

The background of the slide is a soft, watercolor-style illustration of various flowers and floral elements. It features a large yellow sunflower-like flower at the top center, a pink flower with a yellow center at the top right, a yellow flower with a pink center at the bottom center, and a yellow flower with a pink center at the bottom right. There are also several smaller, scattered floral shapes and dots in shades of yellow, pink, and purple. The overall aesthetic is gentle and artistic.

Advance care planning 1

-Think about the treatment you desire and whom you share your thoughts with -

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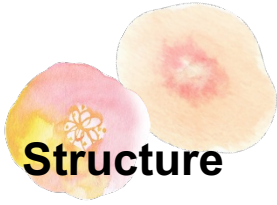
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How to use the patient decision aid



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

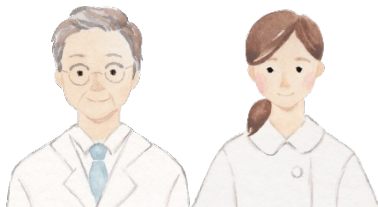
**PtDA_A : -Think about the treatment you desire and
whom you share your thoughts with -**

**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.



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.



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.

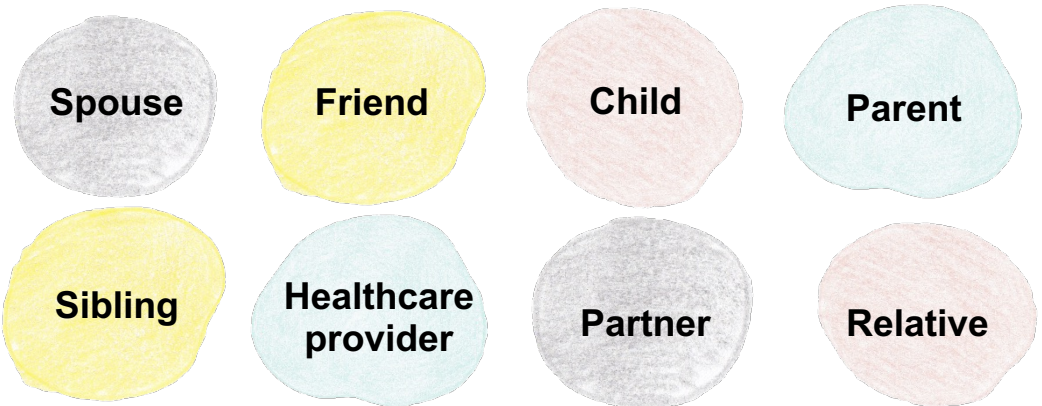
About the Proxy decision-maker (trustworthy person).

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.



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:



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)

<input type="checkbox"/> Being able to continue work and social tasks	<input type="checkbox"/> Doing what I desire
<input type="checkbox"/> Being able to take care of myself	<input type="checkbox"/> Not being a burden on my family
<input type="checkbox"/> Being financially secure	<input type="checkbox"/> Having no financial problems with my family
<input type="checkbox"/> Absence of pain or distress	<input type="checkbox"/> The state of being near family or friends
<input type="checkbox"/> Other ()	
Reasons...	



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

<input type="checkbox"/> I'm in a serious condition and I cannot wake up and express my feelings to people around me.	<input type="checkbox"/> Not being able to control my body
<input type="checkbox"/> Being unable to take care of myself	<input type="checkbox"/> I cannot avoid myself
<input type="checkbox"/> Being in continuous and incurable pain	<input type="checkbox"/> Being dependent on medical equipment. (e.g., ventilator)
<input type="checkbox"/> Being unable to eat or drink by myself	<input type="checkbox"/> I do not know
<input type="checkbox"/> 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 decisions 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.

.....

.....

.....

.....

.....

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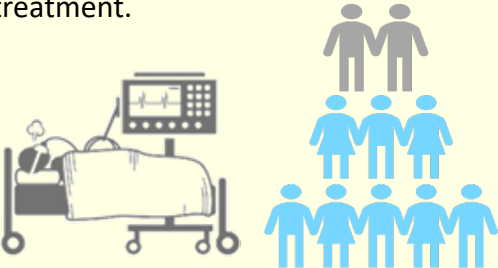

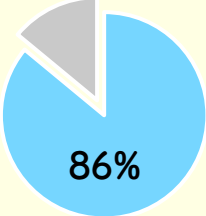
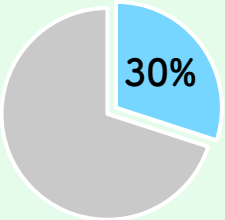


STEP
3

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.	
<p>8 out of 10 surrogate decision-makers fully understood the patient's desire for treatment.</p> 	<p>1 ~ 2 of the 10 surrogate decision-makers fully understood the patient's desire for treatment.</p> 
<p>About 86% of the patients' autonomy was respected until the end of their lives.</p> 	<p>About 30% of patients' autonomy was respected until the end of their lives.</p> 

Anxiety you felt before surgery

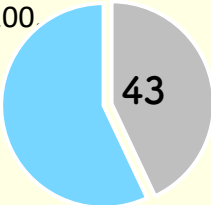

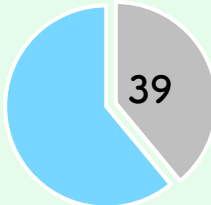

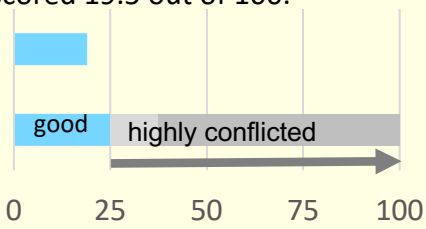
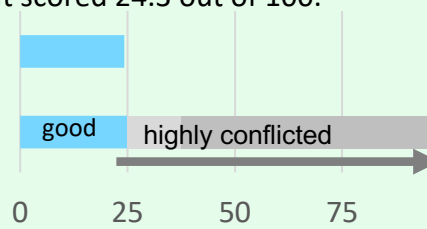
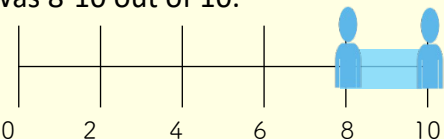
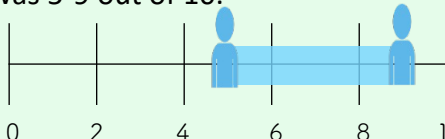
Before surgery, you should consider how you would like to be treated in a life-threatening situation. We compared patients who thought about it with those who didn't. Results revealed that there is no difference in the degree of anxiety in both patients. However, in some cases, ACP before surgery may 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	
<p>When anxiety is scored, it is reported to be 43/100.</p>  	<p>When anxiety is scored, it is reported to be 39/100.</p>  
The conflict that the surrogate decision-maker has after making surrogate decisions about your treatment.	
<p>It scored 19.5 out of 100.</p>  <p>0 25 50 75 100</p> <p>good highly conflicted</p>	<p>It scored 24.3 out of 100.</p>  <p>0 25 50 75 100</p> <p>good highly conflicted</p>
Did the surrogate decision-makers make decisions in accordance with your preferences? * Degree of confidence	
<p>It was 8-10 out of 10.</p>  <p>0 2 4 6 8 10</p> <p>median</p>	<p>It was 5-9 out of 10.</p>  <p>0 2 4 6 8 10</p> <p>median</p>

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.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

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.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

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.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

very important

neither

not matter at all

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.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

not matter at all

neither

very important

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

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

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.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

very important

neither

not matter at all



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 ?

Write down your decision,

Date : _____

- 
- 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.

SUPPLEMENT :

A watercolor illustration featuring a bright yellow sun with orange rays in the top left corner. The background is filled with various soft, pastel-colored flowers in shades of pink, orange, and purple. Some flowers are fully bloomed, while others are buds. The style is delicate and artistic, with visible brushstrokes and a soft, ethereal quality.

Let us take a look at the experiences of patients who have been admitted to the intensive care unit (ICU) and treated perioperative period.

Let us look at the experience of other patients. (From decision of surgery to surgery)

Let us imagine by referring to the experiences of those who have been admitted to the ICU after surgery.

Patients who never thought that their lives could have been in danger



The date of the surgery was decided, so I didn't have much time before I was hospitalized. I had a young child, so I prepared so that my family wouldn't be in trouble while I was in the hospital.

It was my 2nd surgery, so I didn't feel nervous. After I was admitted and discharged from the hospital, I worked on my schedule and plans until I returned to work, and mainly adjusted my work accordingly. I was sorting out what I could and couldn't do while I was in the hospital.



Patients who thought they could face a life crisis



I thought I might die, so I expressed my feelings to my family. If I was going to be bedridden or I was going to be a vegetative man, let me die. It's more like, I told them what I thought rather than discussing it.

My physician informed me that there was a high risk of complications after surgery, so I thought about my inheritance and insurance first. I hoped that if bad happens to me, my family would not be in any trouble.



What did patients consider and express about the crisis of their lives?

Patients who discussed with one's family and loved ones

I had been informed by my physicians that there was a high risk of surgical complications, so my family was not supportive of the surgery. However, it is my life. I expressed my intention to my family that I decided to take risks. And I told my family that I asked them if there was an accident. So, on the opposite, I prepared myself for surgery.



Patients whose family was anxious and found it difficult to discuss with them



When I informed my wife of the disease, she was already crying. I couldn't talk to my wife about the future or the prospect of her death. So, I wrote a farewell note. Afterward, I told my wife to look at it if any problems arise.

Patients who lived alone and thought they had no one to discuss with

I have only one daughter. I told my daughter not to do life-prolonging treatment. In fact, my heartbeat stopped and I almost died. At that time, I was unconscious and I don't remember anything, but my daughter and the physician seemed to think of a treatment together based on my hope for treatment.



What do healthcare providers want to know? What do you think?

Healthcare providers have different thoughts and opinions

No treatment provides a 100% benefit. Knowing the patient's values and treatment preferences in advance will be important in the treatment plan.



It is difficult to say to a patient who is undergoing surgery positively, "What if your life is in danger?" I think I make patients nervous. As a healthcare provider, I have the responsibility to save patients at all times.

I want the patient to recover well and be discharged. But I can't say it's 100% good. At the very least, when patients can no longer make their decisions, we want to provide them with the treatment and care they desire.

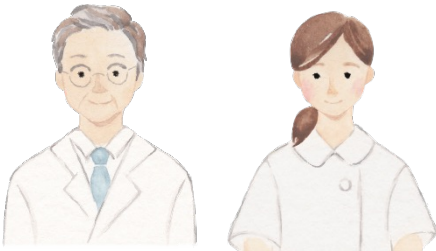


I expect the patient to be very anxious when they are informed and decide on the surgery. When I discuss ACP, I think my anxiety and worry become more intense. I don't want to discuss it because I'm worried about the mental health of patients and their families.

Information the healthcare provider wants to know

Are there any daily activities that you value (e.g., eating by yourself or not being bedridden)?

Is there any event you want to attend? (Weddings, entrance ceremonies for grandchildren, etc.)



What are your wishes and pleasure in life from now on?

Who is your surrogate decision-maker? Is there any treatment you do not want to receive?

Life after discharge



I thought about the pace of going to work as my physical condition recovered. It is encouraging that I am getting better slowly and returning to my society. I'm doing my best, saying, "I'm at ○% return to the community." Words from my friends also encourage me.

I was also worried when my physician informed me that I might die or that there was a high probability of such complications. But now, I can speak like this and do what I want to do. I'm happy to be alive.



I had cancer, so the treatment continued after the surgery. I was treated with anti-cancer drugs and had two surgeries, and I'm still doing well. After the first surgery, I didn't feel sick and was able to return to work right away. What a blessing.

I returned to my job about a week after I was discharged. However, my body and mind were not ready. It didn't work at all because I took time off from work. What I can say now is that it takes more time to return to the daily life before the surgery after I leave the hospital than the surgery. It means that it was harder than the surgery after discharges' life.

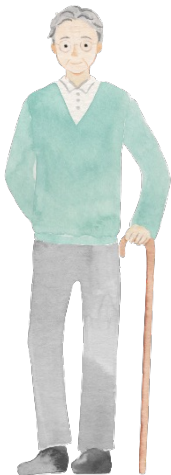


Advice from surgery after discharges' life



Prior to the surgery, I seriously considered my life. I think I was able to undergo a high-risk surgery because I thought about what I value and desire. I discussed with my physician until I was satisfied, and then I discussed with my family, and finally I decided by myself. I think that's important.

I think people have individual choices. I'm the type of person who chooses based on my intuition. Because I believed in my decision, I trusted myself and my physician, and entrusted my life. I think the most important thing is to be able to convince myself that it is all right.



I couldn't understand the detailed explanation of the surgery. Nor could I choose what I wanted to do. It was just that I trusted the healthcare providers. I think some people get anxious when they think about various things. I think you should value what you can believe.



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-

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