1_Intervention_Patient decision aid

How to use the patient decision aid

Structure

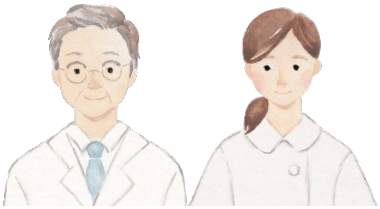
This patient decision aid(PtDA) consists of two books.

PtDA_A ：-Think about the treatment you desire and whom
you share your thoughts with -
PtDA_B：-Think about the treatment you hope for if you have difficulty recovering -

First, read Guide A while checking and writing.
STEP 5 Once you have made your decision, step up to PtDA B.

Do not worry about consulting your healthcare provider if you feel like doing so. Since this is the first time this abbreviation is used, please write the full form followed by the abbreviation in a bracket.

- Please check if this is what you meant.
- Please check if this is what you meant.
- Avoid using contractions like you've, you're, let's in academic writing as they are considered to be informal. Replace them with full forms instead.



STEP 1

What treatment would you like to receive? Whom can you share your thoughts with?

Why do you not take the opportunity of surgery and treatment to make a plan for your future life and how to deal with the disease?
If you cannot decide for yourself, or if your life is in crisis, what kind of treatment would you like to receive?
This guide is designed to help you think about the treatment you want to receive in the event of a surgery.
It is also designed to help you decide whether you want to share it with your healthcare provider and the people you trust (surrogate decision-makers) .
Let us read this guide as you write.

Option

1: Do not communicate your ACP's wishes to surrogate decision-makers and healthcare providers.
2: Communicate your ACP's wishes to surrogate decision-makers and healthcare practitioners.

STEP 2

Advance care plannings' process
-Think about what kind of treatment you wish to receive-

1 While you are undergoing treatment, let us think about whether you are having a hard time living.
What is important to your life?

2 Is there any treatment that you do not want to receive?
Do you think about what it would be like to die, and what it would be like to have this sort of treatment at end of life?

・the condition of being able to take care of oneself

not burdening one's family

having a better quality of life

receiving every life-prolonging treatment possible

3 Next, think about whom you can trust and who can discuss the treatment and care you receive on behalf of yourself, in a crisis.
*These people are called "surrogate decision-makers."

4 You can also discuss the treatment you want or do not want with a surrogate decision-maker or healthcare provider. This choice can be changed even after you have made a decision, depending on your situation.
If you have any questions, you can be in touch with your healthcare providers.

STEP 2

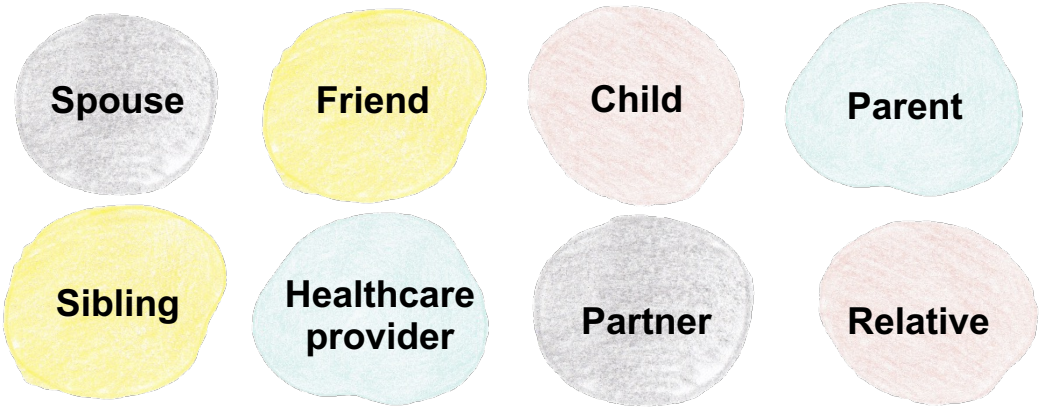
About the Proxy decision-maker (trustworthy person).

What is the role of the surrogate decision-maker (trusting person)?

When you cannot make decisions about the treatment you want rely on a healthcare provider as well as the person who is responsible for thinking and making decisions about the treatment you want to receive. The surrogate decision-maker has no legal rights and is not involved in the division of property. Who understands your way of thinking and living the best?

In the event of an emergency, you will select a person who you believe will decide to treat you the way you want to be treated.

Throughout the document you have majorly used left-alignment without an indent. Hence, I have deleted the indent to make it consistent.



You can have more than one surrogate decision-maker.
For example, you can choose whether you want your three children to discuss and decide, or your wife and daughter to decide.

Who is your surrogate decision-maker? Please fill it out.

Surrogate decision-maker:

STEP 2

How much do you rely on surrogate decision-makers?

What is discretion?

If you tell the surrogate decision-maker about your treatment, the decision will not always go smoothly. In particular, the surrogate decision-maker is at a loss when there is a difference between the best treatment or care for you according to the surrogate decision-maker and the healthcare provider. Therefore, it is also a good idea to decide the extent of your surrogate decision-maker's deciding power.
For example, consider the following:

Check

What do you want to do when your decision-making ability is lost and the surrogate decision-maker or healthcare provider has a different opinion regarding the treatment?

I want you to do what I wanted. Check ☐

Based on the treatment I had desired, I would like the healthcare provider and the surrogate decision-maker to discuss and decide. Check ☐

Even if the treatment is different from what I wanted, it can be decided through discussion between the healthcare provider and the surrogate decision-maker. Check ☐

I am not sure. I do not know. Check ☐

STEP 2

What do you value and desire more?

For example, let us consider the following .

Check

If you have limited time to live, what is important to you among the following: (Multiple answers allowed)

☐ Being able to continue work and social tasks	☐ Doing what I desire
☐ Being able to take care of myself	☐ Not being a burden on my family
☐ Being financially secure	☐ Having no financial problems with my family
☐ Absence of pain or distress	☐ The state of being near family or friends
☐ Other （ ）	
Reasons…	

What makes you feel that it could be difficult to live in a particular situation from the following: (Multiple answers allowed)

☐ I'm in a serious condition and I cannot wake up and express my feelings to people around me.	☐ Not being able to control my body
☐ Being unable to take care of myself	☐ I cannot avoid myself
☐ Being in continuous and incurable pain	☐ Being dependent on medical equipment. (e.g., ventilator)
☐ Being unable to eat or drink by myself	☐ I do not Know
☐ Other	

What is the predicted course of the disease if it worsens during hospitalization?

- ☐ I want to know all the information (I want to make my own decision as much as I can)
- ☐ If it is getting worse, I do not want to know
- ☐ I do not know
- ☐ Other

I have the following plans and pleasures that I want to pursue after I am discharged.

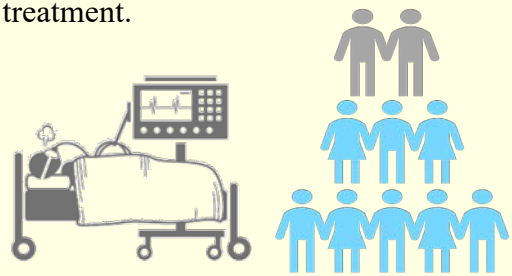
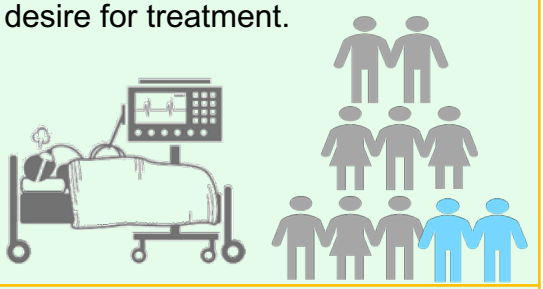
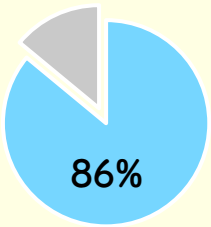
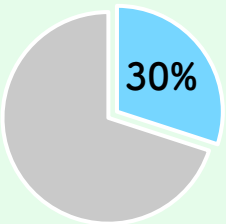
- ☐ Return to the job (when, timing)
- ☐ Role at home
- ☐ Travel
- ☐ Other

Other than that, write down how you think and feel.

STEP 3

Understand the characteristics of the option options (Pros and Cons).

In Step 3, you will consider your options in case your life is in danger . Compare the pros and cons of discussing or not discussing your treatment with surrogate decision-makers before surgery.

Discussion	Not discussion
Your desires are reflected in the treatment.	
8 out of 10 surrogate decision-makers fully understood the patient's desire for treatment. 	1 ~ 2 of the 10 surrogate decision-makers fully understood the patient's desire for treatment. 
About 86% of the patients‘ autonomy was respected until the end of their lives. 	About 30% of patients' autonomy was respected until the end of their lives. 
Anxiety you felt before surgery	
Before surgery, you should consider how you would like to be treated in a life-threatening situation. We compared patients who thought about it with those who didn't. Results revealed that there is no difference in the degree of anxiety in both patients. However, in some cases, ACP before surgery may increase anxiety.	

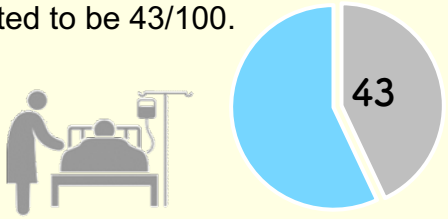
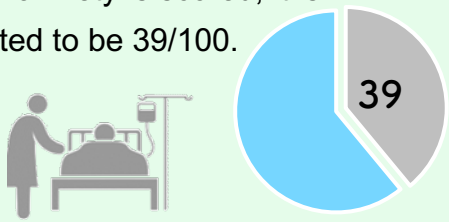
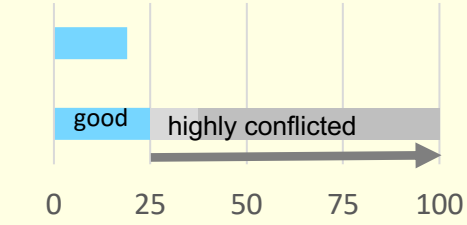
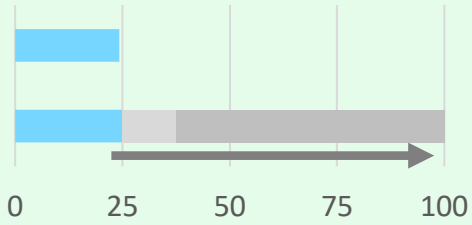
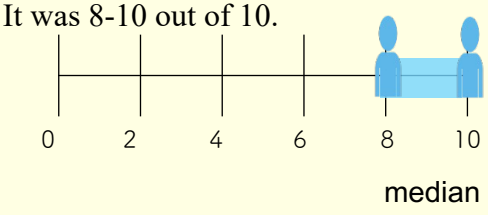
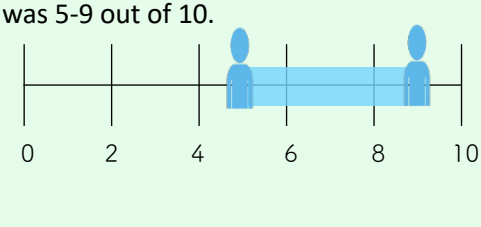
STEP 3

Understand the characteristics of the (Pros and Cons).

If you are unable to make your decision, the healthcare providers and surrogate decision-makers, who are considering treatment for you in the ICU, may experience difficulty or conflict regarding that decision.

・12.1% of conflicts within families

・Conflicts between healthcare providers and surrogate decision-makers are reported to be 57.3%.

Discussion	Not discussion
Preoperative anxiety of surrogate decision-makers. * For the first time	
When anxiety is scored, it is reported to be 43/100. 	When anxiety is scored, it is reported to be 39/100. 
The conflict that the surrogate decision-maker has after making surrogate decisions about your treatment.	
It scored 19.5 out of 100. 	It scored 24.3 out of 100. 
Did the surrogate decision-makers make decisions in accordance with your preferences? * Degree of confidence	
It was 8-10 out of 10. 	It was 5-9 out of 10. 

STEP 4

Examine what is most important to you

Next, you will examine what is most important to you.

For each item, check the one that best matches your preferences and see which way your value is tilted.

Check

Discussion	Not discussion

1. Think for yourself about the treatment you want or do not want before surgery.

☐ ☐ ☐ ☐ ☐

very important — neither — not matter at all

2. Having your surrogate decision-maker know about the treatment you want or do not want before surgery.

☐ ☐ ☐ ☐ ☐

very important — neither — not matter at all

3. Making your healthcare provider aware of the treatments you may or may not want to receive before surgery.

☐ ☐ ☐ ☐ ☐

very important — neither — not matter at all

STEP 4

Examine what is most important to you

Discussion	Not discussion

4. Sharing with the surrogate decision-maker information about the treatment you want or do not want before surgery may increase the surrogate decision-maker's anxiety and worry.

☐ ☐ ☐ ☐ ☐

not matter at all — neither — very important

5. That surrogate decision-makers may feel burdened by making treatment decisions on your behalf after surgery.

☐ ☐ ☐ ☐ ☐

very important — neither — not matter at all

6. When your treatment is not going well after surgery, your healthcare provider should give you any information.

☐ ☐ ☐ ☐ ☐

very important — neither — not matter at all

STEP 5

Decision

In the previous pages, you have considered what you value and would like to decide.
Now let us check how ready you are to decide.

Check

Do you know the benefits and risks of each option?

☐ Yes ☐ No

Do you know the benefits and risks of each option?

☐ Yes ☐ No

Are you clear about which benefits and risks matter most to you?

☐ Yes ☐ No

Do you have enough support and advice to make a choice?

☐ Yes ☐ No

If any one of the responses to the four items above is "no," you may not be ready to decide yet. Is there anything you want to do before you decide ?

STEP 5

Decision

Write down your decision,

_____年　　月　　日

☐ Do not communicate your ACP's wishes to surrogate decision-makers and healthcare providers.

☐ Communicate your ACP's wishes to surrogate decision-makers and healthcare practitioners.

STEP 1

Think about the treatment you hope for if you have difficulty recovering

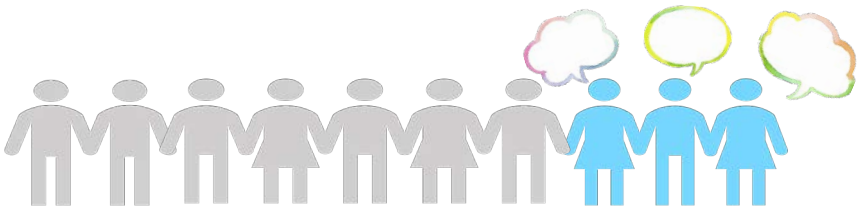
This PtDA is designed to help you plan ahead if you are in a situation where recovery is difficult during the course of treatment and you want to make sure that you are receiving the best treatment you can until the end of your life, or if you want to limit your treatment to switching treatment goals.
As you read through the PtDA, try to clear your mind based on the options that follow.

Option

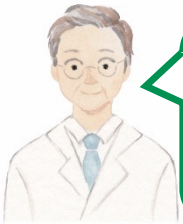
1 Continue to receive all treatment regardless of the survival rate.

2 Discontinue life-sustaining treatment when the survival rate decreases.

When you are in an ICU or when your condition worsens, change happens very quickly. The time to decide treatment is very short, and it is difficult to make a careful decision. At the end of life, when recovery is considered difficult, 70% of patients are reported to be unable to make decisions on their own.



Think about your wish for treatment



Option1

We will provide you with all kinds of treatments so that you can live as long as possible. On the other hand, you may have to be treated differently than you wish.

Option2

This means switching to treatment that focuses on relieving your pain and improving quality of life. However, this can shorten your time.

Undergo full treatment

Benefit

- You may be able to live as long as possible until your heart and breathing stop.
- Your long life will keep your family and loved ones with you for as long as possible.

Discontinue treatment that may prolong life

Benefit

- If you are unlikely to recover, you can avoid futile treatment.
- If following your wishes are no longer possible, they will be reflected and respected as much as possible.

Risk

- You cannot move freely because you are connected to a medical device. In addition, there is a high possibility that your consciousness will not recover even after treatment.
- This treatment may not be the way you wish to live.

Risk

- This treatment may shorten your lifetime.
- Your family and loved ones would spend less time with you.

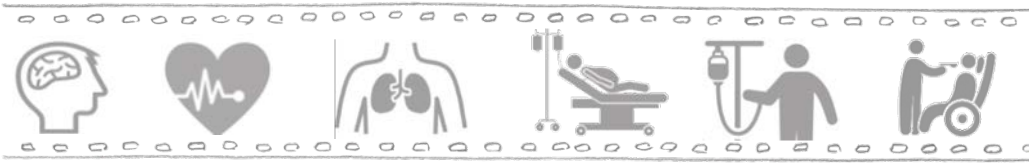
STEP 2

What is a physical condition with a low survival rate?

It refers to any situation where the lifesaving rate becomes low.
One case can be postoperative complications which refers to complications after surgery that can cause some of your organs to malfunction.
Furthermore, a condition in which the function of two or more organs is reduced is called multi-organ failure.

Physical condition

Brain & Nerve	If you have a stroke or bleeding, your cognitive function may deteriorate and you may not regain consciousness. The hands and feet may remain paralyzed.
Circulation	If your heart and blood vessels function poorly, you may not be able to maintain your blood pressure and pulse. This leads to a decline in the function of organs such as the kidneys, liver, and intestine.
Respiratory	There are cases where water accumulates in the lungs, pneumonia, or the lungs collapse with sputum. You cannot take in oxygen by yourself, or carbon dioxide may not be emitted, or both. In such cases, an oxygen mask or a ventilator is worn.
Liver	Poor circulation or poor liver function due to various reasons can lead to jaundice and accumulation of toxins in the body, which leads to life-threatening problems.
Kidney	Your body may hold water, and waste materials in your blood may not be able to pass out of your body. Electrolyte abnormalities can be life threatening.
Blood	If the blood fails to circulate, blood tends to clot throughout the body (clot formation), and if a wound forms, it is difficult to stop the bleeding and bleeding to death is likely.
Other	If you get infected and bacteria circulates in the bloodstream, circulation cannot be maintained. This can lead to dysfunction of various organs.
Daily life	When multiple organ damage progresses and the lifesaving rate is low, daily activities become impossible. For example, you may not be able to go to the bathroom, eat, or walk by yourself.



STEP 2

ICU treatment

In order for you to survive as long as possible, you may receive the following treatment in the ICU. This treatment can be brief or prolonged until your illness or symptoms improve.

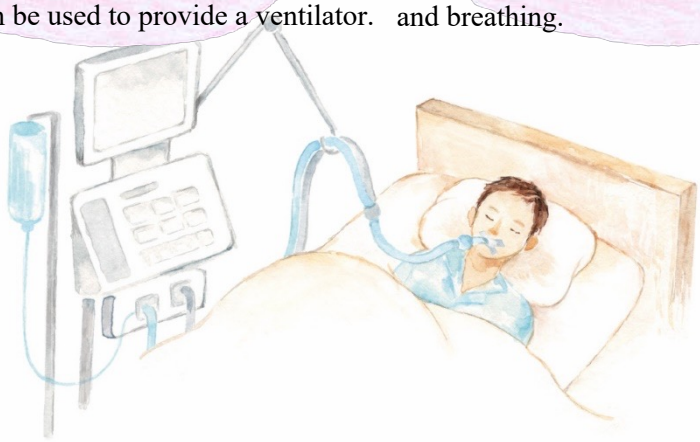
Devices needed to survive. (If it is stopped, it is immediately fatal.)

Ventilator

If you are unable to breathe or inadequately breathing on your own, the machine will help you breathe by inserting a tube into your mouth or throat. *In some cases, a mouth or nose mask can be used to provide a ventilator.

Supplementary circulation device

It is applied when your heart and lung function deteriorate and you cannot maintain circulation and breathing. A tube is inserted through the groin or neck to help circulation and breathing.



Supplementary device for living. (If you stop it, it's not immediately fatal.)

Dialysis

If kidney or liver function deteriorates, dialysis is performed at the bedside. A catheter is inserted through your groin and neck.

Sedative and analgesics

If a drain or tube is inserted, painkillers or drugs that cause sleepiness may be used.

Infusions, blood transfusion, and nutrition

You cannot drink water or eat. In that case, an infusion will be given to you. Fluid and nutrition may also be given through a tube in the nose or abdomen. You may also receive a blood transfusion.

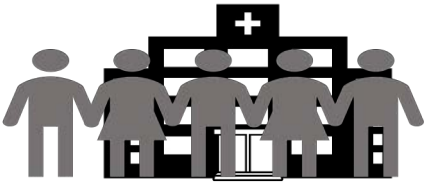
STEP 2

What is Cardiopulmonary Resuscitation?

If the heart stops during treatment, cardiopulmonary resuscitation (CPR) is performed. This is a supplementary procedure for heart massage and artificial respiration to get the heart moving again. In general, the following occurs:

1. **Chest compression**
   We are going to press on your chest to get your heart going again.
2. **Rescue breathing**
   Open the airway, put a mask over your mouth and nose, and pump oxygen.
3. **Electric shock**
   It will send electricity to the heart so that it can move normally.
4. **Drug administration**
   Drugs to increase blood pressure are given.

*CPR usually consists of one set of chest compression and rescue breathing, not. just one or the other.

	Perform CPR	Do not perform CPR
	It is reported that about one in six patients who undergo CPR during hospitalization and can be discharged in good health regardless of disease or condition.  	
Benefit	・If CPR is successful, you can live. 	・It does not cause unnecessary injury to the body. It leads to natural death.
Risk	・If CPR doesn't succeed, you won't be able to live. The chest bones of elderly people may break by cardiac compressions.	・Without treatment, the heart and breathing do not move naturally, so you cannot live. 

However, if the underlying disease is not treated, CPR is often not effective.

STEP 2

Discontinuation of treatment that is expected to prolong life -Focus on painless treatment

In the process of treatment, if it is judged that the survival rate is gradually decreasing and the end of life will come in a few weeks or days, the goal of treatment will be reviewed based on your wishes. Active treatment is discontinued and switched to treatment or care that focuses on relieving your pain as much as possible.

For example

Ventilator attachment and desorption repeated. Next, if breathing worsens, ventilator is not used.

Despite receiving dialysis every day, one remains unconscious. Since recovery is difficult with further continuation, dialysis is discontinued.

An assisted circulation device is installed. If the survival rate is judged to be low, the continued use of the device is discontinued.

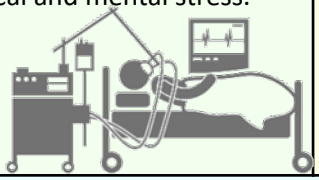
In the ICU, patients may receive high-dose fluids and blood transfusions to maintain blood pressure. In some patients, this may cause swelling throughout the body and a significant change in the face. Skin problems may also be caused due to the insertion of a tube through the mouth for a ventilator or due to the use of many devices or tubes.

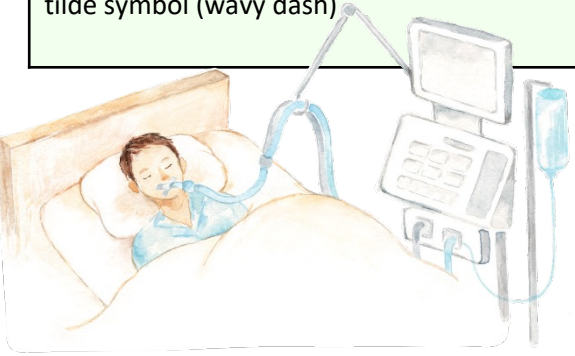
The treatment and care that you switch to are based on your medical goals and values.
Think about what living is like for you.

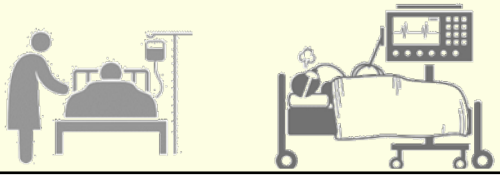
STEP 3

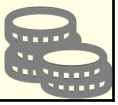
Understand the characteristics of the (Pros and Cons).

Let us compare treatment options when the survival rate becomes low and recovery becomes difficult during treatment.

Undergo full treatment	Discontinue treatment that may prolong life
Content of treatment	
It is more essential to live as long as possible, even if the treatment involves a great deal of physical and mental stress. 	Instead of hoping that the treatment will prolong your life, it will focus on relieving pain as much as possible and treating your way of life. 
Whichever you choose, you can continue to treat your discomfort and distress with medication as long as you want.	
Survival ratio	
It may be possible to prolong life. ・The 1-month survival rate of patients with multiple organ damage is increasing. However, long-term survival (more than one year) is reported to be 37 ~ 74%. Please check if you intended to use the tilde symbol (wavy dash)	・Depending on your condition, your heart and breathing may stop immediately or may stop after a while. ・If your survival rate is low, you may avoid unwanted treatment. Please check



Undergo full treatment	Discontinue treatment that may prolong life
Return to a previous life	
If recovered, more than 70% of patients can be discharged without disability and may be able to return to previous life. 	Depending on when treatment is stopped, patients may not be able to perform daily activities by themselves after discharge. 
Cognitive and mental function	
・If recovery happens, 20-70% of patients may be discharged without cognitive decline.  ・After treatment, 8 to 57% of patients may develop depression and anxiety. It has been reported that 50% of patients may have this symptom for a long time.	・It depends on when you stop the treatment. There is a high possibility that you cannot think and express yourself. ・The pain or discomfort may be controlled by drugs or may not be felt.

Psychological impact of surrogate decision-makers	
Between 10-80% of surrogate decision-makers may experience increased anxiety or depressive tendencies because of your admission to the ICU. 	
Your recovery may reduce the anxiety and stress of the surrogate decision-maker.	When your death occurs, the anxiety and stress of the surrogate decision-maker may increase.
Cost of medical	
The longer you stay in the ICU or stay on life-support, the higher your medical costs.	The medical costs depend on the length of ICU treatment and the contents of treatment. 

STEP 4

Clarify what you value and want to determine

Your wishes for treatment are as important as medical judgment. Let us examine what is important to you. Check the box that best matches your preference.

Check

Undergo full treatment	Discontinue treatment that may prolong life

1. In this judgment, how important is your lifesaving rate?

☐ ☐ ☐ ☐ ☐

not matter at all — neither — very important

2. In this judgment, how important is it whether you can go back to your previous life?

☐ ☐ ☐ ☐ ☐

not matter at all — neither — very important

3. What is an important issue for you?

Brain & nervous	Cardiac heart	Lung	Liver	Kidney	Extremities
☐	☐	☐	☐	☐	☐
Being conscious. What you can judge, etc.	I do not want to use an assisted circulation device, etc.	I do not want to keep using a ventilator for a long time, etc.	I do not want to put on an assistive device, etc.	I do not want permanent dialysis, etc.	I do not want to be unable to walk or move by myself, etc.

Undergo full treatment	Discontinue treatment that may prolong life

4. Additional important issues or concerns for you?

not matter at all neither very important

5. Are there any treatments that you really do not want to receive?

☐ No ☐ Yes

Contents：

6. Is the extent of the medical expenses an important factor in this decision?

not matter at all neither very important

7. In this judgment, is it important to give priority to your opinion at all times?

not matter at all neither very important

8. Is the opinion of the surrogate decision-maker important in this decision?

not matter at all neither very important

9. Is the opinion of the healthcare provider important in this decision?

not matter at all neither very important

STEP 5

Decision

Now let us check how ready you are to decide.

Check

Do you know the benefits and risks of each option?

☐ Yes ☐ No

Do you know the benefits and risks of each option?

☐ Yes ☐ No

Are you clear about which benefits and risks matter most to you?

☐ Yes ☐ No

Do you have enough support and advice to make a choice?

☐ Yes ☐ No

If any one of the responses to the four items above is "no," you may not be ready to decide yet. Is there anything you want to do before you decide ?

STEP 5

Decision

In the previous sections, you thought about what you would value and decide.

☐ Continue to receive all treatment regardless of the survival rate

☐ Discontinue life-sustaining treatment when the survival rate decreases.

Now let us look at how ready you are to decide.
For me, life-prolonging treatment means:

① It is the case where the lifesaving rate is considered to be about ____% according to the judgment of the healthcare practitioner.

② Others:_____.

The following treatments are continued. (Check the treatment you want to receive)

☐ CPR ☐ Mechanical ventilator ☐ Drugs to maintain blood pressure

☐ Dialysis ☐ Assisted circulation device (Percutaneous cardio pulmonary support)

☐ Infusions and nutrition ☐ Blood transfusion

Write down your thoughts

It may be difficult to decide what treatment you want to receive if recovery becomes difficult. Once you decide, there is nothing you cannot change again.
Let us do our best to get over the surgery safely.

References

1 Health, Labour and Welfare Ministry（2018）.Medical care in the final stage of one's desired life. https://www.mhlw.go.jp/stf/seisakunitsuite/bunya/kenkou_iryou/iryou/saisyu_iryou/index.html

2 Kizawa Y. (2017). Project to improve medical systems in the final stages of life. "Advanced Care Planning: Discussion on future treatment and care"

3 Song, M.K. et al.(2005). A randomized controlled trial to improve advance care planning among patients undergoing cardiac surgery. Med Care, 43(10), 1049-53.

4 Chiarchiaro, J., et al.(2015). Perior Advance Care Planning Is Associated with Less Decisional Conflict among Surrogates for Critically Ill Patients. Ann Am thorac, 12(10), 1528-33.

5 Willson, M.K., et al.(2015). A Video to improve patient and surrogate understanding of cardiopulmonary resuscitation choices in the ICU: a randomized controlled trial. Crit Care Med, 43(3), 621-9.

6 Andreu, P., et al.(2018). Impact of a stay in the intensive care unit on the preparation of Advance Directives: Descriptive, exploratory, qualitative study. Anaeth Crit Care Pain Med.37(2), 113-9.

7 Carmen. H.M., et al(2014). Efficacy of Advance Care Planning: A Systematic Review and Meta-Analysis. JAMDA, 15, 477-489.

8 Studdert, D.M. et al.(2003). Conflict in the care of patients with prolonged stay in the ICU: types, sources, and predictors. Intensive Care Med. 29(9).1489-97.

9. Nakayama K & Iwamoto T.（2012）. Patient-centered decision support -care to make a convincing decision-

Develop by Kanako YAMAMOTO
（St. Luke's International University, RN, CNS, Ph.D.）
Illustrator: taneko

Created：July 10, 2020
Revised：March 10, 2021 (This PtDA is periodically reviewed and revised.)
This PtDA is supported by a JSPS 19K19613.

2_Control_Pamphlet

How to use the patient decision aid

Structure

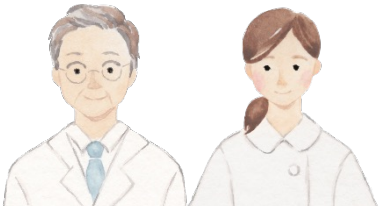
This patient decision aid(PtDA) consists of two books.

PtDA_A ：-Think about the treatment you desire and whom
you share your thoughts with -
PtDA_B：-Think about the treatment you hope for if you have difficulty recovering -

First, read Guide A while checking and writing.
STEP 5 Once you have made your decision, step up to PtDA B.

Do not worry about consulting your healthcare provider if you feel like doing so. Since this is the first time this abbreviation is used, please write the full form followed by the abbreviation in a bracket.

- Please check if this is what you meant.
- Please check if this is what you meant.
- Avoid using contractions like you've, you're, let's in academic writing as they are considered to be informal. Replace them with full forms instead.



STEP 1

What treatment would you like to receive? Whom can you share your thoughts with?

Why do you not take the opportunity of surgery and treatment to make a plan for your future life and how to deal with the disease?
If you cannot decide for yourself, or if your life is in crisis, what kind of treatment would you like to receive?
This guide is designed to help you think about the treatment you want to receive in the event of a surgery.
It is also designed to help you decide whether you want to share it with your healthcare provider and the people you trust (surrogate decision-makers) .
Let us read this guide as you write.

Option

1: Do not communicate your ACP's wishes to surrogate decision-makers and healthcare providers.
2: Communicate your ACP's wishes to surrogate decision-makers and healthcare practitioners.

STEP 2

Advance care plannings' process
-Think about what kind of treatment you wish to receive-

1 While you are undergoing treatment, let us think about whether you are having a hard time living.
What is important to your life?

2 Is there any treatment that you do not want to receive?
Do you think about what it would be like to die, and what it would be like to have this sort of treatment at end of life?

・the condition of being able to take care of oneself

not burdening one's family

having a better quality of life

receiving every life-prolonging treatment possible

3 Next, think about whom you can trust and who can discuss the treatment and care you receive on behalf of yourself, in a crisis.
*These people are called "surrogate decision-makers."

4 You can also discuss the treatment you want or do not want with a surrogate decision-maker or healthcare provider. This choice can be changed even after you have made a decision, depending on your situation.
If you have any questions, you can be in touch with your healthcare providers.

STEP 2

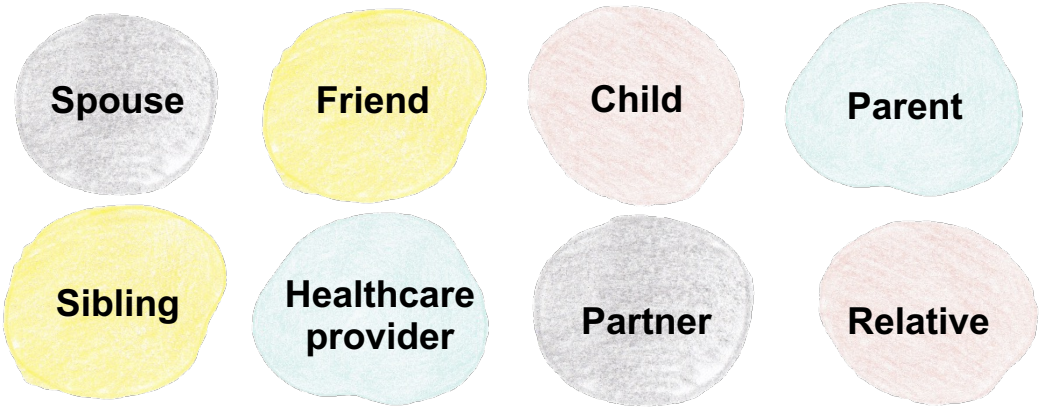
About the Proxy decision-maker (trustworthy person).

What is the role of the surrogate decision-maker (trusting person)?

When you cannot make decisions about the treatment you want rely on a healthcare provider as well as the person who is responsible for thinking and making decisions about the treatment you want to receive. The surrogate decision-maker has no legal rights and is not involved in the division of property. Who understands your way of thinking and living the best?

In the event of an emergency, you will select a person who you believe will decide to treat you the way you want to be treated.

Throughout the document you have majorly used left-alignment without an indent. Hence, I have deleted the indent to make it consistent.



You can have more than one surrogate decision-maker.
For example, you can choose whether you want your three children to discuss and decide, or your wife and daughter to decide.

Who is your surrogate decision-maker? Please fill it out.

Surrogate decision-maker:

STEP 2

How much do you rely on surrogate decision-makers?

What is discretion?

If you tell the surrogate decision-maker about your treatment, the decision will not always go smoothly. In particular, the surrogate decision-maker is at a loss when there is a difference between the best treatment or care for you according to the surrogate decision-maker and the healthcare provider. Therefore, it is also a good idea to decide the extent of your surrogate decision-maker's deciding power.
For example, consider the following:

Check

What do you want to do when your decision-making ability is lost and the surrogate decision-maker or healthcare provider has a different opinion regarding the treatment?

I want you to do what I wanted. Check ☐

Based on the treatment I had desired, I would like the healthcare provider and the surrogate decision-maker to discuss and decide. Check ☐

Even if the treatment is different from what I wanted, it can be decided through discussion between the healthcare provider and the surrogate decision-maker. Check ☐

I am not sure. I do not know. Check ☐

STEP 2

What do you value and desire more?

For example, let us consider the following .

Check

If you have limited time to live, what is important to you among the following: (Multiple answers allowed)

☐ Being able to continue work and social tasks	☐ Doing what I desire
☐ Being able to take care of myself	☐ Not being a burden on my family
☐ Being financially secure	☐ Having no financial problems with my family
☐ Absence of pain or distress	☐ The state of being near family or friends
☐ Other （ ）	
Reasons…	

What makes you feel that it could be difficult to live in a particular situation from the following: (Multiple answers allowed)

☐ I'm in a serious condition and I cannot wake up and express my feelings to people around me.	☐ Not being able to control my body
☐ Being unable to take care of myself	☐ I cannot avoid myself
☐ Being in continuous and incurable pain	☐ Being dependent on medical equipment. (e.g., ventilator)
☐ Being unable to eat or drink by myself	☐ I do not Know
☐ Other	

What is the predicted course of the disease if it worsens during hospitalization?

- ☐ I want to know all the information (I want to make my own decision as much as I can)
- ☐ If it is getting worse, I do not want to know
- ☐ I do not know
- ☐ Other

I have the following plans and pleasures that I want to pursue after I am discharged.

- ☐ Return to the job (when, timing)
- ☐ Role at home
- ☐ Travel
- ☐ Other

Other than that, write down how you think and feel.

STEP 5

Decision

Write down your decision,

_____年　　月　　日

☐ Do not communicate your ACP's wishes to surrogate decision-makers and healthcare providers.

☐ Communicate your ACP's wishes to surrogate decision-makers and healthcare practitioners.

STEP 1

Think about the treatment you hope for if you have difficulty recovering

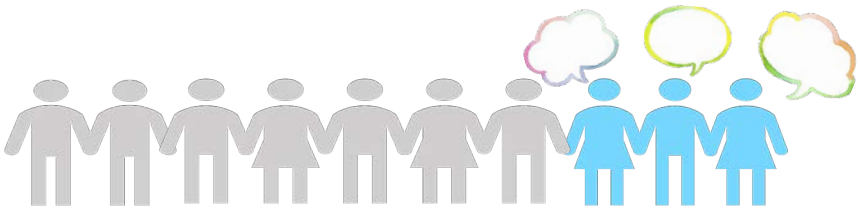
This PtDA is designed to help you plan ahead if you are in a situation where recovery is difficult during the course of treatment and you want to make sure that you are receiving the best treatment you can until the end of your life, or if you want to limit your treatment to switching treatment goals.
As you read through the PtDA, try to clear your mind based on the options that follow.

Option

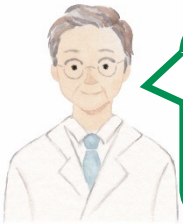
1 Continue to receive all treatment regardless of the survival rate.

2 Discontinue life-sustaining treatment when the survival rate decreases.

When you are in an ICU or when your condition worsens, change happens very quickly. The time to decide treatment is very short, and it is difficult to make a careful decision. At the end of life, when recovery is considered difficult, 70% of patients are reported to be unable to make decisions on their own.



Think about your wish for treatment



Option1

We will provide you with all kinds of treatments so that you can live as long as possible. On the other hand, you may have to be treated differently than you wish.

Option2

This means switching to treatment that focuses on relieving your pain and improving quality of life. However, this can shorten your time.

Undergo full treatment

Benefit

- You may be able to live as long as possible until your heart and breathing stop.
- Your long life will keep your family and loved ones with you for as long as possible.

Discontinue treatment that may prolong life

Benefit

- If you are unlikely to recover, you can avoid futile treatment.
- If following your wishes are no longer possible, they will be reflected and respected as much as possible.

Risk

- You cannot move freely because you are connected to a medical device. In addition, there is a high possibility that your consciousness will not recover even after treatment.
- This treatment may not be the way you wish to live.

Risk

- This treatment may shorten your lifetime.
- Your family and loved ones would spend less time with you.

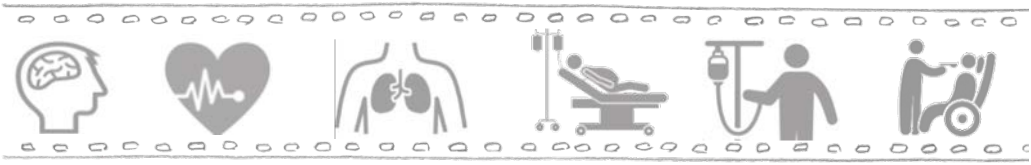
STEP 2

What is a physical condition with a low survival rate?

It refers to any situation where the lifesaving rate becomes low.
One case can be postoperative complications which refers to complications after surgery that can cause some of your organs to malfunction.
Furthermore, a condition in which the function of two or more organs is reduced is called multi-organ failure.

Physical condition

Brain & Nerve	If you have a stroke or bleeding, your cognitive function may deteriorate and you may not regain consciousness. The hands and feet may remain paralyzed.
Circulation	If your heart and blood vessels function poorly, you may not be able to maintain your blood pressure and pulse. This leads to a decline in the function of organs such as the kidneys, liver, and intestine.
Respiratory	There are cases where water accumulates in the lungs, pneumonia, or the lungs collapse with sputum. You cannot take in oxygen by yourself, or carbon dioxide may not be emitted, or both. In such cases, an oxygen mask or a ventilator is worn.
Liver	Poor circulation or poor liver function due to various reasons can lead to jaundice and accumulation of toxins in the body, which leads to life-threatening problems.
Kidney	Your body may hold water, and waste materials in your blood may not be able to pass out of your body. Electrolyte abnormalities can be life threatening.
Blood	If the blood fails to circulate, blood tends to clot throughout the body (clot formation), and if a wound forms, it is difficult to stop the bleeding and bleeding to death is likely.
Other	If you get infected and bacteria circulates in the bloodstream, circulation cannot be maintained. This can lead to dysfunction of various organs.
Daily life	When multiple organ damage progresses and the lifesaving rate is low, daily activities become impossible. For example, you may not be able to go to the bathroom, eat, or walk by yourself.



STEP 2

ICU treatment

In order for you to survive as long as possible, you may receive the following treatment in the ICU. This treatment can be brief or prolonged until your illness or symptoms improve.

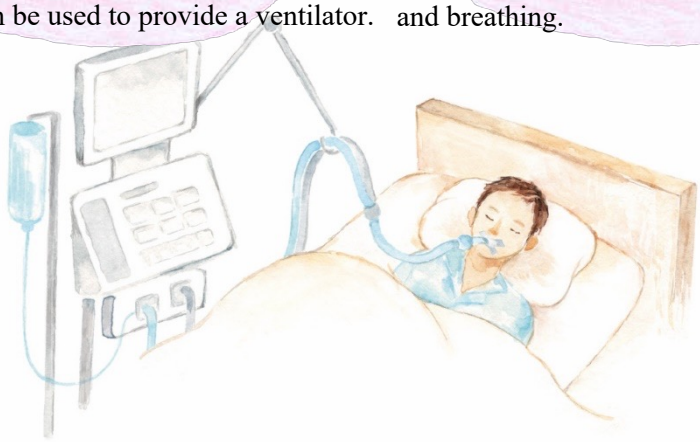
Devices needed to survive. (If it is stopped, it is immediately fatal.)

Ventilator

If you are unable to breathe or inadequately breathing on your own, the machine will help you breathe by inserting a tube into your mouth or throat. *In some cases, a mouth or nose mask can be used to provide a ventilator.

Supplementary circulation device

It is applied when your heart and lung function deteriorate and you cannot maintain circulation and breathing. A tube is inserted through the groin or neck to help circulation and breathing.



Supplementary device for living. (If you stop it, it's not immediately fatal.)

Dialysis

If kidney or liver function deteriorates, dialysis is performed at the bedside. A catheter is inserted through your groin and neck.

Sedative and analgesics

If a drain or tube is inserted, painkillers or drugs that cause sleepiness may be used.

Infusions, blood transfusion, and nutrition

You cannot drink water or eat. In that case, an infusion will be given to you. Fluid and nutrition may also be given through a tube in the nose or abdomen. You may also receive a blood transfusion.

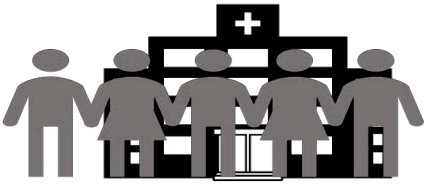
STEP 2

What is Cardiopulmonary Resuscitation?

If the heart stops during treatment, cardiopulmonary resuscitation (CPR) is performed. This is a supplementary procedure for heart massage and artificial respiration to get the heart moving again. In general, the following occurs:

1. **Chest compression**
   We are going to press on your chest to get your heart going again.
2. **Rescue breathing**
   Open the airway, put a mask over your mouth and nose, and pump oxygen.
3. **Electric shock**
   It will send electricity to the heart so that it can move normally.
4. **Drug administration**
   Drugs to increase blood pressure are given.

*CPR usually consists of one set of chest compression and rescue breathing, not. just one or the other.

	Perform CPR	Do not perform CPR
	It is reported that about one in six patients who undergo CPR during hospitalization and can be discharged in good health regardless of disease or condition.  	
Benefit	・If CPR is successful, you can live. 	・It does not cause unnecessary injury to the body. It leads to natural death.
Risk	・If CPR doesn't succeed, you won't be able to live. The chest bones of elderly people may break by cardiac compressions.	・Without treatment, the heart and breathing do not move naturally, so you cannot live. 

However, if the underlying disease is not treated, CPR is often not effective.

STEP 2

Discontinuation of treatment that is expected to prolong life -Focus on painless treatment

In the process of treatment, if it is judged that the survival rate is gradually decreasing and the end of life will come in a few weeks or days, the goal of treatment will be reviewed based on your wishes. Active treatment is discontinued and switched to treatment or care that focuses on relieving your pain as much as possible.

For example

Ventilator attachment and desorption repeated. Next, if breathing worsens, ventilator is not used.

Despite receiving dialysis every day, one remains unconscious. Since recovery is difficult with further continuation, dialysis is discontinued.

An assisted circulation device is installed. If the survival rate is judged to be low, the continued use of the device is discontinued.

In the ICU, patients may receive high-dose fluids and blood transfusions to maintain blood pressure. In some patients, this may cause swelling throughout the body and a significant change in the face. Skin problems may also be caused due to the insertion of a tube through the mouth for a ventilator or due to the use of many devices or tubes.

The treatment and care that you switch to are based on your medical goals and values.
Think about what living is like for you.

STEP 5

Decision

In the previous sections, you thought about what you would value and decide.

☐ Continue to receive all treatment regardless of the survival rate

☐ Discontinue life-sustaining treatment when the survival rate decreases.

Now let us look at how ready you are to decide.
For me, life-prolonging treatment means:

① It is the case where the lifesaving rate is considered to be about ____% according to the judgment of the healthcare practitioner.

② Others:_____.

The following treatments are continued. (Check the treatment you want to receive)

☐ CPR ☐ Mechanical ventilator ☐ Drugs to maintain blood pressure

☐ Dialysis ☐ Assisted circulation device (Percutaneous cardio pulmonary support)

☐ Infusions and nutrition ☐ Blood transfusion

References

1. Advance Care Planning: Should I Stop Treatment That Prolongs My Life? (Healthwise)
[https://www.healthwise.net/ohridecisionaid/Content/StdDocument.aspx?DOCHWID=tu1430, 2020.3.4]

2 Desai SV et al. (2011). Long-term complications of critical care. Crit Care Med, 39, 371-379.

3 Hervey MA et al. (2016). Postintensive Care Syndrome: Right Care. Right Now…and Later. Crit Care Med, 44, 381-358.

4 Winter BD et al.(2010). Long-term mortality and quality of life in sepsis: A systematic review. Crit Care Med. 38, 1276-1283

5 Coulter A et al.(2013). A systematic development process for patient decision aids. BMC Med Inform Decis Mak, 13 Suppl 2:S2.

6 Nakayama K & Iwamoto T.（2012）. Patient-centered decision support -care to make a convincing decision-

Develop by Kanako YAMAMOTO
（St. Luke's International University, RN. CNS, Ph.D.）
Illastrator : taneko
Created ：July 10, 2020
Revised ：March 10, 2021 (This PtDA is periodically reviewed and revised.)
This PtDA is supported by a JSPS 19K19613.