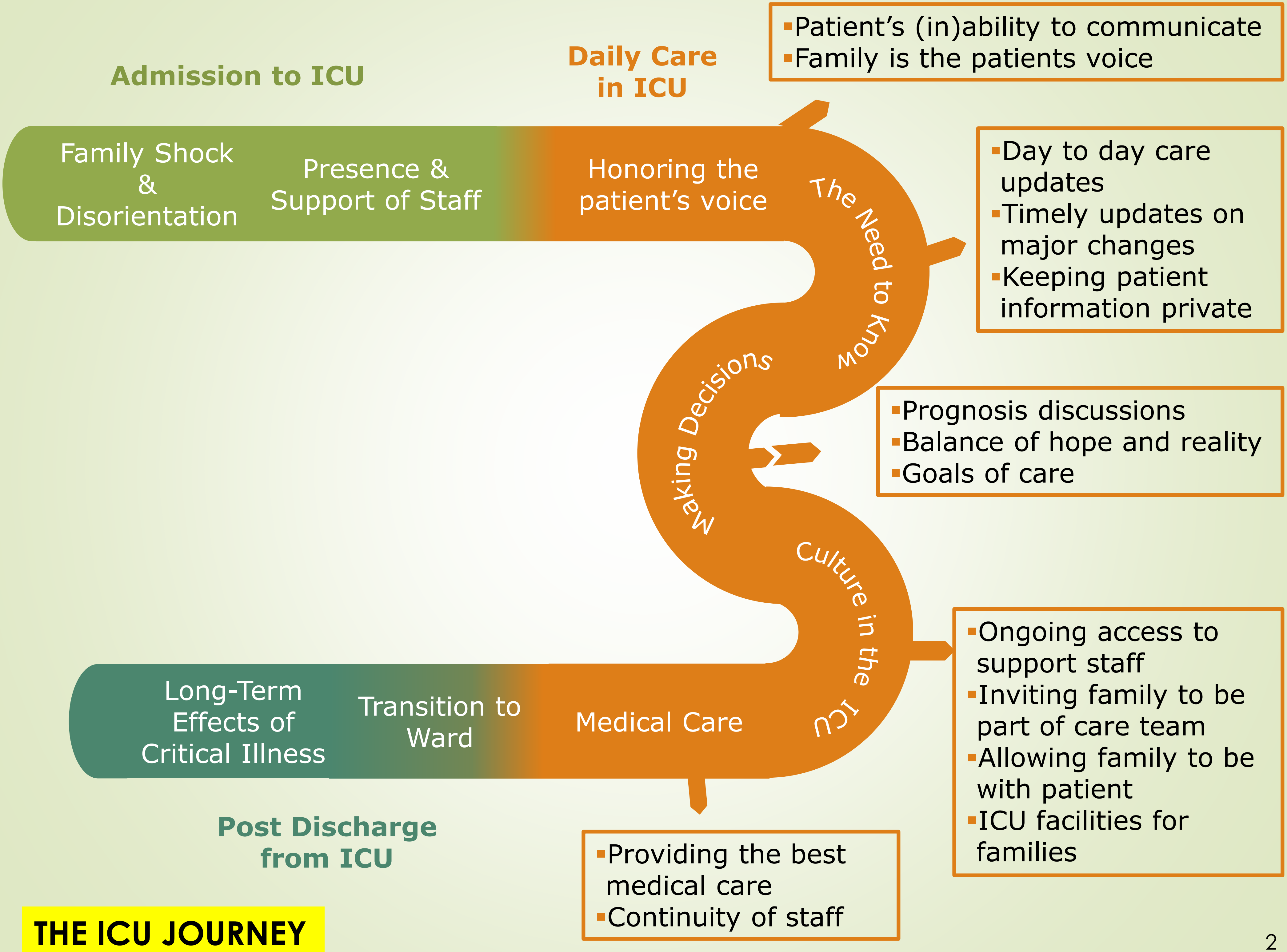
A RESEARCH STUDY TO UNDERSTAND PATIENT & FAMILY EXPERIENCES WITH CRITICAL CARE

The ICU Journey … characterized by many themes in 3 phases

Adapted from: Gill M, Boulton D, Oswell D, et al. Understanding patient and family experiences in the daily care of critically ill patients. Patient & Community Engagement Research (PaCER) Report 2014.

Created by: Peter Oxland
May 31, 2020

THE ICU JOURNEY



Admission to ICU

Family Shock
&
Disorientation

Presence &
Support of Staff

Daily Care in ICU

Honoring the patient's voice

- Patient's (in)ability to communicate
- Family is the patients voice

The Need to Know

- Day to day care updates
- Timely updates on major changes
- Keeping patient information private

Making Decisions

- Prognosis discussions
- Balance of hope and reality
- Goals of care

Culture in the ICU

- Ongoing access to support staff
- Inviting family to be part of care team
- Allowing family to be with patient
- ICU facilities for families

Medical Care

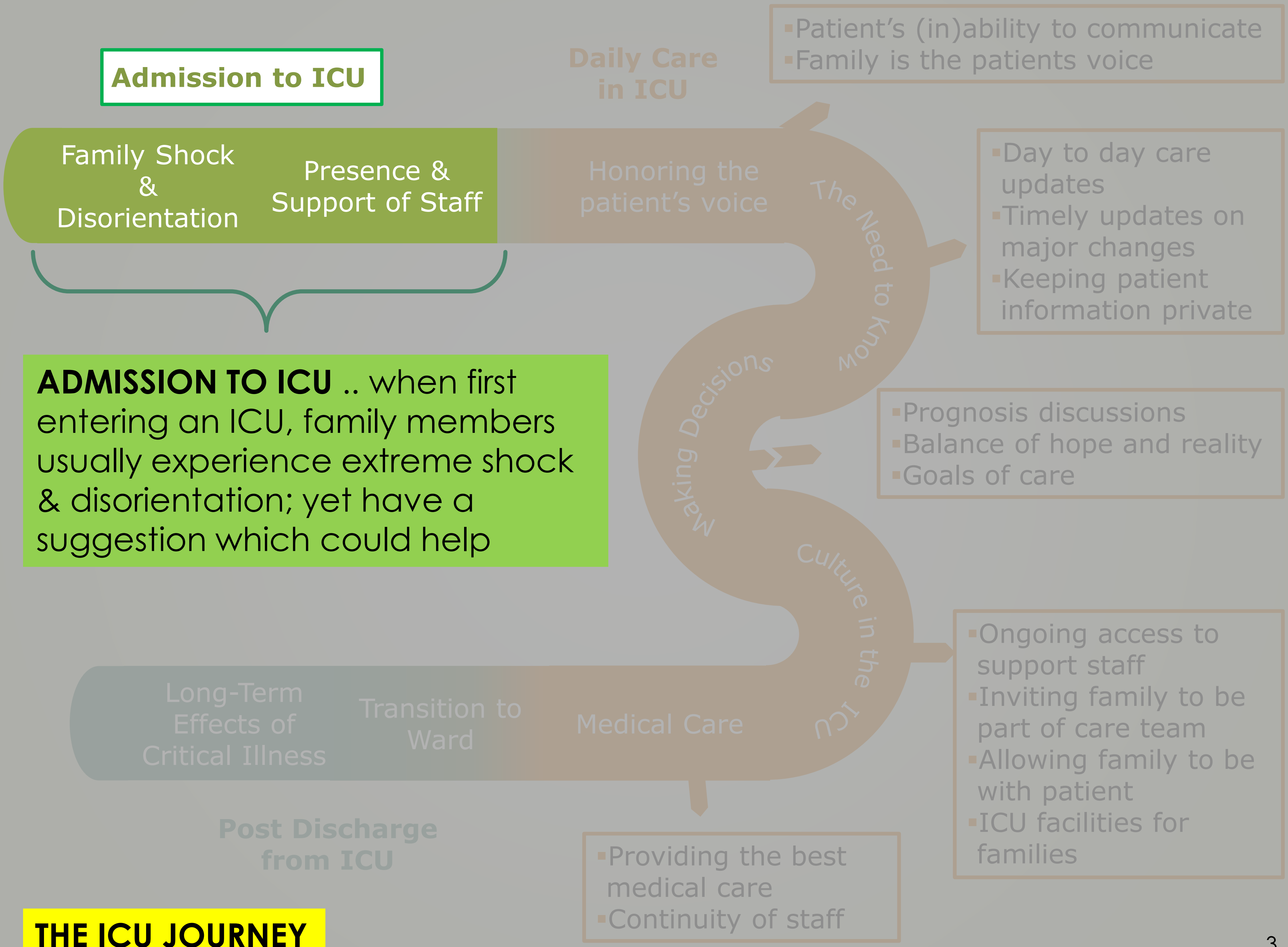
- Providing the best medical care
- Continuity of staff

Post Discharge from ICU

Transition to Ward

Long-Term Effects of Critical Illness

THE ICU JOURNEY



Admission to ICU

Family Shock
&
Disorientation

Presence &
Support of Staff

ADMISSION TO ICU .. when first entering an ICU, family members usually experience extreme shock & disorientation; yet have a suggestion which could help

Daily Care in ICU

- Patient's (in)ability to communicate
- Family is the patients voice

Honoring the patient's voice

The Need to Know

- Day to day care updates
- Timely updates on major changes
- Keeping patient information private

Making Decisions

- Prognosis discussions
- Balance of hope and reality
- Goals of care

Culture in the ICU

- Ongoing access to support staff
- Inviting family to be part of care team
- Allowing family to be with patient
- ICU facilities for families

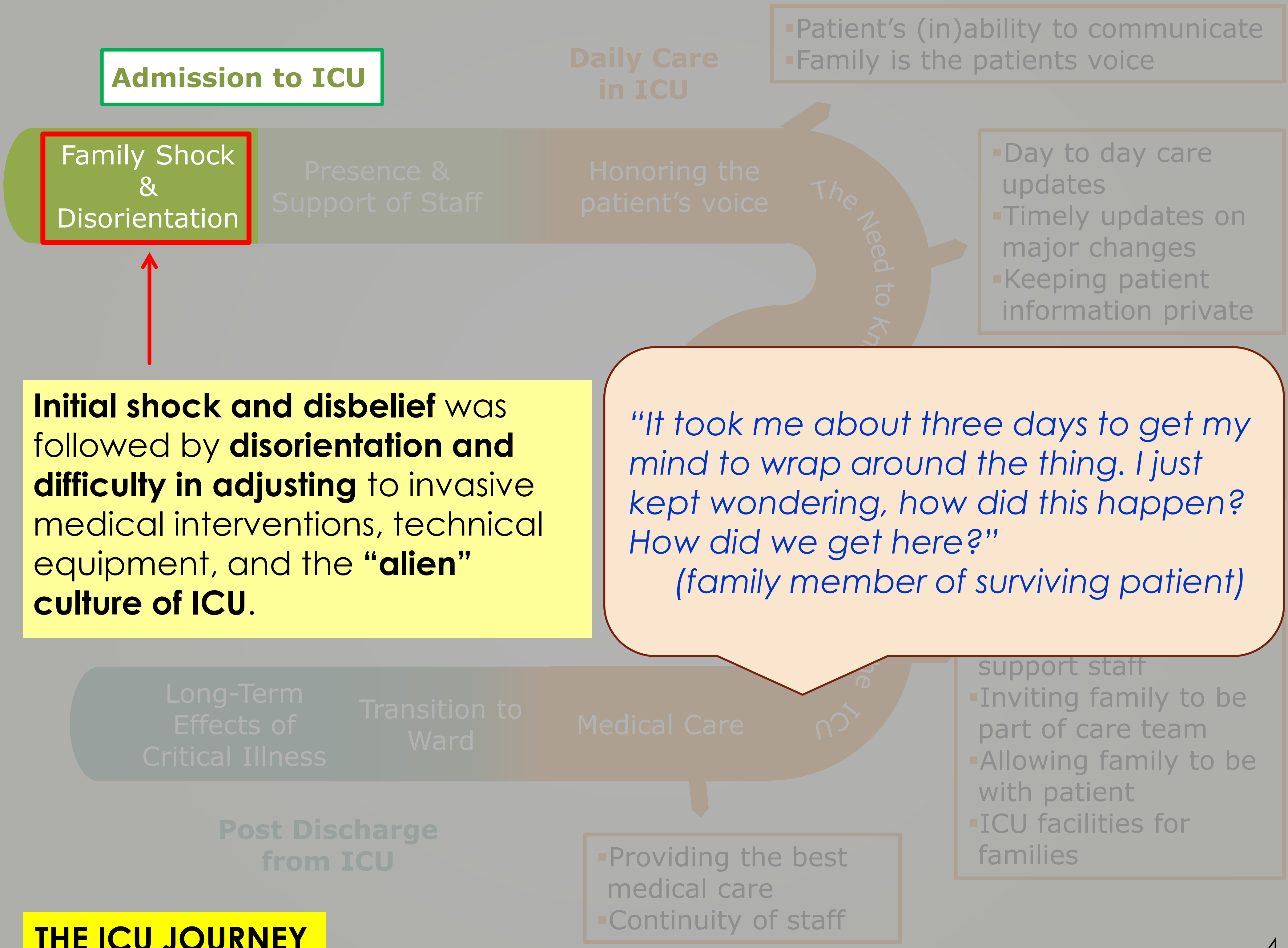
Medical Care

- Providing the best medical care
- Continuity of staff

Transition to Ward

Long-Term Effects of Critical Illness

Post Discharge from ICU



Admission to ICU

Family Shock & Disorientation

Presence & Support of Staff

Honoring the patient's voice

Daily Care in ICU

- Patient's (in)ability to communicate
- Family is the patients voice

The Need to Kn

- Day to day care updates
- Timely updates on major changes
- Keeping patient information private

Initial shock and disbelief was followed by **disorientation and difficulty in adjusting** to invasive medical interventions, technical equipment, and the **"alien" culture of ICU**.

"It took me about three days to get my mind to wrap around the thing. I just kept wondering, how did this happen? How did we get here?"
(family member of surviving patient)

support staff
- Inviting family to be part of care team
- Allowing family to be with patient
- ICU facilities for families

e ICU

Long-Term Effects of Critical Illness

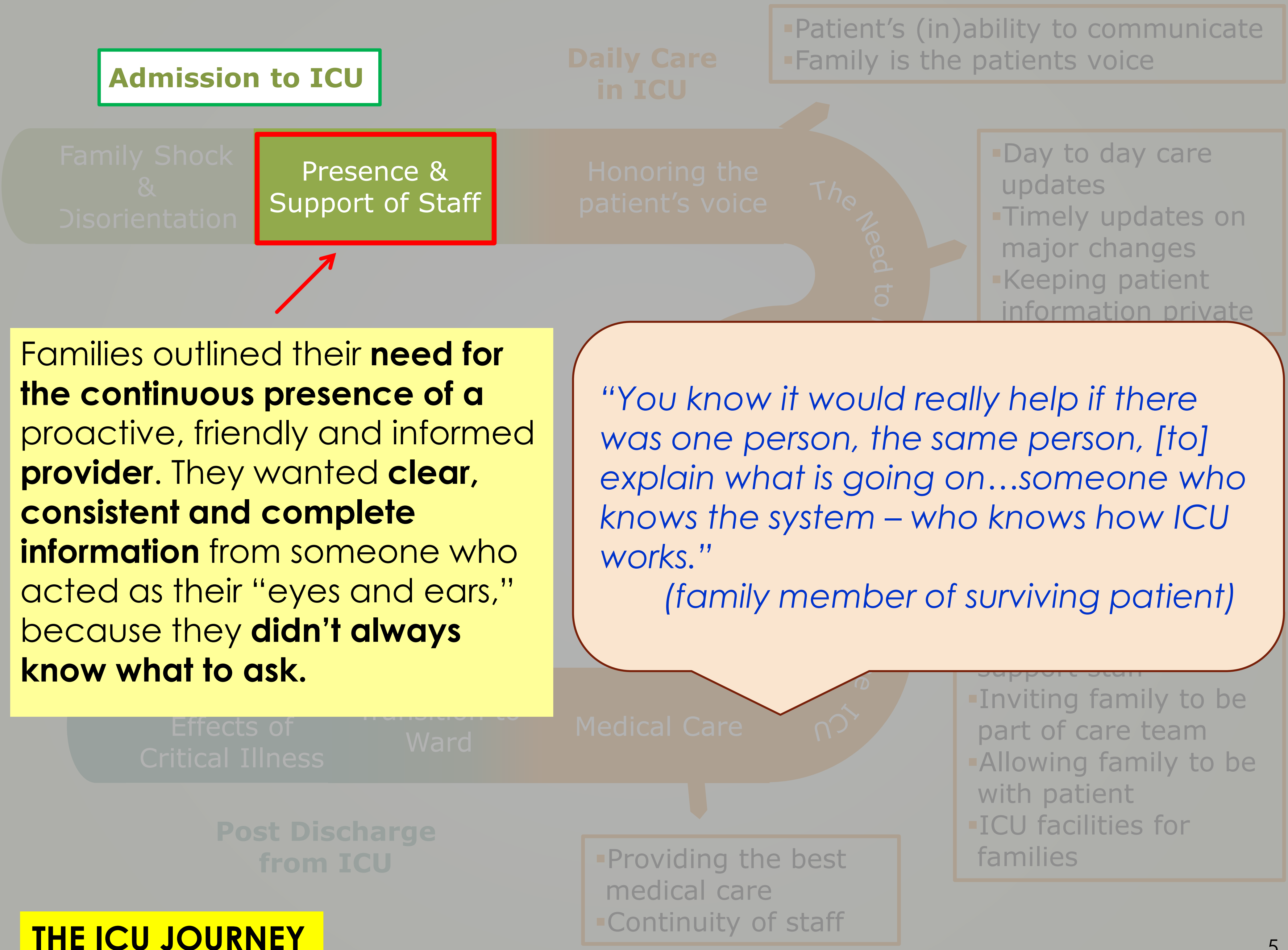
Transition to Ward

Medical Care

Post Discharge from ICU

- Providing the best medical care
- Continuity of staff

THE ICU JOURNEY



Admission to ICU

Family Shock & Disorientation

Presence & Support of Staff

Honoring the patient's voice

Daily Care in ICU

- Patient's (in)ability to communicate
- Family is the patients voice

The Need to

- Day to day care updates
- Timely updates on major changes
- Keeping patient information private

support staff

- Inviting family to be part of care team
- Allowing family to be with patient
- ICU facilities for families

Effects of Critical Illness

Transition to Ward

Medical Care

ICU

Post Discharge from ICU

- Providing the best medical care
- Continuity of staff

Families outlined their **need for the continuous presence of a** proactive, friendly and informed **provider**. They wanted **clear, consistent and complete information** from someone who acted as their "eyes and ears," because they **didn't always know what to ask.**

"You know it would really help if there was one person, the same person, [to] explain what is going on…someone who knows the system – who knows how ICU works."

(family member of surviving patient)

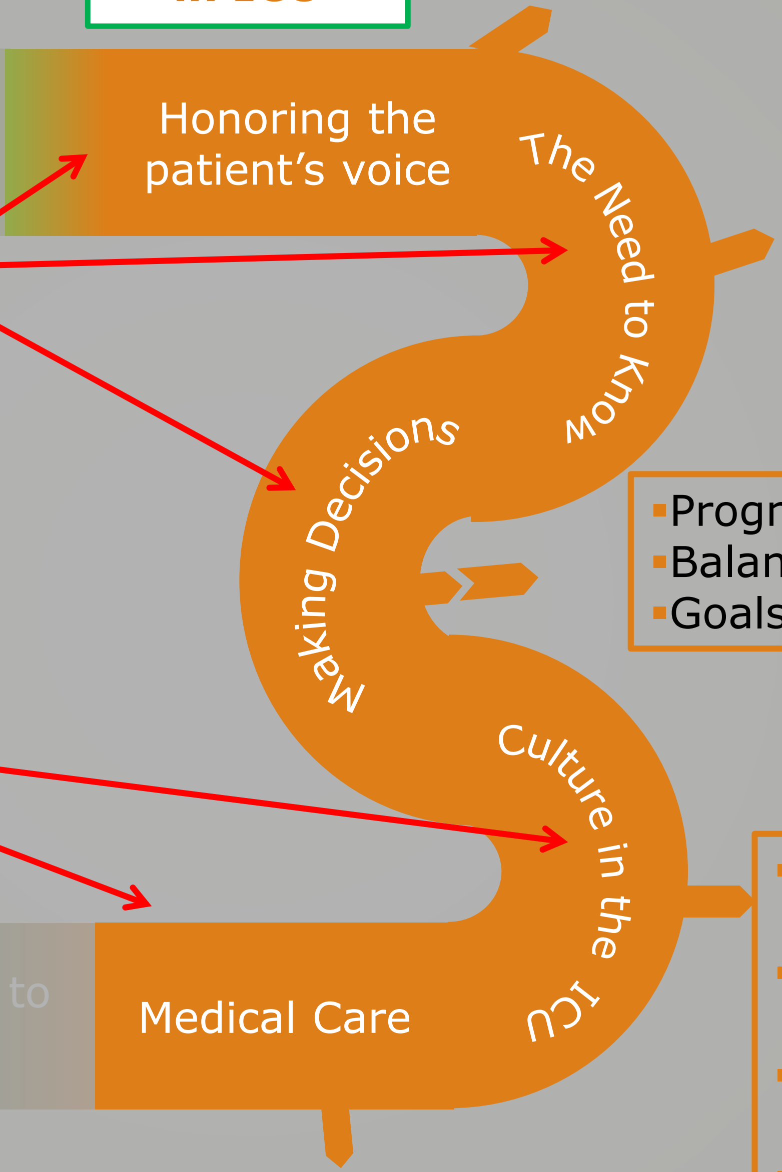
THE ICU JOURNEY

DAILY CARE IN ICU .. family members in ICU need to be updated, listened to and involved in decisions to feel well cared for, respected and valued

Daily Care in ICU

Comfort and Trust *between patients, families and ICU providers, changes and is influenced by:*

Appropriate Interactions *of ICU providers with patients and families enhance patient and family centred care, and are influenced by:*



- Patient's (in)ability to communicate
- Family is the patients voice

- Day to day care updates
- Timely updates on major changes
- Keeping patient information private

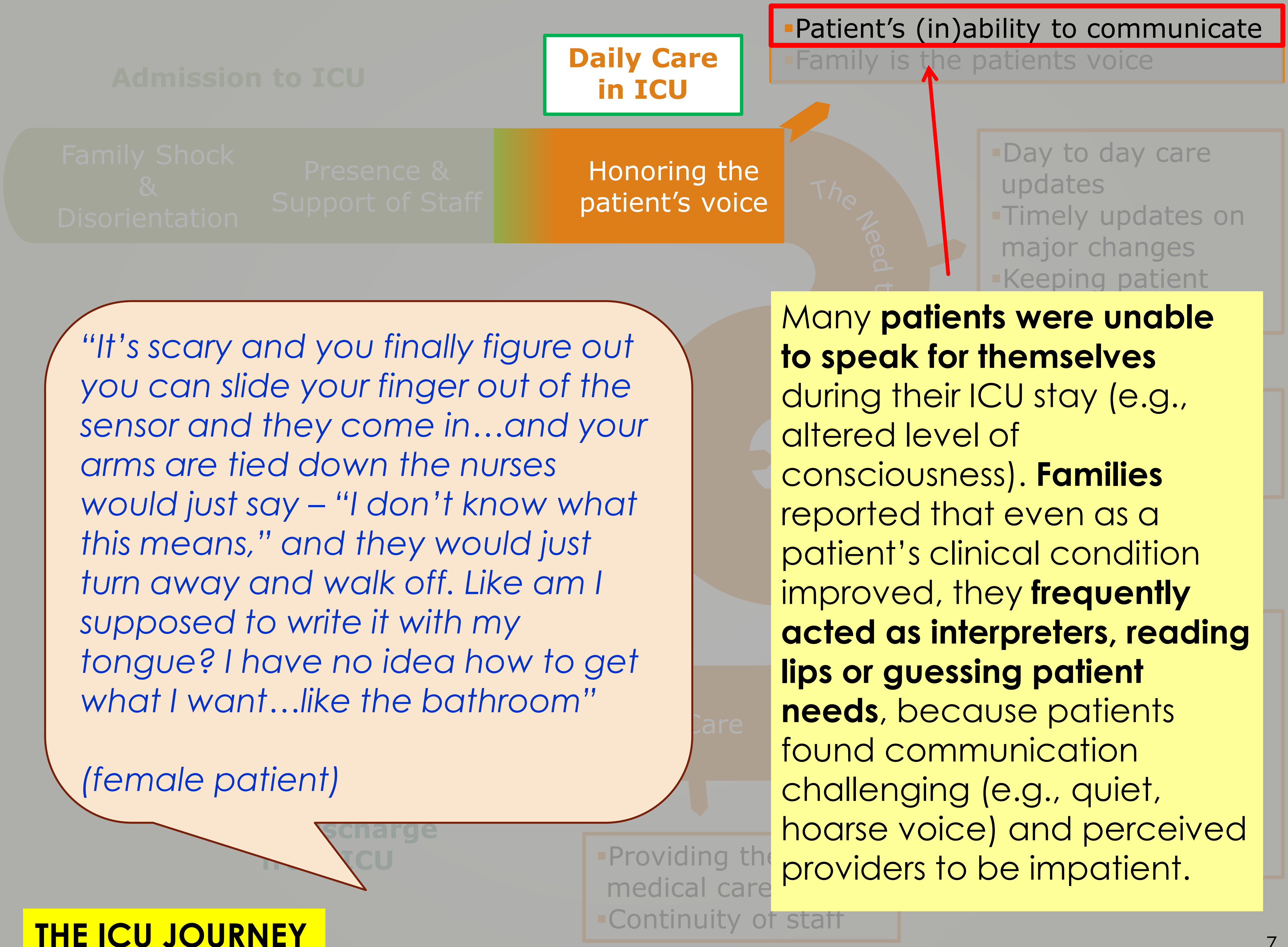
- Prognosis discussions
- Balance of hope and reality
- Goals of care

- Ongoing access to support staff
- Inviting family to be part of care team
- Allowing family to be with patient
- ICU facilities for families

- Providing the best medical care
- Continuity of staff

These themes were described as integral for a '**community of caring**'

THE ICU JOURNEY



- Patient's (in)ability to communicate
- Family is the patients voice

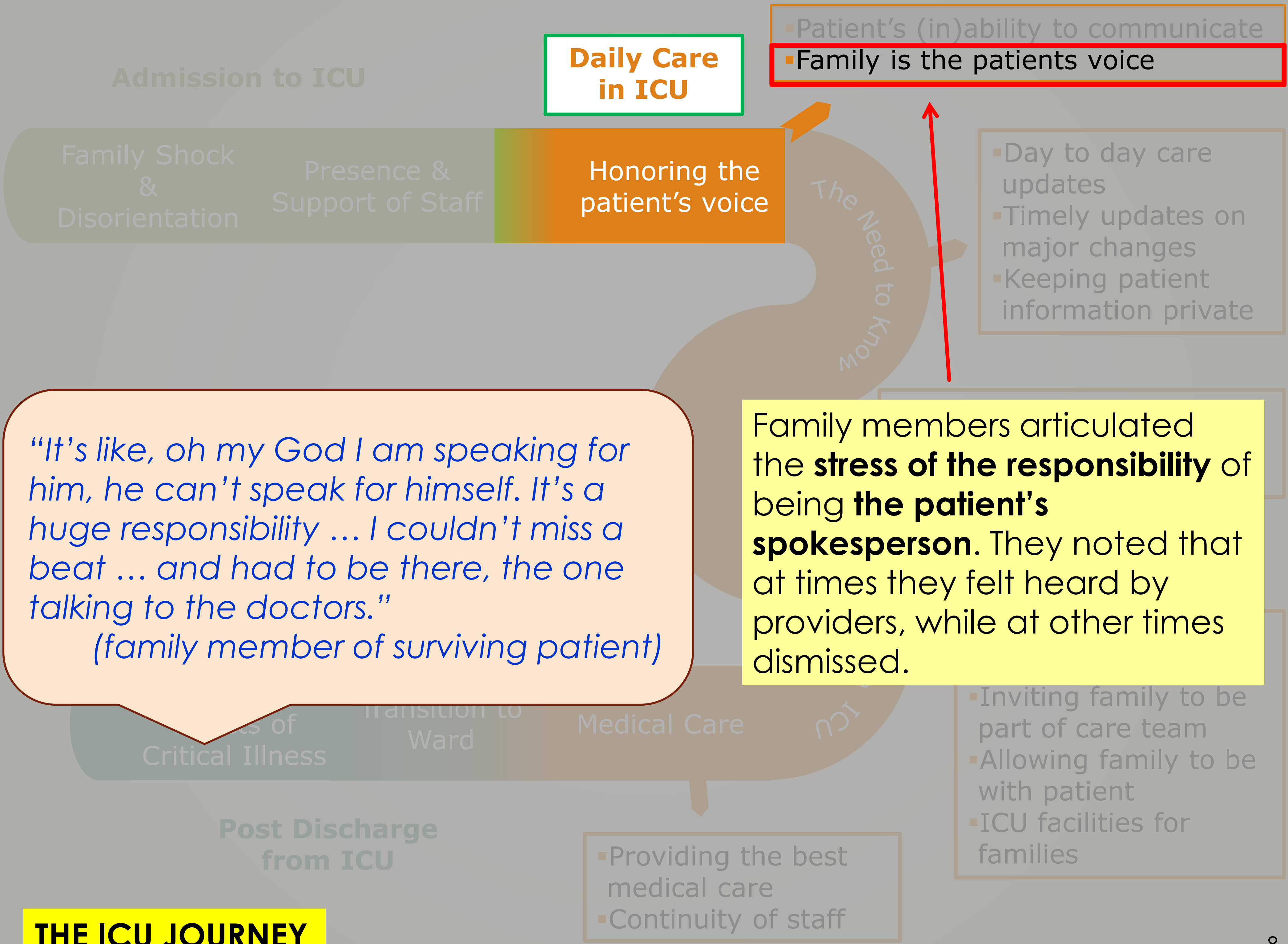
- Day to day care updates
- Timely updates on major changes
- Keeping patient

- Providing the
medical care
- Continuity of staff

> *"It's scary and you finally figure out you can slide your finger out of the sensor and they come in…and your arms are tied down the nurses would just say – "I don't know what this means," and they would just turn away and walk off. Like am I supposed to write it with my tongue? I have no idea how to get what I want…like the bathroom"*
>
> *(female patient)*

Many **patients were unable to speak for themselves** during their ICU stay (e.g., altered level of consciousness). **Families** reported that even as a patient's clinical condition improved, they **frequently acted as interpreters, reading lips or guessing patient needs**, because patients found communication challenging (e.g., quiet, hoarse voice) and perceived providers to be impatient.

THE ICU JOURNEY



“It’s like, oh my God I am speaking for him, he can’t speak for himself. It’s a huge responsibility … I couldn’t miss a beat … and had to be there, the one talking to the doctors.”
(family member of surviving patient)

Family members articulated the **stress of the responsibility** of being **the patient’s spokesperson**. They noted that at times they felt heard by providers, while at other times dismissed.

THE ICU JOURNEY

Admission to ICU

Daily Care in ICU

- Patient's (in)ability to communicate
- Family is the patients voice

Family Shock

…oring the …t's voice

- Day to day care updates
- Timely updates on major changes
- Keeping patient information private

- Prognosis discussions

"We always knew what was going on … we knew his condition daily … it was always clear as to what they were doing."
(family member of deceased patient)

"They didn't tell us a lot of what was going on … I wanted to know, hear the truth, options, alternatives not just 'it's day to day'. That means nothing."
(family member of patient)

The **degree** to which family members were **informed about patient status varied enormously** and ranged from being given little or no information to receiving substantial information. Families who had **good knowledge** of day-to-day (and even moment-by-moment) activities appeared to be **much more comfortable** in ICU and **more trusting of the staff** that those who had **less knowledge/information**.

…iness

Ward

…ical C…

Post Discharge from ICU

- Provid… medica…
- Contin…

THE ICU JOURNEY

THE ICU JOURNEY

Admission to ICU

Daily Care in ICU

- Patient's (in)ability to communicate
- Family is the patients voice

Family Shock &

Presence & Support of Staff

Honoring the patient's voice

The Need to Know

- Day to day care updates
- **Timely updates on major changes**
- Keeping patient information private

- Prognosis discussions
- Balance of hope and reality
- Goals of care

> *"I felt like I missed it. I felt like I should have been there … I left the hospital and they didn't phone me and it was such a major change."*
> *(family member of surviving patient)*

Families expressed a great **need to have timely updates** on the patient. Those who were kept **well-informed** were **more trusting** of providers. Some families found it **difficult to leave the hospital** because they **lacked trust** that they would be informed of changes in patient status.

Long-Term Effects of Critical Illness

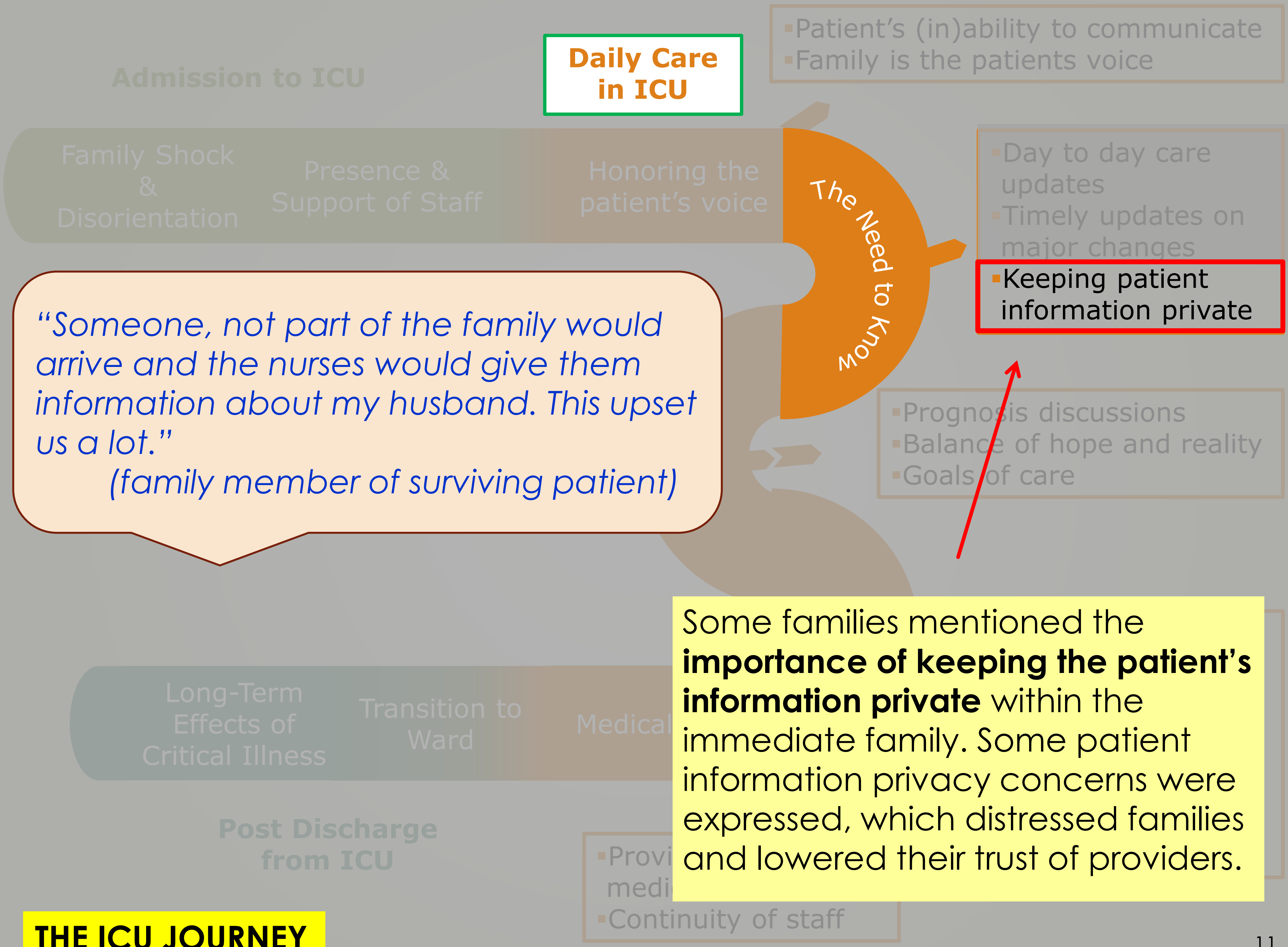
Transition to Ward

Medical

Post Discharge from ICU

- Provi
  medi
- Continuity of staff

Daily Care in ICU



- Patient's (in)ability to communicate
- Family is the patients voice

- Day to day care updates
- Timely updates on major changes
- **Keeping patient information private**

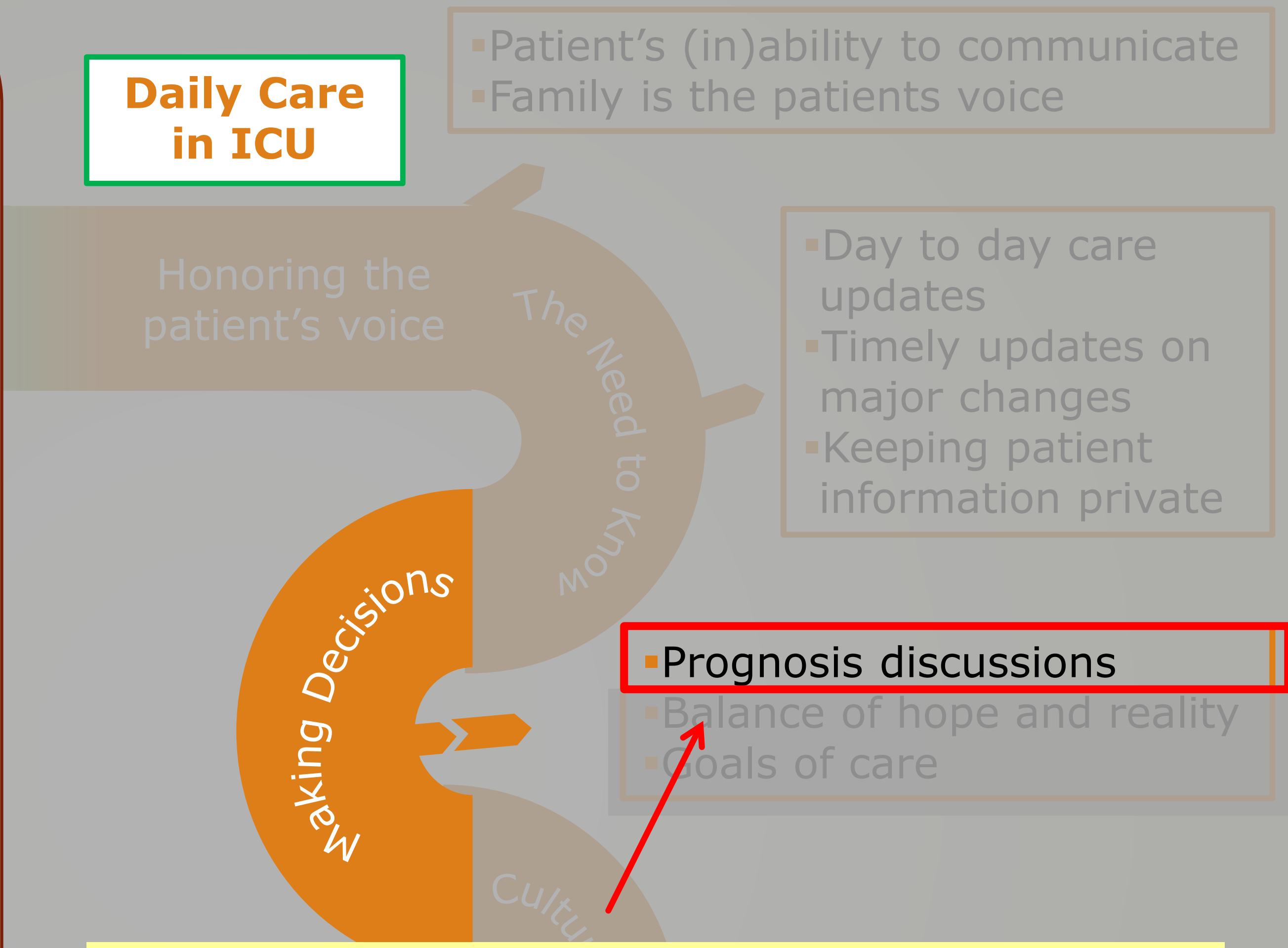
- Prognosis discussions
- Balance of hope and reality
- Goals of care

- Provi
medi
- Continuity of staff

> *"Someone, not part of the family would arrive and the nurses would give them information about my husband. This upset us a lot."*
> *(family member of surviving patient)*

Some families mentioned the **importance of keeping the patient's information private** within the immediate family. Some patient information privacy concerns were expressed, which distressed families and lowered their trust of providers.

Husband: When she got into ICU he [physician] informed me that she probably would have to go to … a nursing home so why not just let [her] go … [she] was in the room and she was awake and she heard it.
Wife: I don't remember it.
Husband: … you don't remember but you heard – you had a shocked look on your face. You couldn't talk because you had the breathing tube but she had a very shocked look on her face. She understood. She didn't want to die. (family member and patient conversation)



Daily Care in ICU

- Patient's (in)ability to communicate
- Family is the patients voice

Honoring the patient's voice

The Need to Know

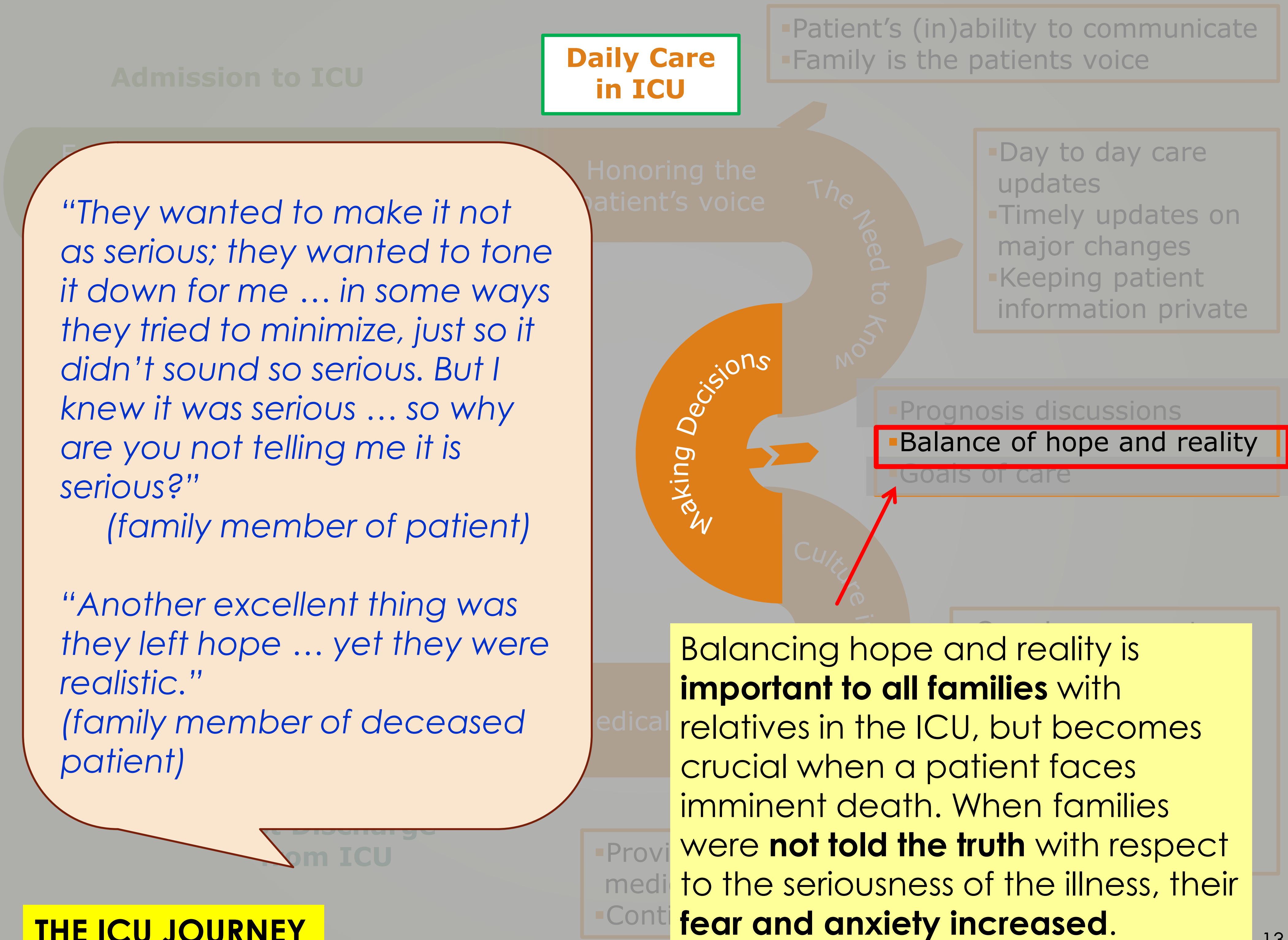
- Day to day care updates
- Timely updates on major changes
- Keeping patient information private

Making Decisions

- **Prognosis discussions**
- Balance of hope and reality
- Goals of care

Prognosis discussions is an **important topic**, regardless **whether the patient lived or died**. They usually take place in family meetings, especially around making decisions around the removal of life support. Sometimes the **time and place of discussions or statements** made was deemed to be **inappropriate**.

THE ICU JOURNEY



"They wanted to make it not as serious; they wanted to tone it down for me … in some ways they tried to minimize, just so it didn't sound so serious. But I knew it was serious … so why are you not telling me it is serious?"
(family member of patient)

"Another excellent thing was they left hope … yet they were realistic."
(family member of deceased patient)

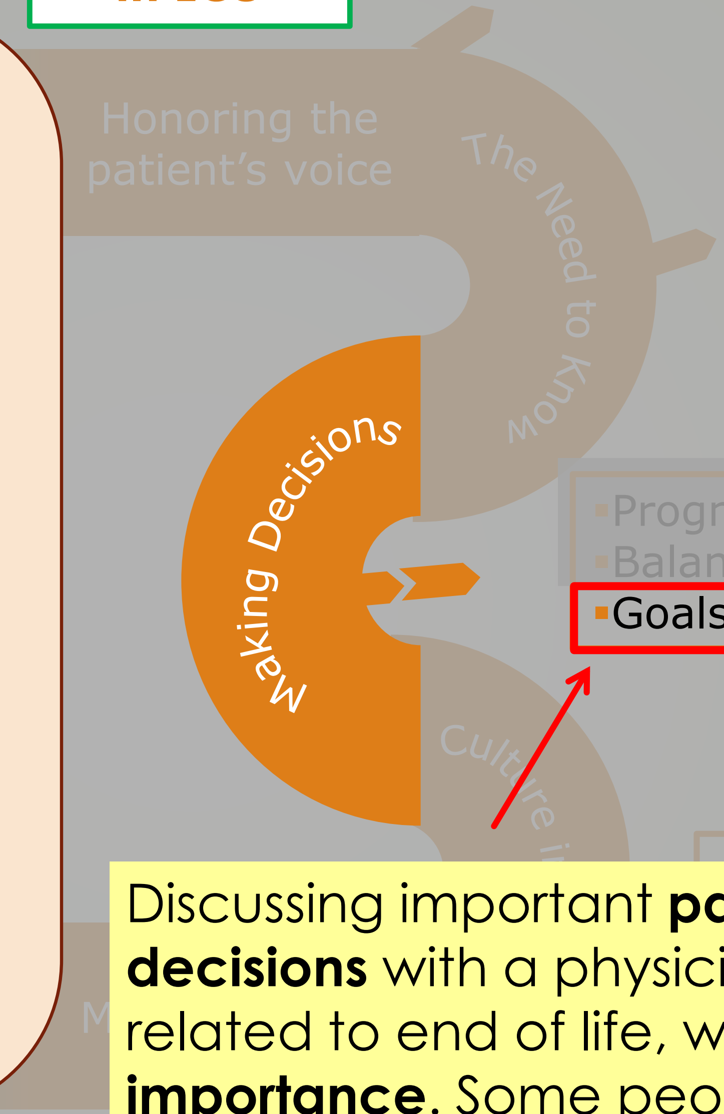
Balancing hope and reality is **important to all families** with relatives in the ICU, but becomes crucial when a patient faces imminent death. When families were **not told the truth** with respect to the seriousness of the illness, their **fear and anxiety increased**.

THE ICU JOURNEY

Admission to ICU

Daily Care in ICU

- Patient’s (in)ability to communicate
- Family is the patients voice



Honoring the patient’s voice

The Need to Know

Making Decisions

Culture i

M

- Day to day care updates
- Timely updates on major changes
- Keeping patient information private

- Prognosis discussions
- Balance of hope and reality
- Goals of care

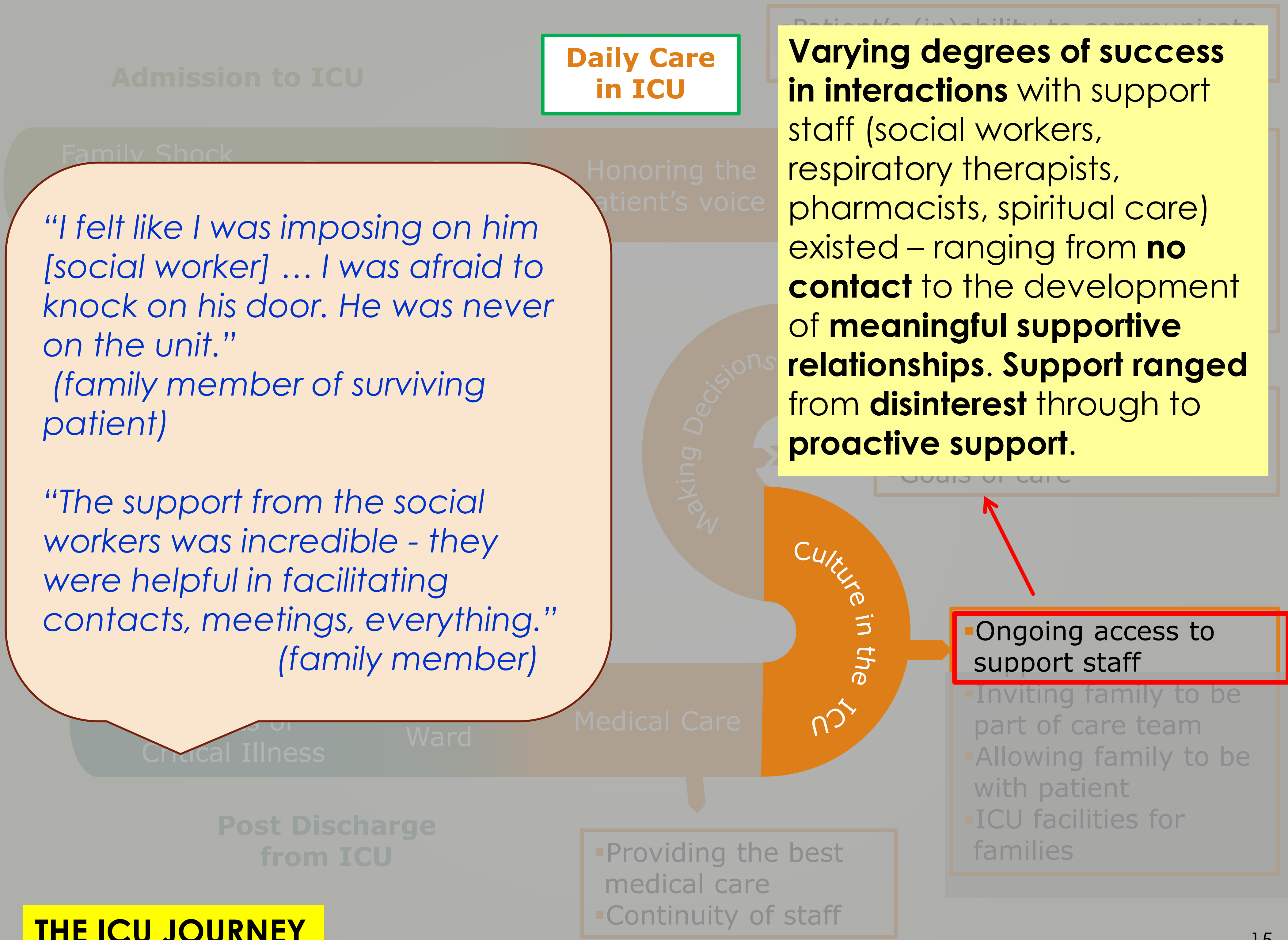
“There was nothing signed. It was all verbal. No one had ever said that he was going to be Do Not Resuscitate.
(family member of surviving patient)

“I am familiar with the Goals of Care and they brought it up right away with our family … you decide which level you want to be at, the doctor signs it and you get it when you go home.”
(family member of patient)

Discussing important **patient care decisions** with a physician, especially related to end of life, was of **utmost importance**. Some people **never heard of Goals of Care designations** - yet were **not upset**, even if the patient died as they felt they had ‘reached the end of the road’. Others were **very upset.**

Post Discharge from ICU

THE ICU JOURNEY



"I felt like I was imposing on him [social worker] … I was afraid to knock on his door. He was never on the unit."
(family member of surviving patient)

"The support from the social workers was incredible - they were helpful in facilitating contacts, meetings, everything."
(family member)

Varying degrees of success in interactions with support staff (social workers, respiratory therapists, pharmacists, spiritual care) existed – ranging from **no contact** to the development of **meaningful supportive relationships**. **Support ranged** from **disinterest** through to **proactive support**.

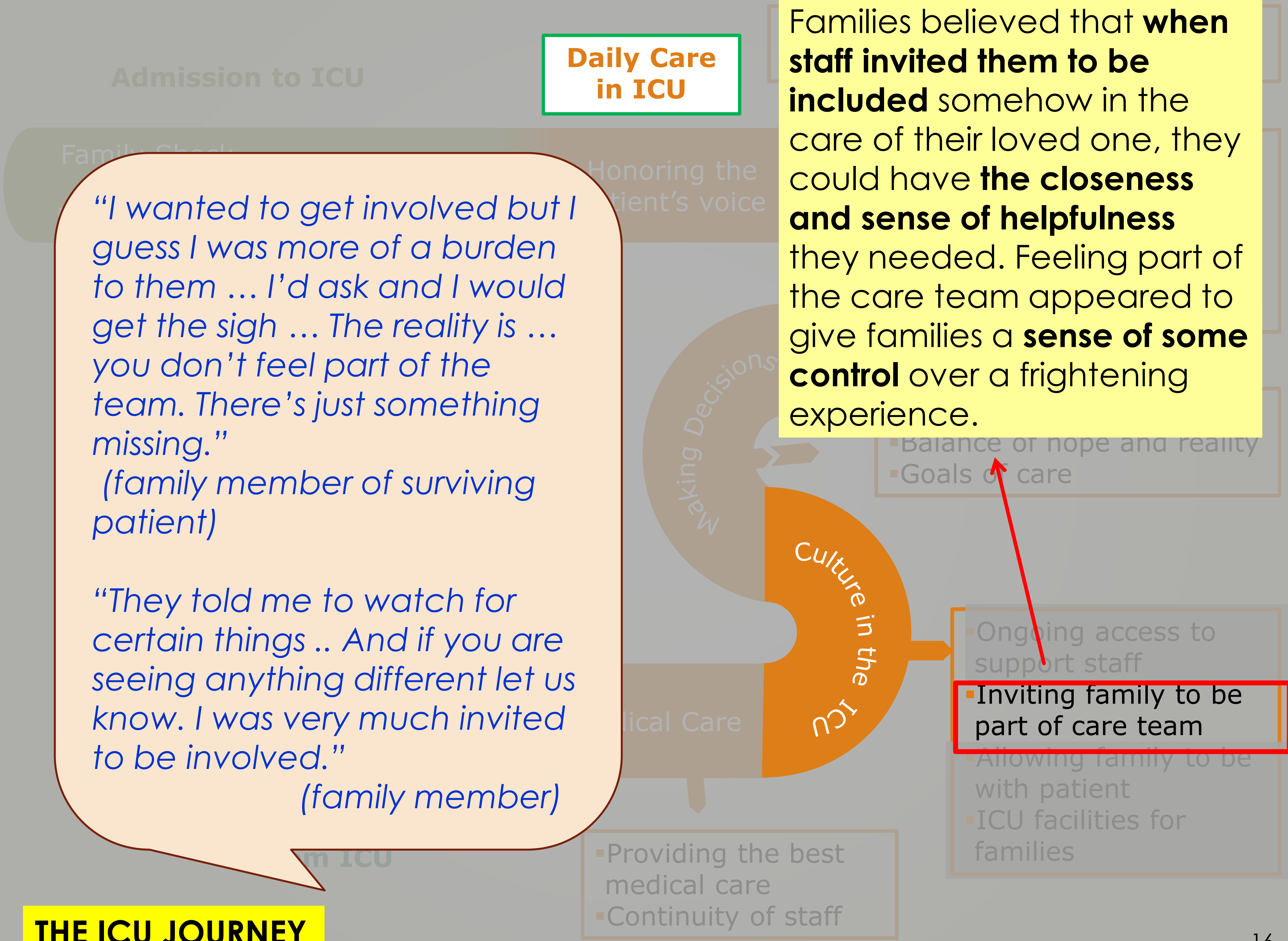
THE ICU JOURNEY

Daily Care in ICU

"I wanted to get involved but I guess I was more of a burden to them … I'd ask and I would get the sigh … The reality is … you don't feel part of the team. There's just something missing."
(family member of surviving patient)

"They told me to watch for certain things .. And if you are seeing anything different let us know. I was very much invited to be involved."
(family member)

Families believed that **when staff invited them to be included** somehow in the care of their loved one, they could have **the closeness and sense of helpfulness** they needed. Feeling part of the care team appeared to give families a **sense of some control** over a frightening experience.



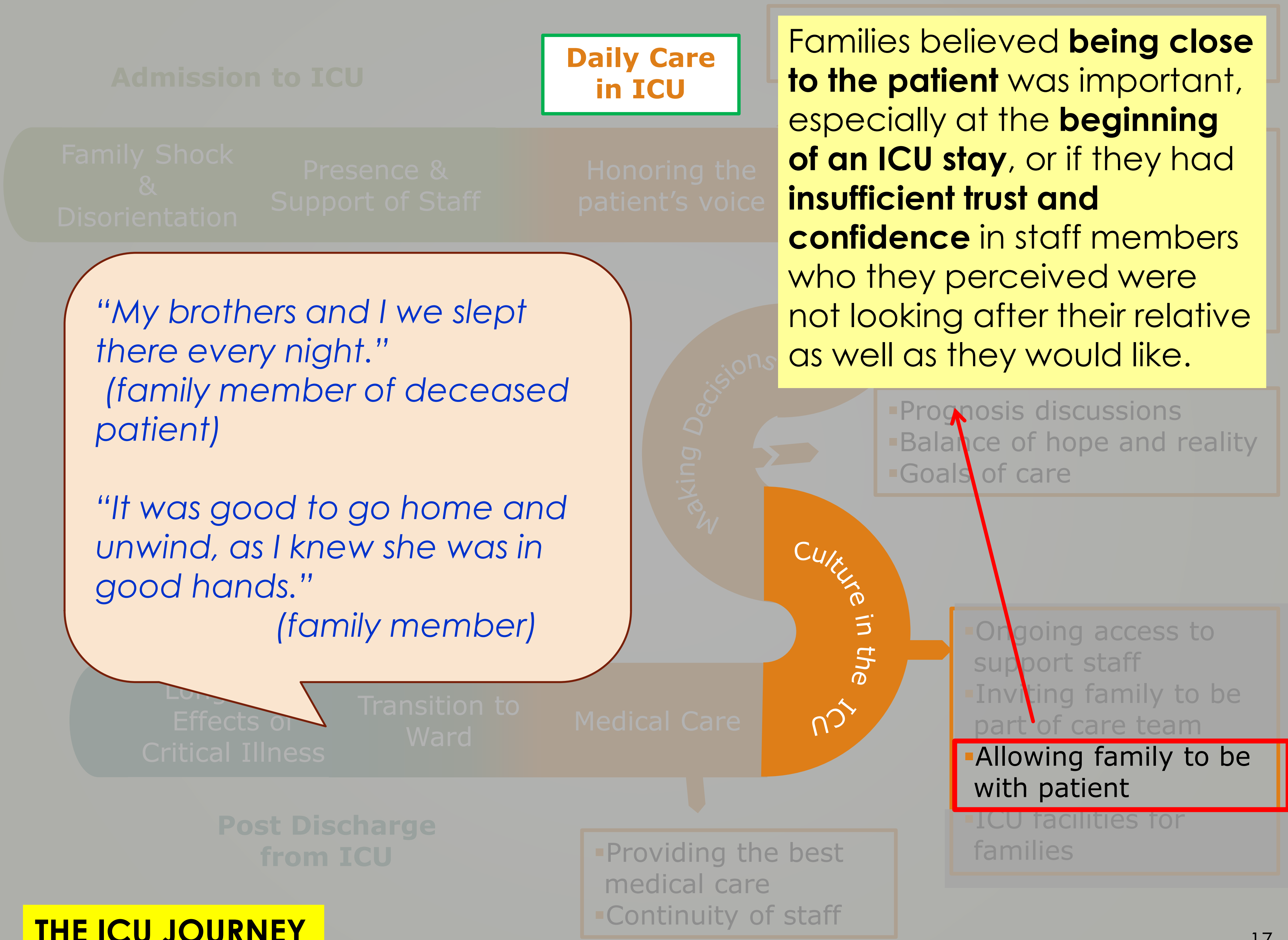
THE ICU JOURNEY

Daily Care in ICU

Families believed **being close to the patient** was important, especially at the **beginning of an ICU stay**, or if they had **insufficient trust and confidence** in staff members who they perceived were not looking after their relative as well as they would like.

"My brothers and I we slept there every night."
(family member of deceased patient)

"It was good to go home and unwind, as I knew she was in good hands."
(family member)



Admission to ICU

Family Shock & Disorientation

Presence & Support of Staff

Honoring the patient's voice

Making Decisions

- Prognosis discussions
- Balance of hope and reality
- Goals of care

Culture in the ICU

- Ongoing access to support staff
- Inviting family to be part of care team
- **Allowing family to be with patient**
- ICU facilities for families

Medical Care

- Providing the best medical care
- Continuity of staff

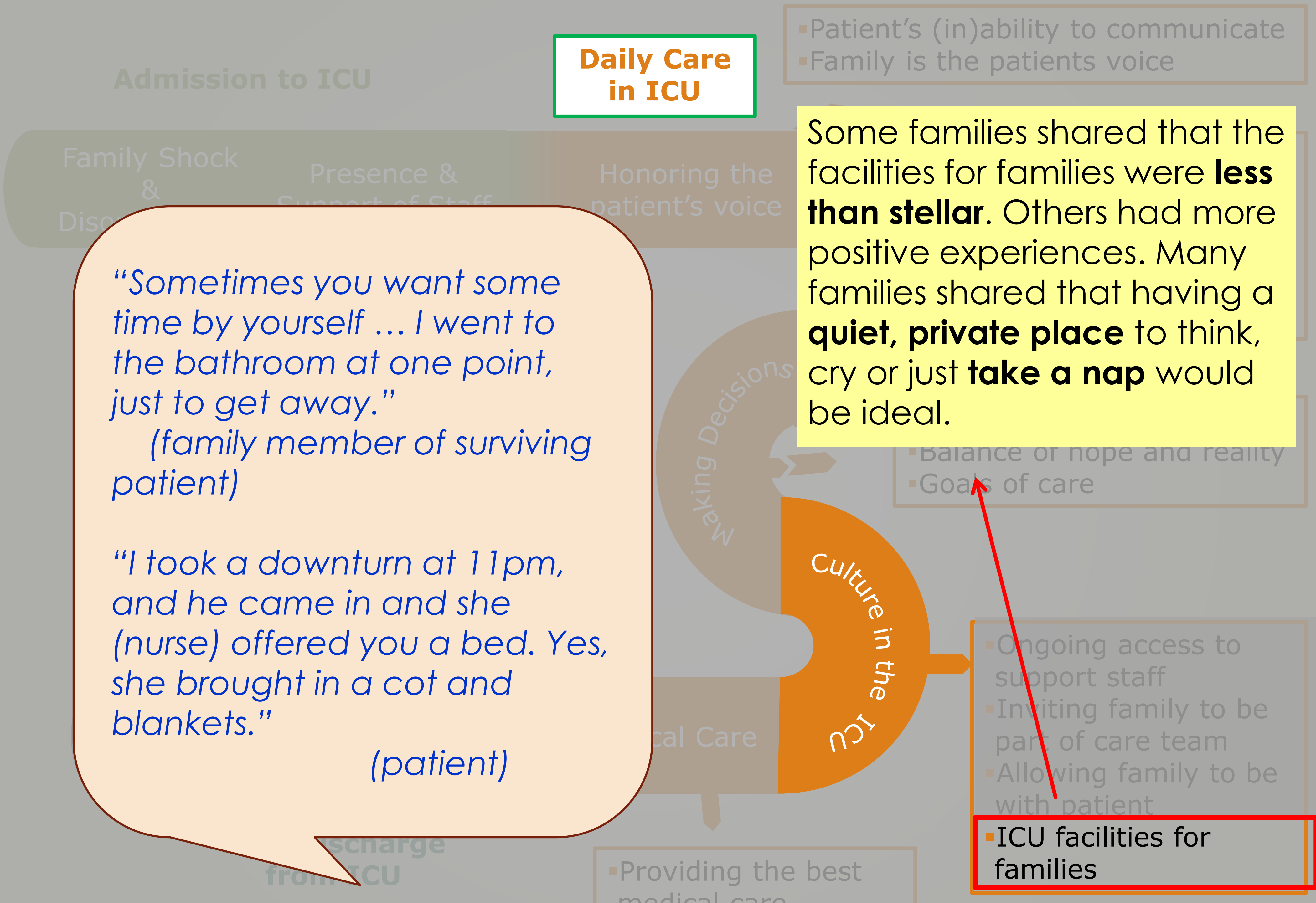
Transition to Ward

Long Effects of Critical Illness

Post Discharge from ICU

THE ICU JOURNEY

Daily Care in ICU



- Patient's (in)ability to communicate
- Family is the patients voice

Some families shared that the facilities for families were **less than stellar**. Others had more positive experiences. Many families shared that having a **quiet, private place** to think, cry or just **take a nap** would be ideal.

- Balance of hope and reality
- Goals of care

"Sometimes you want some time by yourself … I went to the bathroom at one point, just to get away."
(family member of surviving patient)

"I took a downturn at 11pm, and he came in and she (nurse) offered you a bed. Yes, she brought in a cot and blankets."
(patient)

- Ongoing access to support staff
- Inviting family to be part of care team
- Allowing family to be with patient
- ICU facilities for families

- Providing the best medical care
- Continuity of staff

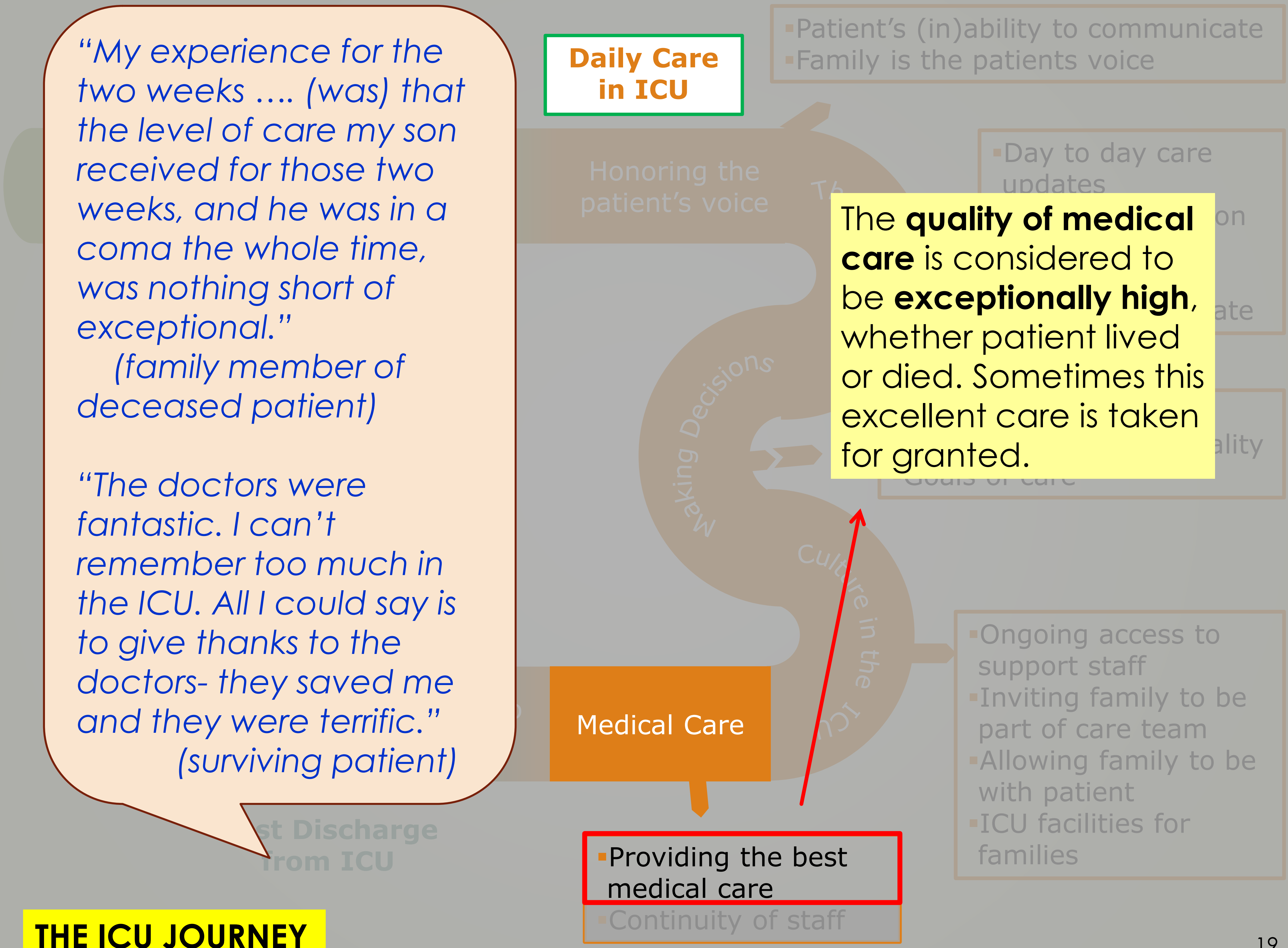
THE ICU JOURNEY

"My experience for the two weeks …. (was) that the level of care my son received for those two weeks, and he was in a coma the whole time, was nothing short of exceptional."

(family member of deceased patient)

"The doctors were fantastic. I can't remember too much in the ICU. All I could say is to give thanks to the doctors- they saved me and they were terrific."

(surviving patient)



Daily Care in ICU

- Patient's (in)ability to communicate
- Family is the patients voice

Honoring the patient's voice

Th

- Day to day care updates

on

ate

ality

Goals of care

Making Decisions

Culture in the ICU

The **quality of medical care** is considered to be **exceptionally high**, whether patient lived or died. Sometimes this excellent care is taken for granted.

- Ongoing access to support staff
- Inviting family to be part of care team
- Allowing family to be with patient
- ICU facilities for families

Medical Care

- Providing the best medical care
- Continuity of staff

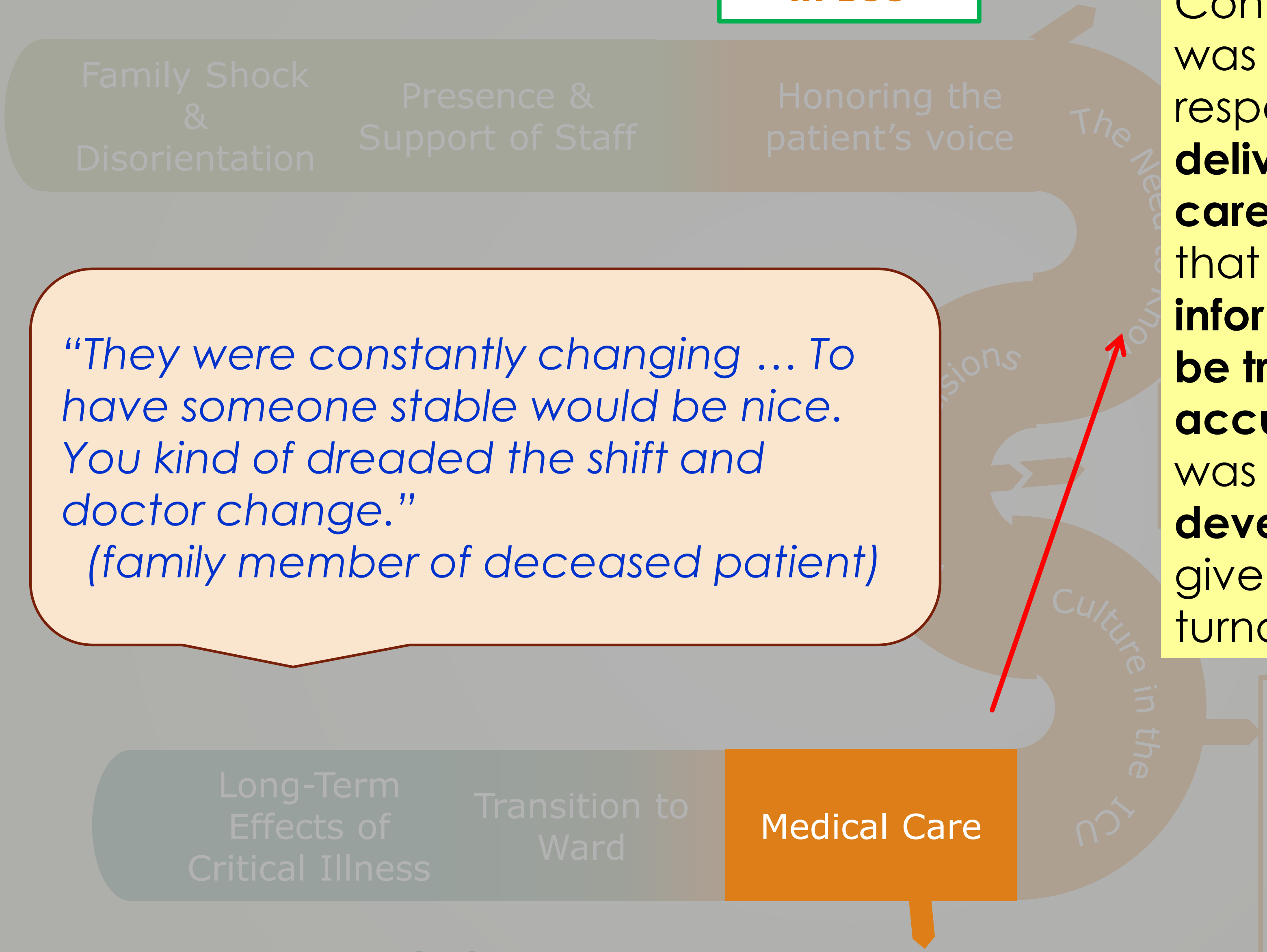
st Discharge from ICU

THE ICU JOURNEY

Admission to ICU

Daily Care in ICU

- Patient’s (in)ability to communicate
- Family is the patients voice



Family Shock & Disorientation

Presence & Support of Staff

Honoring the patient’s voice

Long-Term Effects of Critical Illness

Transition to Ward

Medical Care

Continuity of providers was a **concern** with respect to **smooth delivery of medical care**. Families worried that **patient information might not be transferred accurately**, and felt it was **difficult to develop relationships** given high staff turnover.

> *“They were constantly changing … To have someone stable would be nice. You kind of dreaded the shift and doctor change.”*
> *(family member of deceased patient)*

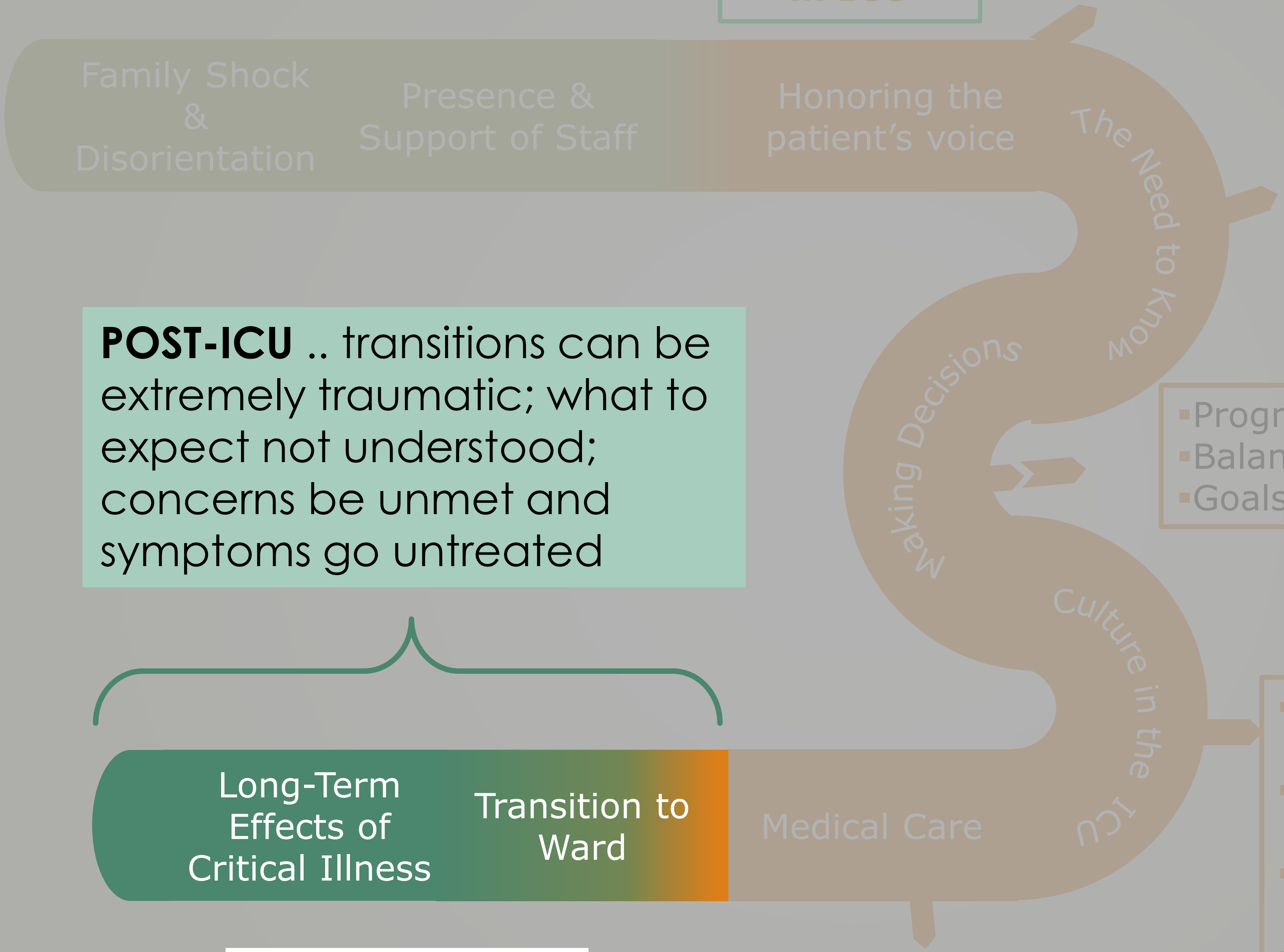
- Ongoing access to support staff
- Inviting family to be part of care team
- Allowing family to be with patient
- ICU facilities for families

Post Discharge from ICU

- Providing the best medical care
- Continuity of staff

THE ICU JOURNEY

THE ICU JOURNEY



Admission to ICU

Daily Care in ICU

- Patient's (in)ability to communicate
- Family is the patients voice

- Day to day care updates
- Timely updates on major changes
- Keeping patient information private

- Prognosis discussions
- Balance of hope and reality
- Goals of care

- Ongoing access to support staff
- Inviting family to be part of care team
- Allowing family to be with patient
- ICU facilities for families

- Providing the best medical care
- Continuity of staff

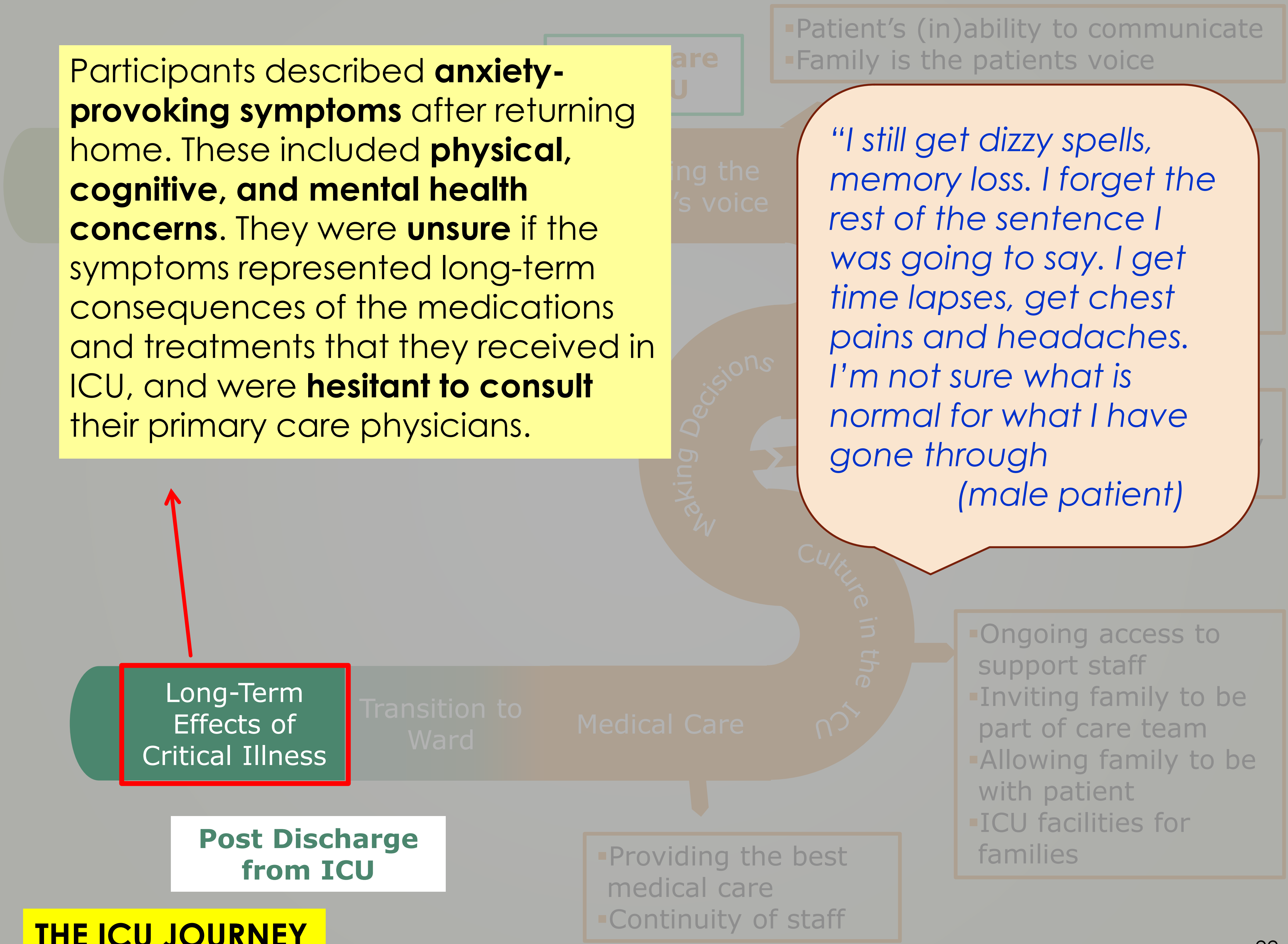
POST-ICU .. transitions can be extremely traumatic; what to expect not understood; concerns be unmet and symptoms go untreated

Post Discharge from ICU

Participants described **anxiety-provoking symptoms** after returning home. These included **physical, cognitive, and mental health concerns**. They were **unsure** if the symptoms represented long-term consequences of the medications and treatments that they received in ICU, and were **hesitant to consult** their primary care physicians.

"I still get dizzy spells, memory loss. I forget the rest of the sentence I was going to say. I get time lapses, get chest pains and headaches. I'm not sure what is normal for what I have gone through

(male patient)



- Patient's (in)ability to communicate
- Family is the patients voice

- Ongoing access to support staff
- Inviting family to be part of care team
- Allowing family to be with patient
- ICU facilities for families

- Providing the best medical care
- Continuity of staff

Post Discharge from ICU

THE ICU JOURNEY

Admission to ICU

Family Shock &

Presence & Support of Staff

Patients and family members agreed that the transition from ICU to a hospital ward was an **extremely traumatic experience**.

"I'm trying to understand the picture of the future and the people in ICU had no idea about rehab. The ability of people to look down the chain would have been helpful."
(family member of surviving patient)

"Going from ICU to that ward was a real culture shock. All the things you are not supposed to do in ICU, you are told on the ward, 'can't you do that for yourself?' … I wasn't supposed to bend over and when I couldn't get my slipper on a nurse said 'well I guess you'll have to go without one.'"
(patient)

Long-Term Effects of Critical Illness

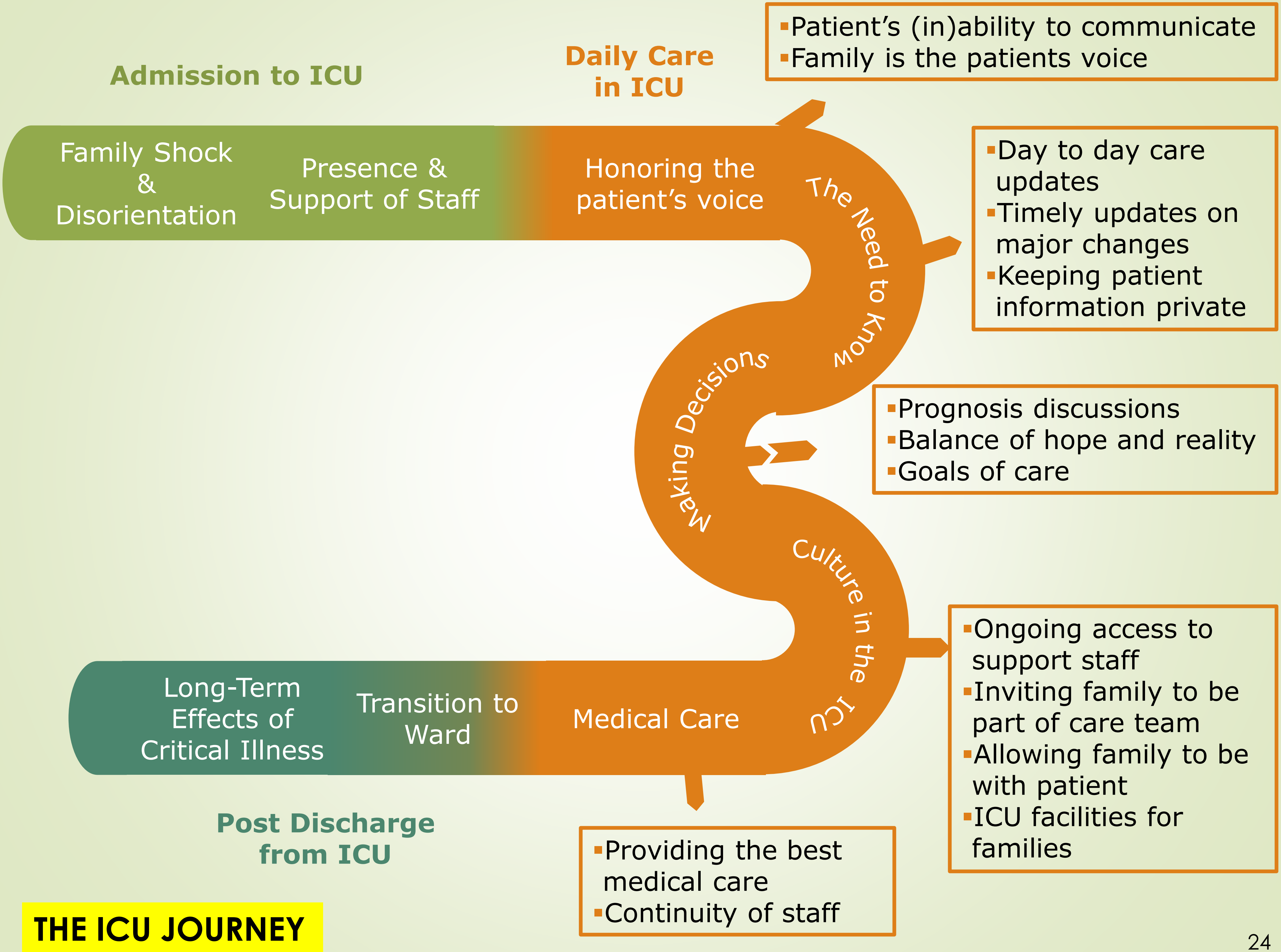
Transition to Ward

- Allowing family to be with patient
- ICU facilities for families

- Providing the best medical care
- Continuity of staff

Post Discharge from ICU

THE ICU JOURNEY



Admission to ICU

Family Shock
&
Disorientation

Presence &
Support of Staff

Daily Care in ICU

Honoring the patient's voice

- Patient's (in)ability to communicate
- Family is the patients voice

The Need to Know

- Day to day care updates
- Timely updates on major changes
- Keeping patient information private

Making Decisions

- Prognosis discussions
- Balance of hope and reality
- Goals of care

Culture in the ICU

- Ongoing access to support staff
- Inviting family to be part of care team
- Allowing family to be with patient
- ICU facilities for families

Medical Care

- Providing the best medical care
- Continuity of staff

Transition to Ward

Long-Term Effects of Critical Illness

Post Discharge from ICU

THE ICU JOURNEY

A RESEARCH STUDY TO UNDERSTAND PATIENT & FAMILY EXPERIENCES WITH CRITICAL CARE

Summary of Results & Key Messages

Five Suggestions for Improvement from Patients and Families (PaCER final report)

1. Provide a Dedicated Family Navigator
2. Increase Provider Awareness of the Fragility of Family Trust
3. Understand the Importance of the Mode, Tone and Content of Provider Communications
4. Improve ICU to Hospital Ward Transitions
5. Inform Patients about Long-Term Effects of

Top Five Opportunities for Improvement in Alberta ICUs*

1. Delirium Screening
2. Early Mobilization
3. **Family Presence and Effective Communication**
4. Transition of Patient Care Between Providers
5. Transitions of Care from ICU to Hospital Ward

Key Messages

- Patients and families identified 9 themes, 14 sub-themes, and 5 specific suggestions, based on their experiences in Intensive Care.
- These results are being used to help inform change through the provincial Critical Care Patient and Family Centred Care initiative, through:
  - Family Presence Guiding Principles
  - a 24-Hour Supportive Care Bundle
  - future Supportive Care Bundles

Alberta Health Services

UNIVERSITY OF CALGARY

Alberta Innovates Health Solutions

UNIVERSITY OF ALBERTA

---

* The top five opportunities were an outcome of a multi-phase research project to assess and improve the integration of best science into daily care of critically ill patients (the Evidence-Care-Gap project). In parallel to PaCER's work with patients and families, the research team engaged the opinions of over 1000 Alberta frontline providers. Perspectives from both data streams were combined and reconciled through an iterative process. The body of work from this phase of the study is being published.