



Chronic Critical Illness Decision Aid

A Tool for Patients and Families



THE OHIO STATE UNIVERSITY

WEXNER MEDICAL CENTER



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This book is for informational purposes only. Talk to your doctor or health care team if you have any questions about your care.

For more health information, go to wexnermedical.osu.edu/patiented or contact the Library for Health Information at 614-293-3707 or health-info@osu.edu.

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Making Informed Decisions

Getting health care often involves choices that impact your life and wellbeing in different ways. Making decisions about a serious illness may feel scary and confusing. You may feel under pressure to make these decisions. All of these are normal emotions. But you have a say in your care or the care of your loved one.

We want to be sure you know the details of this process, so you can make the right choices for you or your loved one.

This book is not to replace conversations with your care team. Use it as a guide to help you or your loved one through this process.

These are not easy choices

Having a chronic critical illness means having to make choices about care at different points in the process. We want to help support you by explaining those decision points and what your care options are.

Take time to review this book and think about the decisions that may be right for you or your loved one.

You will want to consider things such as:

- Do I want to have treatment that could extend my life, but could mean I will live the rest of my life in hospitals?
- Do I want to have everything done to keep me or my loved one alive, or not?
- Do I want to be kept comfortable until I die and not be kept alive with machines?

Talk to your family, friends, and others that support you.

Ask questions of your doctor or others on your care team if there is anything that is not clear.

Having those difficult conversations now can help make difficult decisions a little easier in the future for you and your loved ones.



Life with Organ Failure

Ongoing or Chronic Critical Illness

If 1 or more organs in your body are failing, you will need ongoing medical care. While there may be enough improvement in your condition to leave the intensive care unit or the hospital, you are often too sick to be able to go home. Care may be needed in a **long term acute care hospital, also called LTACH**.

Care in the LTACH

The long term acute care hospital can provide support for the person who needs a ventilator, dialysis, tube feedings, wound care, and daily care. They can also provide therapy as the person is able to tolerate it. Most patients are sent to the LTACH because their care is too involved to be done at home.

A LTACH is not the same level of care as in an **intensive care unit or ICU**. The nurses and support staff will be caring for more patients each shift than in an ICU.

While in the LTACH, the progress of the patient will be checked to see if there is improvement. Most often that may result in 1 of 3 outcomes:

- There is **improvement seen in the first 2 to 6 weeks** and the person is able to be moved to a **skilled nursing facility (SNF)** to continue rehab. A few patients may be able to go home with caregiver support.
- There is **slight improvement, but treatments are still needed to support their failing organs**. The patient care may need to continue in the LTACH, or the patient may be moved to an SNF or an **extended care facility (ECF)**. Another option is to change the goals of treatment to comfort which can be done with the support of hospice. Treatments would be removed that are not helping the patient.
- There is **worsening of the organ failure or other medical problems occur**. Patients at the LTACH have an increased risk of complications. The patient may need to return to the ICU multiple times. Each trip to the ICU weakens the body and more damage may occur to your organs. A cycle can begin where you are more at risk for problems that need more intense care, so often you end up going back and forth between the ICU and the LTACH. The options are to treat the patient in the ICU as needed, or to change the care goals to focus on comfort care until death.

Treatments

Based on the failing organ or organs, available treatment may include:

- **Breathing machine**, also called a **ventilator**, to support breathing. Often, this will require a tube being placed in the neck, called a **tracheostomy or trach**.
- **Dialysis** to filter the blood when the kidneys are not working. This may be needed every 2 to 3 days.
- **Feeding tube** that may first be in the nose to the stomach, called a **nasogastric or NG tube**. If a feeding tube is needed long term, it would be placed into the stomach through the belly wall, called a PEG tube.
- **Wound care** because of slow healing and risk of skin breakdown because of serious condition.
- **Daily care**, such as bathing, feeding, and turning due to weakness and inability to do own care.

Types of care facilities explained

- **Skilled Nursing Facility (SNF):** Skilled nursing facilities (SNFs) provide skilled nursing care up to 24 hours a day and offer medical care and medicines. They provide meals and laundry and help with dressing, bathing, and using the toilet. This is a costly type of care. But it may be the best choice for many people who have a lot of trouble with daily tasks and need medical care.
- **Extended Care Facility (ECF):** Extended care facilities provide long-term care that may be custodial (non-skilled personal), nursing, or medical care. They can provide help with activities of daily living (dressing, bathing, using the bathroom), or more intensive therapy or medical care.
- **Rehabilitation Hospital:** Rehabilitation hospitals are specialty hospitals or parts of acute care hospitals that offer intensive inpatient rehabilitation therapy. It provides intensive rehabilitation, continued medical supervision, and coordinated care that comes from your doctors and therapists working together. It is sometimes called an inpatient “rehab” facility, IRF or acute care rehabilitation.
- **Intensive Care Unit (ICU):** An intensive care unit (ICU) is a part of the hospital where very sick people get care. It could be a special unit for people with heart, breathing, or other serious medical problems. Or it could be a place to recover after surgery.

Adding Positive, Hopeful Feelings

When facing a serious illness, it can be hard to stay positive and hopeful. But a hopeful, positive outlook is a key part of resilience, that inner strength that helps you get through tough times.

Here are some ideas to help add more positive, hopeful feelings to each day:

- **Remind yourself you’re not alone.**
- **Manage all the symptoms you can.** Palliative care, for example, can help you manage symptoms, pain, or side effects from treatment or medicines.
- **Set little goals.** Pick a goal each day that you know you can reach to give you a needed feeling of success.
- **Keep a gratitude journal.** Spend a few minutes each day to write down the positives — even small ones.
- **Manage stress.** Whatever your illness, managing stress can help improve your overall health and wellbeing.
- **Reach out for support.** Social support can have a huge impact on your mental health when you’re facing the stress of a serious medical condition. Don’t let worries about being a burden stop you from asking for help.
- **Focus on what’s going well.** Write down up to 3 things that have gone well in the past day.
- **Build yourself up.** When you need it, lean on others or your beliefs to build more strength. Say to yourself often, “I am strong.”



Is a Long Term Acute Care Hospital (LTACH) Right for Me?

Your care team has decided that your condition has stabilized and ICU care will not give any further benefit at this time. Either organ function has leveled off or more time may be needed to see if your organs are able to recover more. Your care options are to transfer to LTACH or to consider focusing on comfort with the help of hospice care.

Options for LTACH care

The case manager or social worker will help you and your family get information about LTACH care options.

- In the Columbus area, there are 3 LTACH sites run by Select Specialty Care.
- If you are from outside the Columbus area, other options closer to home can be explored.
- The arrangements for the referral and transportation to the LTACH would be arranged by the case manager or social worker.

Facts about patients with critical illness

- Most patients (4 to 8 of every 10 people) who are sick enough to need LTACH at the time of ICU discharge will die within a year. The persons most likely to die:
 - Are over age 75
 - Not able to do their own daily care
 - Have kidney failure or diabetes
- 4 in 10 patients discharged to LTACH were readmitted to the ICU within 90 days.
- Most patients who go to LTACH are later discharged to a skilled nursing facility.
- Very few of these patients are able to return home.

Choosing comfort care

The focus of comfort care is the quality of your life, care, and comfort. Treatments, such as the ventilator or dialysis, are stopped. The hospice team helps to manage your pain, shortness of breath, or anxiety.

Comfort care can happen in your home, in a hospice unit or facility, or in some skilled nursing facilities. It can also happen in the LTACH unit where you are.

The care provided includes medical, emotional, and spiritual support for you and your family as you near the end of your life. Even if your life cannot be extended, comfort can be provided.

Remember, choosing comfort care does not mean that your care team is giving up on you. It is just a different treatment path.

Caregiver impact

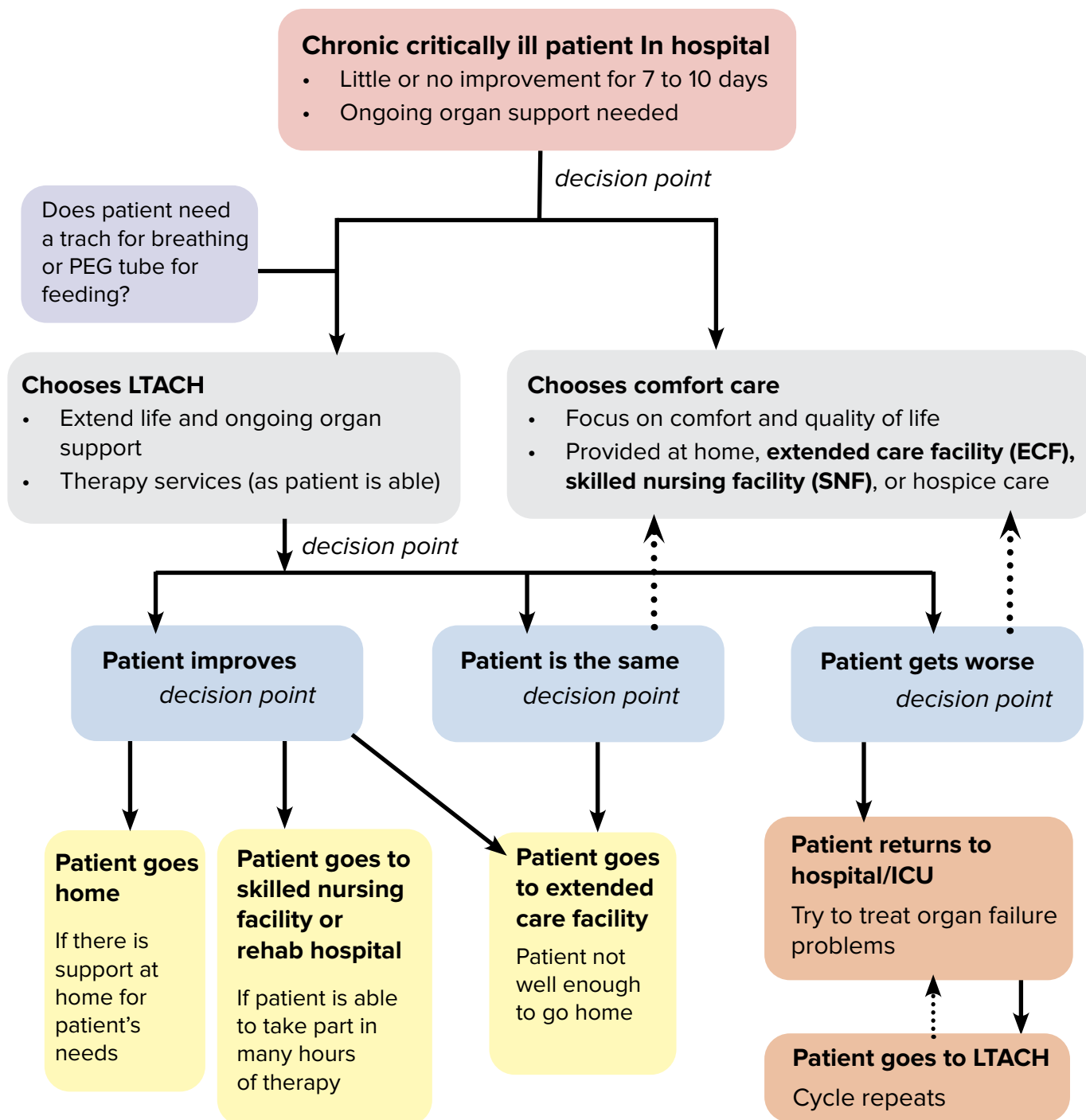
Most caregivers are happy to help their loved one with their condition and care. Others may feel overwhelmed, stressed, and feel a financial strain.

Your illness and decisions for next steps impact your family and caregivers, so they need to be part of the decision with you.

Support for caregivers is discussed later in this book.

Decision points on the care path

When someone is critically ill, there are decision points along the care path, depending on your care goals. Here is a typical path with decision points. Discuss this with your care team, family, and other support people in your life about what choices you may make at these points and why.



4 out of 10 patients discharged to LTACH are back in the hospital within 90 days.

Things to Consider Worksheet

These are some questions or statements that may help you and your family to guide your decisions. This may also help you to know what other questions you discuss with your care team.

How do I want to live the rest of my life?

What are my hopes and fears?

What are my concerns?

Questions I have for my care team about the LTACH.

Questions I have for my care team about comfort care or hospice.

What questions do I have for my family?

What are my family members' thoughts and feelings?

What other information do I need to make my decision?

Questions I have

For my doctor, case manager, or social worker:

For my family and caregiver:

For me:

I want to do everything I can to live as long as I can, even if it means having major surgery and being dependent on 1 or more machines.

Strongly agree Agree Neutral Disagree Strongly disagree

I am at peace with the life I have lived, and feel it is my time.

Strongly agree Agree Neutral Disagree Strongly disagree

The most important thing to me now is:

Palliative Care and Hospice

What are palliative care and hospice?

Palliative care is an area of medicine that helps give you care for quality of life issues. It includes treating symptoms like pain, nausea, or sleep problems. It can also include helping you and your family and friends to:

- Understand your illness better.
- Talk more openly about your feelings.
- Decide what treatments you want or don't want.
- Communicate better with your doctors, nurses, and each other.



Hospice care is a type of palliative care. But it is for people who are near the end of life.

What kinds of care are involved?

- Palliative care: This treatment helps you feel better physically, emotionally, and spiritually while doctors also treat your illness. Your care may include pain relief, counseling, or nutrition advice.
- Hospice care: The goal of this type of care is to help you feel better. And it can help you get the most out of the time you have left. But you no longer get treatment to try to cure your illness.

When does care happen?

- Palliative care: This care can happen at any time during a serious illness. You don't have to be near death to get this care.
- Hospice care: In most cases, you can choose hospice care when your doctor believes that you have no more than about 6 months to live.

Where does the care happen?

- Palliative care: This care often happens in hospitals or long-term care facilities like nursing homes. It can take place wherever you are treated, even in your home.
- Hospice care: Hospice care is often done in the person's home, but it could also be a nursing home, retirement center, hospice center, hospital, and other places.

Who provides the care?

- Palliative care: There are doctors and nurses who specialize in this field, but your own doctor may also give some of this care. There are many other experts who may help you, including social workers, counselors, therapists, and nutrition experts.
- Hospice care: In hospitals, hospice centers, and other facilities, care is given by doctors, nurses, and others who are trained in hospice care. In the home, a family member is often the main caregiver. But the family member gets help from care experts. They are on call 24 hours a day.

How palliative care can help

Good communication is a large part of palliative care. Your palliative care providers will encourage you to listen to your feelings and to talk about what is most important to you. They will also try to explain things in ways you can understand. Then they will work with your primary care doctor to make sure that your care is meeting your goals, such as managing symptoms or making plans for the future.

You might talk about many things during a palliative care visit, such as:

- **Treatment**

You get to decide how well your treatment is working and if you want to continue it. Maybe you really want to see your grandson graduate, so you decide to keep having treatment even though it makes you feel sick. Or maybe you prefer to stop or limit treatment because you would rather focus on the quality of your life rather than the length of your life.

- **Pain and treatment side effects**

You may think you have to live with side effects or pain. But a palliative care doctor can often prescribe medicines to help. There are also non-medicine ways to manage pain. All types of treatment have pros and cons. But you can work with your doctor to find the right mix of medicines for you.

- **Emotional and social challenges**

A palliative care team can help you and your family and friends talk about feelings and solve problems. Palliative care team members may talk to you about your feelings about living with a serious illness. They may help you work through stressful family situations. They might even be able to help you arrange transportation or find resources to help pay for medicines.

- **Spiritual support**

Your palliative care team may include a spiritual adviser or chaplain. Spiritual advisers can help you with questions that don't have clear answers. It doesn't matter what your spirituality or religion is. Your beliefs will be honored and respected.

- **Goals and lifelong dreams**

Palliative care can help you live well. Even when the end of your life is near, you can still try to live as well as possible. Remember to do the things that you love. For example, if you love to garden, you may still be able to garden if you don't overdo it.

Talk with your palliative care provider about what you feel you still want to do in your life. If you have always wanted to take a dream vacation, they may be able to help you to feel well enough to travel. If you want to reunite with family you have lost touch with, your palliative care provider may be able to help you reach out to them.

- **Hospice care**

When you, your family, or your doctors feel that you may have less than 6 months to live, you may want to think about hospice. This kind of care is given wherever you are, whether that is a nursing home, a hospital, or your own home.

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Getting Support

Support for you

Support has a big impact on your health, your emotions, and how you experience life. Support may not look the same for different people or different conditions. And what you need may change over time.

Here are some ways you can seek support when you have a chronic condition.

- **Work with your health care team.** They can help you make decisions about treatments that are right for you.
- **Get help from a counselor.** A trusted counselor can help you adjust to the changes your condition has on your life.
- **Reach out to others.** Ask for what you need from neighbors, friends, family, and others in your community. Maybe someone could deliver groceries or go with you to appointments.
- **Connect with others who have the same health condition.** Look for a support group. You may find some comfort in knowing others who have similar experiences.
- **Strengthen your social support.** Social support can come from your local community, others who have the same health condition, co-workers, spiritual or religious groups, friends, and family.



Support for caregivers

Caregiving can be stressful, even in the best of situations. Here are some important things you need to find time to do—just for yourself.

- **Take a class on caregiving.** Meet other caregivers and learn new ways to deal with challenging situations. Find classes in your area at Family Caregiver Alliance (www.caregiver.org).
- **Get some exercise.** You may feel better and sleep better if you exercise. Experts say to aim for at least 2½ hours of moderate activity a week.
- **Eat healthy meals and snacks.** When you are busy giving care, it may seem easier to eat fast food than to prepare healthy meals. But healthy meals are easy to prepare, and healthy eating will give you more energy to carry you through each day.
- **Get enough sleep.** If you aren't getting enough sleep at night, take a nap during the day. Plan to get at least 1 full night's rest each week.
- **Make time for an activity you enjoy.** For example, make time to read, listen to music, paint, do crafts, or play an instrument—even if you can only do it for a few minutes a day.
- **Get regular medical checkups.** Even if you have always been healthy, you need to stay healthy. Know about the signs of depression, and watch for them not only in the person you are caring for but also in yourself. If you see signs like lingering sadness, talk with your doctor.
- **Get the support you need.** Helping a loved one with health problems can be emotionally difficult. If you are having trouble coping with your feelings, seek advice and counseling from family members, trained mental health professionals, or spiritual advisors.

Document and Share Your Wishes

It is important to complete advance directives before you are faced with a serious illness or unexpected accident, so you have someone who can make health care decisions for you, if you are unable to speak for yourself.

Your family is a key part of this process. Discuss your options with them. Clearly state your wishes. This will help your family make choices at a difficult time if that should be needed.



Advance health care directive

An advance directive is a legal form you fill out. It says what kinds of medical care you want if you aren't able to make decisions for yourself. It tells your family and your doctor what to do if you're badly hurt or have a serious illness that keeps you from saying what you want.

There are two main types of advance directives:

- **Living will:** A living will (also called a declaration) is a legal document. It states your wishes for medical care if you cannot speak or make decisions for yourself. A medical power of attorney (also called a durable power of attorney for health care) lets you choose a health care agent (also called a health care proxy or health care surrogate).
- **Medical power of attorney:** A medical power of attorney (also called a durable power of attorney for health care) lets you choose a health care agent (also called a health care proxy or health care surrogate). This person can make treatment decisions for you if you can't make them for yourself, not only at the end of your life but any time you cannot speak for yourself.

Learn more at **Writing an Advanced Directive at go.osu.edu/write_AHCD.**

Do-not-resuscitate (DNR) order

A do-not-resuscitate order, or DNR order, is a medical order written by a doctor. It instructs health care providers not to do cardiopulmonary resuscitation (CPR) if a patient's breathing stops or if the patient's heart stops beating. A DNR order allows you to choose whether or not you want CPR in an emergency and it is best to set this up before an emergency happens. It does not have instructions for other treatments, such as pain medicine or nutrition. The doctor writes the order only after talking with the patient (if possible), the proxy, or the patient's family.

Being an organ donor

Some people who are critically ill need an organ transplant to live. But there are a lot more organs needed than are available. Many people choose to donate organs upon their death. If you choose to be a donor, include your wish when you prepare a living will or advance directive. Learn more at lifelineofohio.org in Ohio or at organdonor.gov.

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Tools and Resources

Decision tools

There are tools you can use to give you more ways to think through your options and your feelings about your choices. Here are a few related to advanced care planning.

Each decision point is designed to guide you through a key health decision. Decision points combine medical information with your personal values to help you make wise health decisions.

Tools to help with key medical care decisions include:

- [Advance Care Planning: Should I Stop Treatment That Prolongs My Life?](#)
- [Advance Care Planning: Should I Have Artificial Hydration and Nutrition?](#)
- [Advance Care Planning: Should I Receive CPR and Life Support?](#)
- [Advance Care Planning: Should I Stop Kidney Dialysis?](#)

To use these tools, visit go.osu.edu/decision_tools.

Resources

- **Choices – Living Well at the End of Life:** This book provides information about living wills, DNR (do not resuscitate) orders and health care power of attorney. The health care decision forms used by Ohio are also included in this book. Visit go.osu.edu/pted1596.
- **Caregiver Support: Talking About Advance Care Planning:** Discusses questions to ask the doctor, things to talk about with your loved one, and other related information. It includes videos. Visit go.osu.edu/caregiver_support.
- **Caregiver Wellness Book:** Developed for Dodd Rehabilitation Hospital, this book covers topics that may be helpful for any caregiver. It includes strategies to take care of yourself, self assessment, coping, stress, health tips, nutrition, and relaxation. Visit go.osu.edu/pted3912.
- **Chronic Illness: Help for Caregivers:** Discusses tips for helping your loved one and taking care of yourself. Visit go.osu.edu/chronic_illness.
- **Long-Term Care Choices:** This explains what long-term care is, types of services, and types of facilities. Videos are also included. Visit long-term_care_choices
- **Relaxation Techniques:** Learn relaxation techniques to reduce stress and anxiety. Try different techniques to find what works best for you. Practice these techniques often and your ability to relax will improve over time. Visit wexnermedical.osu.edu/integrative-health/resources.
- **Managing Stress:** Tools to understand, manage, and avoid stress through relaxation practices, mindfulness, yoga, breathing exercises, and more. Visit go.osu.edu/stress_less.



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