4Step iCare Plan
Goals of Care Coalition of NJ

SPIRITUAL CARE PROVIDER

Conversation Assistant

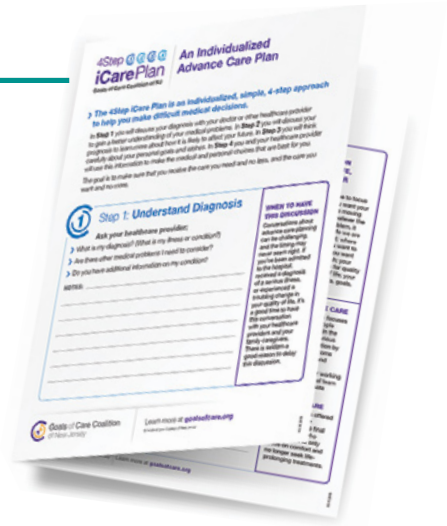
The 4Step iCare Plan is an individualized, simple, 4-step approach to help patients or their health care proxy make difficult medical decisions when facing a life-threatening illness.

Spiritual Care Providers' core training competencies, such as empathetic listening and reflection, uniquely support the patient in feeling 'heard' and integrating their diagnoses and prognoses with their personal values, beliefs, and intentions. As a result, patients and loved ones are better prepared to work in partnership with their physician and interdisciplinary team to align their medical treatment options with their personal wishes and document them appropriately for the medical paradigm.

Spiritual Care competencies embedded in the 4Step iCare Plan include:

- Assessing the patient's spiritual state, potential distress, goals and values, family dynamics, ethical concerns, and possible organizational influences.
- Facilitating clear communication and processing of the patient's feelings, needs, and decisions within the family unit and the healthcare team.
- Compassionate caregiving ranging from simple "presence" to exercising "pastoral authority."
- Leadership and advocating to assist the patient in defining and articulating their goals of care with loved ones and the healthcare team; and ensuring those wishes are honored.

The 4Step iCare Plan will guide you and your patients through a conversation about Advance Care Planning. Spiritual Care Providers can help patients and families Understand and Process their Diagnosis **(Step 1)**, their Prognosis **(Step 2)**, Reflect on their Goals of Care **(Step 3)**, and Support Patients in Documenting their Wishes for Treatment **(Step 4)**.



HELPFUL FACT:

Studies show that patients who have visited with a chaplain and received high level spiritual support are more likely to discuss their goals of care with loved ones, sign documents, and opt for hospice when that is in alignment with their values.

(Lee AC, McGinness CE, Levine S, O'Mahony S, Fitchett G. Using Chaplains to Facilitate Advance Care Planning in Medical Practice. JAMA Intern Med. 2018;178(5):708–710. doi:10.1001/jamainternmed.2017.7961; Caring for the Human Spirit Magazine, Fall/Winter 2017; Health Affairs 30.9 (2011): 1772-1778.)

Goals of Care Coalition of New Jersey

Learn more at **goalsofcare.org**

7.31.2020

4Step iCarePlan
Goals of Care Coalition of NJ

SCP Conversation Assistant

Step 1

Help Patients Understand and Process Their Diagnosis

A Spiritual Care Provider's response to the patient's receipt of diagnosis will range from presence to pastoral authority. When speaking with the patient and family, consider the contextual elements of the conversation such as the patient's cognitive responses, family dynamics, healthcare team dynamics, and the time frame for making any health care decisions. Be aware of the patient's cultural and religious norms and whether they feel comfortable speaking with you.

Step 1: Understand Diagnosis

Ask your healthcare provider:

- What is my diagnosis? (What is my illness or condition?)
- Are there other medical problems I need to consider?
- Do you have additional information on my condition?

NOTES: _____

- **Assess and acknowledge:**

…**how well the patient understands and expresses their diagnosis.**

What is your understanding of your illness? Do you wish to know more, such as what to expect; or is there someone else who you would prefer to rely on?

Who do you have supporting you? Is there a family member, friend, or clergy person that you wish to share this information with? May I call them for you? Would you like me to be present when you speak with them?

…**expressions of spiritual distress, ethical concerns, or challenging family or healthcare dynamics.**

I can't imagine what it was like to hear this news. Was this a shock? Or, it sounds like you may have been expecting something like this.

What are some of your feelings right now? Does this feel scary… difficult…confusing…make you angry?

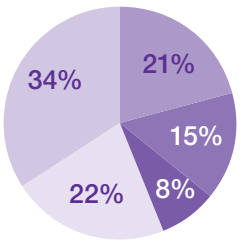
What are your biggest fears and concerns right now?

- **Discern your role as Spiritual Care Provider**

What would feel most helpful for you right now? Offer to just listen, come back later, or help connect them with support people.

Do you have questions about the diagnosis, or what will happen next? Would you like me to help you frame the questions for the healthcare team?

TOP QUESTIONS OF SERIOUSLY ILL PATIENTS:



- **34%** Meaning (of my life)
- **21%** Death and Dying (physical aspects)
- **15%** Relationships
- **8%** Religious Issues
- **22%** Other

Conclusion: "the role of hospital chaplaincy has changed. Today it entails specialized competence and is needed in existential discussions with different patients in crisis, regardless of their personal faith or lack of faith."

Journal of Palliative Medicine, Vol. 5, No. 6, Strang, 2004.

4Step iCarePlan
Goals of Care Coalition of NJ

SCP
Conversation Assistant

Step 2

Help Patients Understand and Process Their Prognosis

The patient will be better able to develop their care goals and wishes for their end of life if they have integrated their prognosis and understand how it will impact their life going forward. This may trigger feelings of grief as they contemplate their new limitations and adjust to an awareness of the eventuality of death.

Step 2: Discuss the Prognosis

Ask your healthcare provider:

- What is my prognosis, how will my condition affect my future?
- How much time will I have?
- Will I be able to do my favorite activities and live independently?
- Will I have pain or trouble sleeping?
- How will the time I have or the quality of that time change with or without aggressive medical treatment?

NOTES: _____

Assess and acknowledge...

... how well the patient and family understands the prognosis.

Do you feel like you have a full understanding of your healthcare future and how it will impact your day to day life?

... the patient's understanding and ability to express how their day-to-day life will change with this prognosis, and any possible areas of spiritual or emotional distress.

What are your biggest fears and worries about your future now?

What abilities are so critical to your life that you can't imagine living without them?

What will you still be able to do, or miss doing that matters most to you right now?

Are their people you would like to call?

... the patient's ability to incorporate their prognosis into their advance care plan and goals of care.

Are there things you wish to do now that seem to have more importance than before?

Do you have a plan for who will be able to take care of you when you are physically incapable?

If you become more unwell, how much are you willing to go through for the possibility of gaining more time?

Discern your role as Spiritual Care Provider

What would feel most helpful for you right now?

Given your illness, have you had to adjust to limiting your activities in the past? What has helped you cope with these limitations?

Who and what comes to mind when you think about how you have gotten through difficult times before?

It sounds like you may still have questions. Would you like me to help you frame those questions for the healthcare team?

HELPFUL FACT:

Witnessing a **Life Review** with Patient and/or Family can be a calming, clarifying and meaningful way to process the significance of difficult news; approach new ways of living; heal memories and relationships; and come to terms with their mortality.

4Step iCarePlan
Goals of Care Coalition of NJ

SCP
Conversation Assistant

Step 3

Help Patients Reflect on their Goals of Care

A Spiritual Care Provider may assist a patient in clarifying how they wish to live with illness during their remaining time. Not all patients come to terms with their diagnosis and prognosis. You may help the patient process the new information and think about what is important to them at this time.

Step 3: Identify Goals of Care

Tell your healthcare provider:

- What matters most to you at this time?
- How important is it for you to remain at home?
- How much quality of life are you willing to sacrifice to live longer?
- How important is it for you to remain comfortable and avoid unpleasant treatments?
- At what point would you want to avoid aggressive treatment and focus on the best quality of life?

NOTES: _____

- **Assess and acknowledge...**

... **the patient's struggle to balance their new health condition and how they wish to live their daily life.**

Understanding what you know now and that your time remaining may be limited, what matters most to you at this point and moving forward?

Are there specific events that you would like to attend or goals that you would like to accomplish? How do you wish to spend your time?

... **the patient's willingness to discuss their desires to speak about aggressive treatment, quality of life, and comfort measures.**

Have you explored the impact of your diagnosis and prognosis? Would you like to explore what you would want to do if you become more unwell?

Have you thought about whether you want to be home or in the hospital? What kind of care do you want and in which setting?

Do you want people in the room with you, or would you like to be alone? Who would you like in the room with you? Who do you NOT want to be in the room? What would be nice for you to have around you such as music, pets, or art?

Do you know about the benefits of hospice for you and your loved ones?

... **the patient's confidence and ability to express and advocate for how they wish to live the rest of their life.**

Do you feel like your family and healthcare team understand your wishes?

Whom have you chosen to speak for you in the event that you cannot speak for yourself (Healthcare Proxy/Medical Power of Attorney)? Have you discussed your wishes with that person? Do you feel confident in their ability to make difficult choices in order to honor your wishes?

GOOD TO KNOW:

When asked to prioritize healthcare outcomes, patients ranked independence as #1, pain relief as #2, symptom relief as #3, and living longer as #4.

Arch Intern Med. 2011 November 14; 171(20): 1854–1856. doi:10.1001/archinternmed.2011.424.

continues >

4Step iCarePlan
Goals of Care Coalition of NJ

SCP Conversation Assistant

Step 3 (continued)

Help Patients Reflect on their Goals of Care (continued)

… the patient's emotional, spiritual, and relationship needs.

Are there any relationships you'd like to heal . . .with a loved one. . .with someone who has already died. . .with God?

Are there any conversations you would like to have with a friend, a loved one, God?

Do you have a time frame of when you want to have these conversations?

What would it feel like if you called or wrote a letter...?

Who would you like to spend time with now?

Is there anyone you want to forgive or ask for forgiveness?

Are there any stories in your heart that you would like to share?

… the patient's potential concerns about financial and legal matters in planning their final life stages.

Are there any legal or financial matters that you would like to focus on?

Are there any special items that you wish to give away?

Do you wish to talk about or plan your funeral?

› Discern your role as Spiritual Care Provider

What would feel most helpful for you right now? Would you like me to help frame a conversation with your family or your medical team about your wishes?

Step 3: Identify Goals of Care

Tell your healthcare provider:

- What matters most to you at this time?
- How important is it for you to remain at home?
- How much quality of life are you willing to sacrifice to live longer?
- How important is it for you to remain comfortable and avoid unpleasant treatments?
- At what point would you want to avoid aggressive treatment and focus on the best quality of life?

NOTES: _____

KNOW YOUR DOCUMENTS:

Health Care Proxy form is used to select person who can speak for the patient.

Advance Directive is a written statement of a person's wishes regarding medical treatment.

POLST (Physicians Orders for Life Sustaining Treatments) is an actionable medical order.

GOOD TO KNOW:

Some 70 percent of people over the age of 60 who were in an inpatient setting and had to make a decision about treatment during the last week of life were physically unable to communicate their wishes to family or clinicians.[1] Yet research indicates that only about 1 in 3 Americans has completed any advance care plan for the end of life.[2]

(1) Maria J Silveira, Scott Y. H. Kim, and Kenneth M Langa, "Advance Directives and Outcomes of Surrogate Decision Making Before Death," New England Journal of Medicine 362, no.13 (2010): 1211-18, https://dx.doi.org/10.1056/NEJMsa0907901.

(2) Kuldeep N. Yadav et al. "Approximately One in Three US Adults Complete Any Type of Advance Directive for End-Of-Life Care, " Health Affairs 36 no. 7 (2017): 1244-51, http://dx.doi.org/10.1377/hlthaff.2017.0175 Journal of Palliative Medicine, Vol. 5, No. 6, Strang, 2004.

4Step iCarePlan
Goals of Care Coalition of NJ

SCP Conversation Assistant

Step 4

Support Patients in Documenting Wishes for Treatment

A Spiritual Care Provider may help the patient understand that some medical treatments may be in contrast with what they value about living. Be available to support conversations between patient, family, and healthcare team to discuss whether treatment is aligned with the patient's goals of care, and ensure their wishes are documented.

Step 4: Align Treatment

Ask your healthcare provider:

- What are the treatment options given my prognosis and goals of care?
- What are the benefits and risks of these options?
- What other treatments are there or which doctors I should consult?
- What treatments or medications are no longer necessary?
- Under what circumstances would returning to the hospital be necessary?
- To what extent would beginning or continuing artificial nutrition (feeding tube) and hydration (IV fluids) align with my goals?
- What are my chances of surviving cardiopulmonary resuscitation (CPR) and how would emergency procedures like that help me achieve my goals of care?
- Is a NJ POLST* form appropriate for me at this time?

NOTES: _____

- **Assess and acknowledge...**

... **the patient's understanding of what "aggressive care," "appropriate care," or "inappropriate care" mean to them.**

Do you understand the impact of what is known as aggressive treatments such as CPR, feeding tubes, and intubation on the way you wish to live?

Do you want aggressive treatment even if it may be painful or if it will not change or cure your condition?

What would impact your choices?

Is there any kind of care or treatment that feels absolutely necessary, or unacceptable for you if it is an option?

Is there a point at which you think switching the focus of treatment to comfort care would be better for you?

Is there a point at which allowing a natural death would seem appropriate?

Is there anything you need clarified?

... **the patient's understanding of the need to have 'the' conversation and documenting their wishes.**

Has the healthcare team discussed documenting your wishes with you?

Are you ready to go ahead with documentation?

Do you understand you can change your wishes at any time?

- **Discern your role as Spiritual Care Provider**

What would feel most helpful right now? Can I arrange a conversation with your healthcare team to discuss your wishes? Can I help you document what we have talked about? Are there any lingering questions you have for your healthcare team or family, or conversations you wish have?

To further help patients, Goals of Care Coalition of New Jersey created a series of online videos guiding them through each step. The 4Step iCare Plan and the Spiritual Care Provider Conversation Assitant are also available for download:

goalsofcare.org/patients-family/4step-icare-plan

7.31.2020