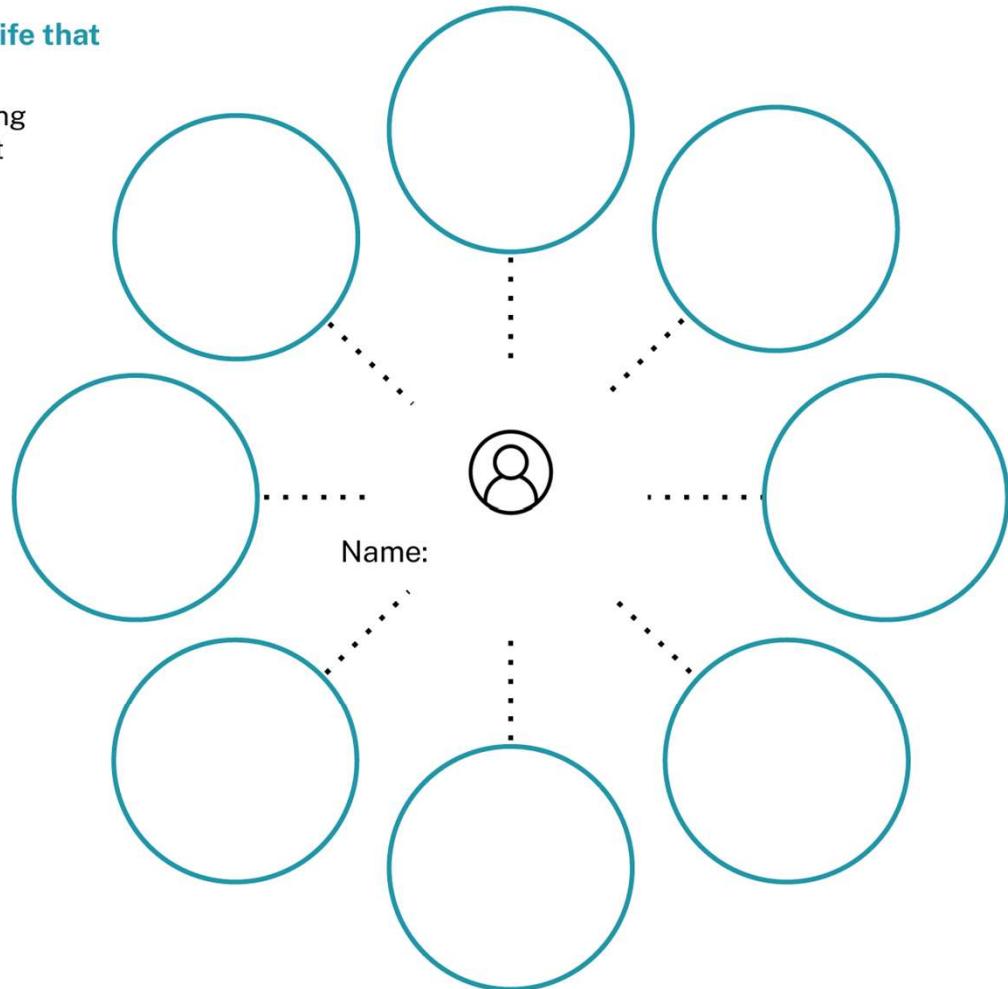
Community Connections

(e.g., Faith Groups)

-
-

Other

-
-



Invite Yourself

Initiate conversations with your healthcare team. Don't assume no news is good news. Passive, polite patients are encouraged to be respectfully assertive.



ASK QUESTIONS

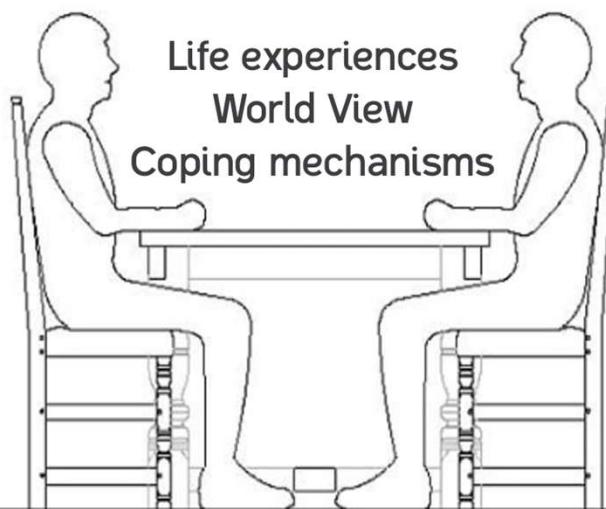
Seek information so you can understand how to plan, prepare, and make decisions.

Person Living with Illness

Goals
Values
Priorities

Illness

Symptoms – Change in function



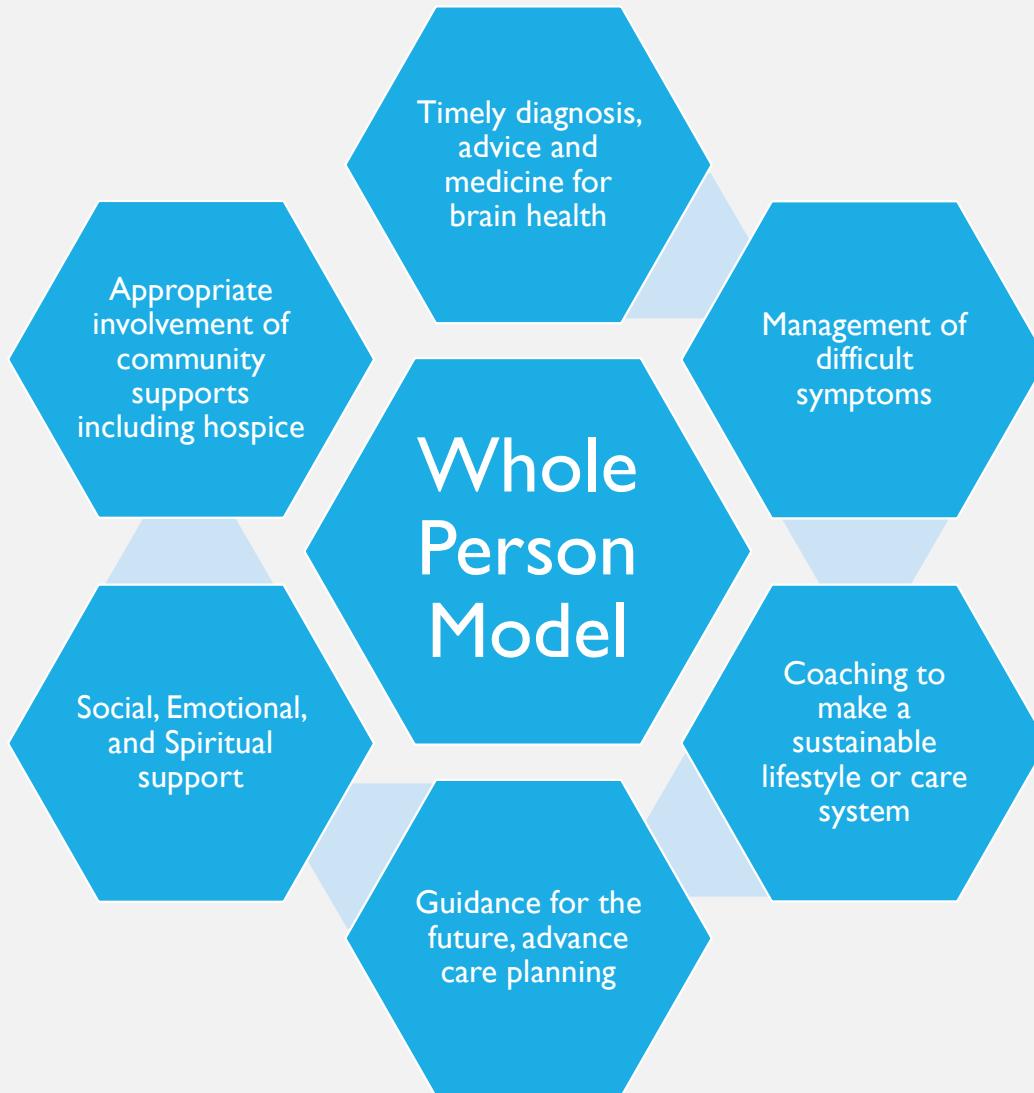
Medical Professional

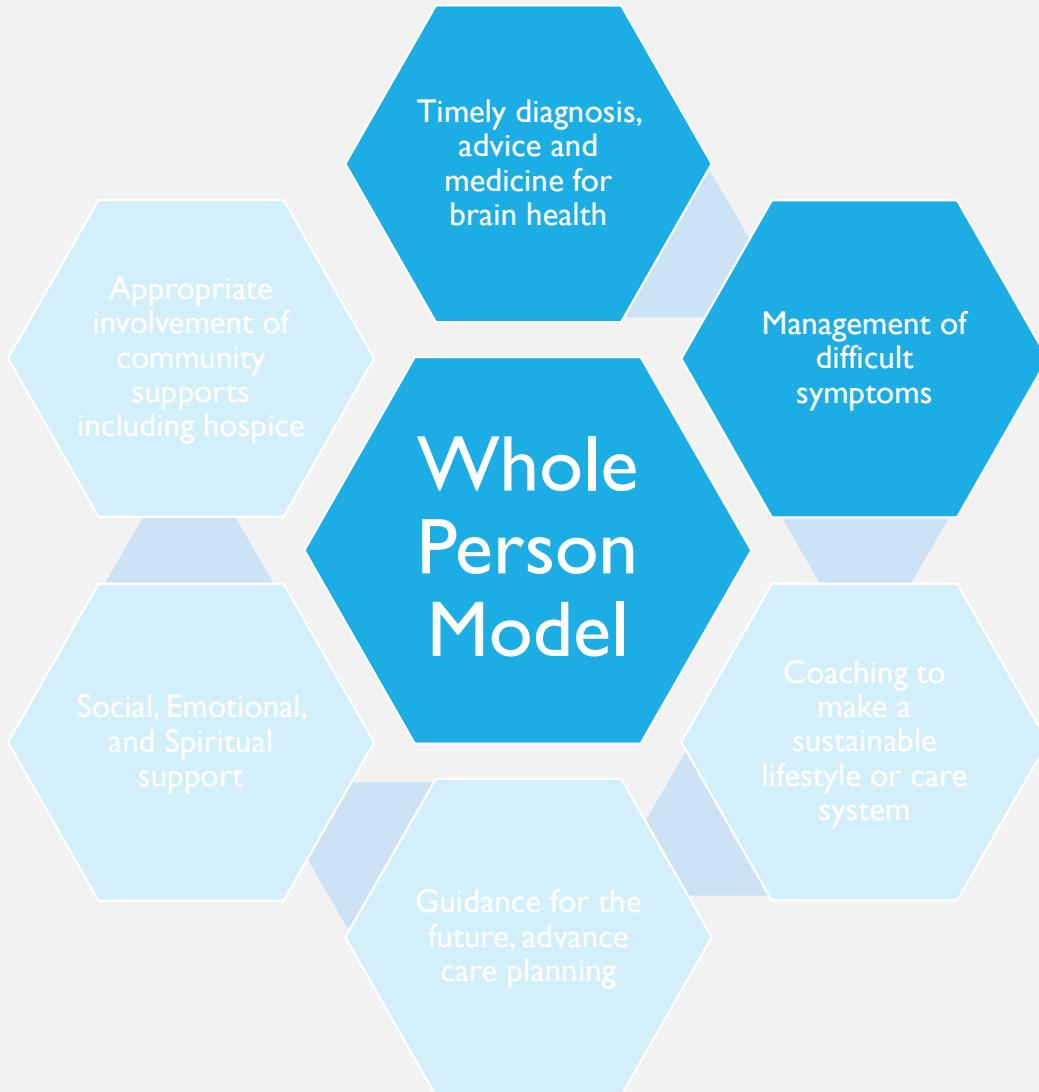
Training
Skill Set
Occupational
pressures

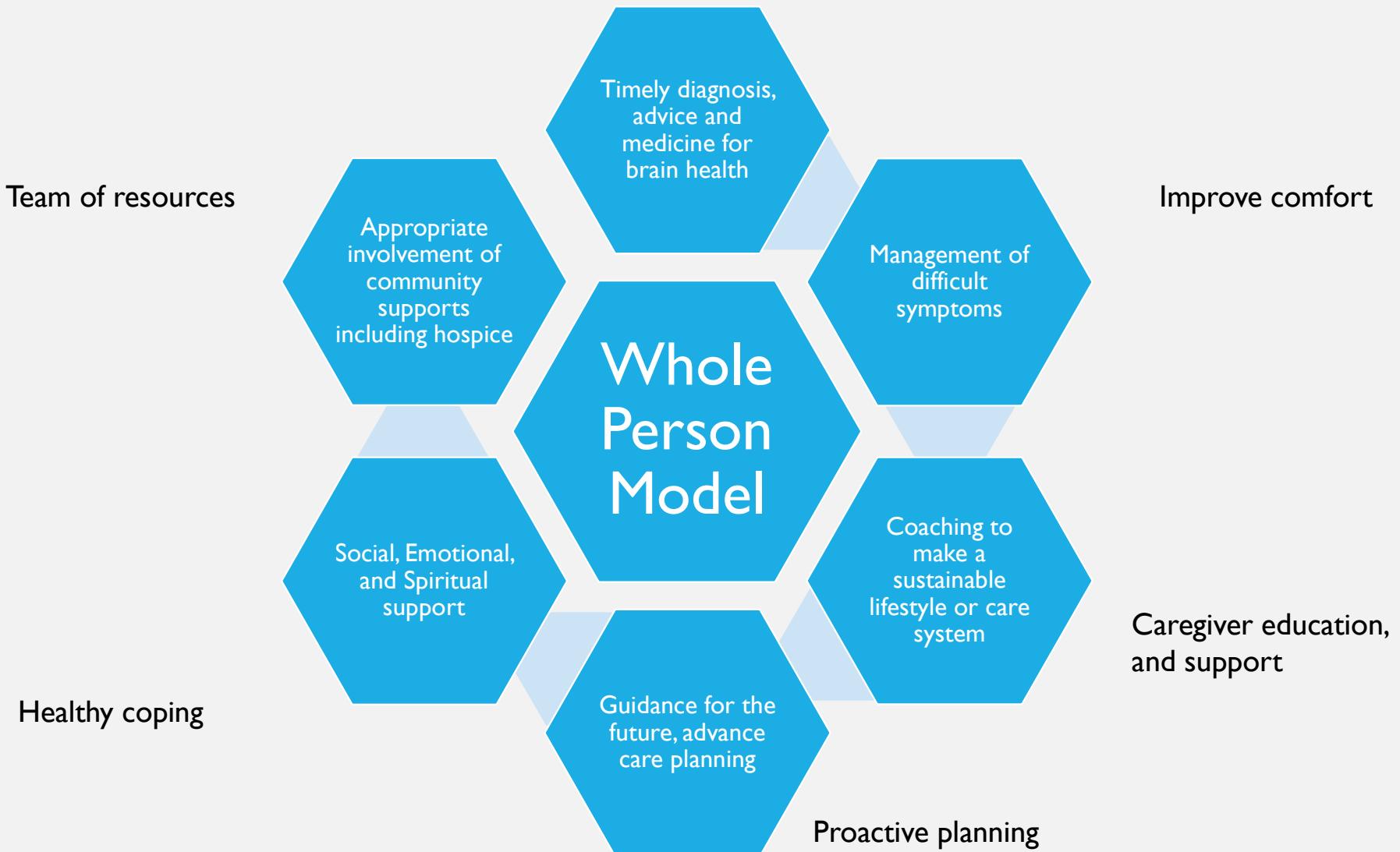
Environment & Community

Available resources









PATIENTS AND FAMILIES:

7 Keys for Navigating a Life-Changing Diagnosis

<h4>Walk Two Roads</h4> <p>Balance staying positive while also seeking honest, accurate information. This helps you stay hopeful and grounded in reality.</p> <p>ASK YOURSELF What you are hoping for and what you need to plan for just in case?</p> 	<h4>Zoom Out</h4> <p>Every illness has a known pattern to it. Understanding this storyline gives you a birds-eye and long view of where you are at in your illness.</p> <p>ASK YOUR PROVIDER What will my illness look like over time? What can I expect along the way?</p> 
<h4>Know Your Style</h4> <p>Your unique way of being will have as much impact on your illness experience as the illness itself. Harness information about your style to gain more control.</p> <p>REFLECT What are your tendencies when facing stressful situations and how those might play out in your illness?</p> 	<h4>Customize Your Order</h4> <p>Ideally you want to tailor your care to match your values. Share what's important to you to ensure that your care matches who you are as a unique person.</p> <p>ASK YOURSELF What do you want people to know about you? What do you value most?</p> 
<h4>Anticipate Ripple Effects</h4> <p>Your inner crew (e.g. family and caregivers) will have a parallel illness journey. Their lives will be affected in multiple ways.</p> <p>CONSIDER What support do you need from your inner crew? Encourage them to get information and support too.</p> 	<h4>Connect the Dots</h4> <p>You and your inner crew need to play a central role in co-ordinating information. This enhances continuity and safety, especially at transition points</p> <p>ASK YOURSELF Who in your crew will be the manager of your illness journey?</p> 
<h4>Invite Yourself</h4> <p>Initiate conversations with your healthcare team. Don't assume no news is good news. Passive, polite patients are encouraged to be respectfully assertive.</p> <p>ASK QUESTIONS Seek information so you can understand how to plan, prepare, and make decisions.</p> 	<p>The Waiting Room REVOLUTION</p>  <p>For more tools and resources visit waitingroomrevolution.com</p> <p><small>© Seow and Winemaker. 2021. All rights reserved.</small></p>



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“Thank you for talking with me, not as a doctor talking with a patient, but as a human being talking with another human being.”

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