

# 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.

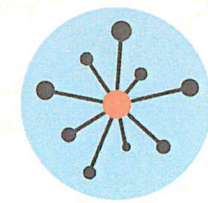


#### CONSIDER

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

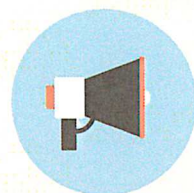


#### ASK YOURSELF

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.

Adapted from the book "Hope for the Best, Plan for the Rest" and workbook "Applying the 7 Keys for Navigating a Life-Changing Diagnosis."

**The Waiting Room  
REVOLUTION**



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## HOW YOU MIGHT BE FEELING

- A wide range of emotions
- Recovering from the chaos of moving
- Learning how things work
- Adjusting to new rhythms and routines

## WHAT TO FOCUS ON

Understanding your current health, what may lie ahead, personal priorities and hopes, and making sure everyone understands their role in supporting the best care.

**TIP**

Share with your health care providers what they need to know about you and your family to provide the best care possible.

## KEY QUESTIONS TO DISCUSS WITH YOUR CARE TEAM

- Can you help us understand my person's overall health right now?
- Where are we now in the big picture of the illness or health conditions? (Beginning, middle, late or end stages)
- What changes might we expect over time?
- How will we know if overall health is changing and who will tell us?
- What is the role of family? And what's the best way for us to share observations or concerns?
- When and how can we request a check-in meeting about my person's health?

## ADDITIONAL QUESTIONS & NOTES

## CONVERSATION STARTERS FOR ANYTIME

## HOW YOU MIGHT BE FEELING

- More familiar with a regular routine
- Uncertain about the future
- Looking for signs of change

## WHAT TO FOCUS ON

Monitoring change, supporting quality of life, and working collaboratively with the care team.

## KEY QUESTIONS TO ASK YOUR CARE TEAM

- Can we check in about how things are going overall right now?
- Where are we now in the big picture of this illness?
- Has the care team noticed anything different or new that I/we should be aware of? (Physical, cognitive, emotional, or functional)
- What are important things to think about now to be more prepared for what might come later?
- What can we do now to support the best quality of life? (Comfort, enjoyment, routines, relationships, meaning)

**TIP**

You are encouraged to ask questions, and more than once. If something you are seeing feels concerning, confusing, or upsetting, you are encouraged to speak up. Information is your superpower.

## ADDITIONAL QUESTIONS & NOTES



# CONVERSATION STARTERS FOR MAJOR CHANGES

## HOW YOU MIGHT BE FEELING

- Stressed and anxious about unknowns
- Unsure what the best course of action is
- Overwhelmed by decisions that need to be made

## WHAT TO FOCUS ON

Making sense of sudden or significant changes and deciding next steps.

### TIP

Check out the quick guides focused on **Understanding** and **Navigating Changes** and key things to consider.

## KEY QUESTIONS TO ASK YOUR CARE TEAM

- Is what we're noticing expected, given my loved one's underlying conditions?
- Would you describe this as a gradual change or a sudden change?
- How does this change fit into the bigger picture of their overall health and trajectory?
- What are the benefits and burdens of managing this change in long-term care versus going to the ER?
- What does this change mean for the future? And how can we better prepare for what lies ahead?

## ADDITIONAL QUESTIONS & NOTES



# UNDERSTANDING CHANGES

## HOW THIS CAN HELP YOU

In long-term care, changes in a person's health condition are common but can still be distressing if they are unexpected or misunderstood. Some changes are sudden and significant, while others are gradual and expected, as part of aging, a progressive illness, or the natural dying process. Knowing the difference can reduce fear and help families know when to ask questions.

## TWO DIFFERENT KINDS OF CHANGE

### GRADUAL EXPECTED CHANGE

These are changes that happen slowly (weeks to months) and follow a known pattern of decline. They are often due to aging, chronic illness, frailty, and the natural dying process.

#### Key features:

- Gradual decline
- Seen more clearly in hindsight
- Not usually reversible
- Part of the body slowing down

#### Common examples:

- Slowly decreasing appetite without hunger
- Increasing fatigue and sleeping more
- Gradual loss of strength and mobility
- Needing more help with daily activities
- Less stamina for socializing
- Weaker voice or slower communication
- Spending more time sitting or in bed

#### Ask questions if you notice:

- Ongoing decline over weeks or months
- Reduced eating, activity, or strength
- Increasing need for help

#### What to ask:

- "Is this an expected part of their condition?"
- "What changes should we expect next?"
- "How can we support comfort and quality of life?"

### SIGNIFICANT UNEXPECTED CHANGE

These are changes that happen quickly (hours to days) and may not be part of the usual pattern for the person. They may signal a new problem that needs prompt assessment.

#### Key features:

- Abrupt onset
- Noticeable change from yesterday
- Sometimes reversible or treatable
- Usually triggers prompt evaluation

#### Common examples:

- Sudden confusion or agitation
- New or severe shortness of breath
- Chest pain
- Fever or signs of infection
- A fall with injury
- Sudden weakness or trouble speaking
- Acute pain that is new or escalating quickly
- Rapid decline over hours or a day

#### Ask for explanation if you notice:

- A rapid change over hours or a day
- New pain, distress, or confusion
- Something feels very different from baseline

#### What to ask:

- "This seems sudden. What could be causing it?"
- "Does it need urgent investigation or treatment?"
- "What are our options right now?"



# NAVIGATING CHANGES

## HOW THIS CAN HELP YOU

When you notice a change, it can be scary. Not every change in health needs the same response. This guide can help everyone weigh important factors to make informed decisions. Remember, goals can change over time. What felt right earlier in an illness may feel different now. The best decision is the one that most closely matches your loved one's wishes and supports comfort.

### 1 START WITH WHAT MATTERS MOST TO THEM

Before thinking about additional tests or treatments, ask: **"What would the resident want right now?"**

If the resident cannot vocalize their own wishes or you haven't had this discussion, use what you know about their life, values, and past experiences to guide you.

People's goals of care often focus on things like:

- Being comfortable
- Having the best quality of life possible
- Staying as independent as they can
- Treating problems that can be fixed
- Avoiding stressful hospital visits or procedures

#### ASK EACH OTHER:

- If they could speak for themselves, what would they say matters most?
- What would improve comfort or quality of life?
- Would more treatment help them feel better or put them through more discomfort?

### 2 THINK ABOUT WHERE THEY ARE IN THEIR ILLNESS

Looking at the "big picture" can help you understand what this change might mean.

- **If the change is gradual or expected**, this may be part of the illness progressing. Care then often focuses on being comfortable, managing symptoms, and supporting emotional and practical needs.
- **If the change is sudden, unexpected or significant**, this could be a new problem that might need investigations and/or treatment.

#### ASK THE CARE TEAM:

- Is this change expected at this phase of their illness?
- What treatment options are available?
- Can this be treated here?

### 3 WEIGH THE BENEFITS AND BURDENS

Every medical decision has trade-offs. The 'right' decision depends on:

- Goals of care
- Overall health and stage of illness
- How much benefit or burden are treatments likely to bring

#### ASK THE CARE TEAM:

- What might happen if we treat this?
- What might happen if we don't?
- Would further tests, treatments, or hospital transfers do more harm than good?

# ROADMAP OF GENERAL DECLINE

## HOW THIS CAN HELP YOU

People often ask "how much time is left?," which is sometimes hard to predict. But knowing where you are within the general pattern of decline can be helpful. Since people move through changes at different speeds, use this guide with your care team to understand where you are at.

|                 | What's Happening                                                                                                                                                                  | What You May Notice                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
|-----------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| EARLY CHANGES   | <b>The Body Begins to Slow Down</b><br><br>(often months before death)                                                                                                            | <ul style="list-style-type: none"> <li>• More tiredness; needing more rest</li> <li>• Slower walking, dressing, or movement</li> <li>• Less interest in busy routines or social activity</li> <li>• Eating smaller amounts or skipping meals without hunger</li> </ul> <p><b>What this means:</b> The body is <b>beginning to conserve energy</b>. These changes are often subtle and clearer only in hindsight.</p>                                                                                                  |
| ONGOING CHANGES | <b>Increasing Fatigue and Support Needs</b><br><br>(often months to weeks before death)                                                                                           | <ul style="list-style-type: none"> <li>• Increasing weakness and fatigue</li> <li>• Needing help with activities that were once done independently</li> <li>• More sitting or napping during the day</li> <li>• Reduced appetite without distress or hunger</li> </ul> <p><b>What this means:</b> The body is <b>slowing down further</b>. Loss of strength and appetite is part of this process, not starvation.</p>                                                                                                 |
| LATER CHANGES   | <b>Rest Becomes the Priority</b><br><br>(often weeks before death)                                                                                                                | <ul style="list-style-type: none"> <li>• Spending most of the day and night sitting or sleeping in bed</li> <li>• Needing help to transfer or use the bathroom</li> <li>• Using a bedside commode, urinal, or briefs</li> <li>• Very low food intake; some interest in fluids</li> </ul> <p><b>What this means:</b> The body is <b>prioritizing rest and comfort</b>. Energy is limited, and activity naturally decreases.</p>                                                                                        |
| FINAL CHANGES   | <b>The Body Is Approaching End of Life</b><br><br>(often weeks to days before death)                                                                                              | <ul style="list-style-type: none"> <li>• Staying in bed or sleeping all the time</li> <li>• Minimal or no eating and drinking</li> <li>• Little or no verbal communication; very soft voice if awake</li> <li>• Changes in breathing (faster, slower, pauses) or wet-sounding</li> <li>• Cool hands and feet; changes in skin colour (marbling pattern on skin)</li> </ul> <p><b>What this means:</b> The body is <b>carrying out the dying process</b>. These changes are expected and do not reflect suffering.</p> |
| END OF LIFE     | <b>Death is Imminent</b><br><br>Eventually: <ul style="list-style-type: none"> <li>• Breathing stops</li> <li>• The heart stops beating</li> <li>• The person has died</li> </ul> | <p>Important Reassurance About Suffering:</p> <ul style="list-style-type: none"> <li>• A person actively dying has no appetite as the body is programmed to wind down. Encouraging food and fluid now can cause discomfort.</li> <li>• The natural process of dying doesn't automatically involve pain.</li> <li>• Symptoms do not necessarily worsen as death nears.</li> </ul> <p>The focus near the end of life is <b>comfort and dignity</b>.</p>                                                                 |



# CONVERSATION STARTERS FOR END OF LIFE

## HOW YOU MIGHT BE FEELING

- Emotional, sad, scared, exhausted
- Overwhelmed by juggling medical, logistical, and family dynamics

## WHAT TO FOCUS ON

Comfort, understanding what is happening, and knowing what to expect.

### TIP

Use the **Roadmap of General Decline Guide** to understand and demystify the natural process of dying that most will experience.

## KEY QUESTIONS TO ASK YOUR CARE TEAM

- Can you help us understand the changes we're seeing right now?
- What signs suggest we may be in the last weeks, days, or hours of life?
- What supports are available for the family during this time?
- How are you ensuring comfort, and how do you assess pain or distress?
- Is our person suffering, hungry, or thirsty?
- What happens when our person dies and what should we prepare for?

## ADDITIONAL QUESTIONS & NOTES