Advance Health Care Directives

An Informational Booklet on Health Care Decisions for Individuals who have Developmental Disabilities, their Families, Services Providers and Advocates on Health Care Decisions

Advance Health Care Directives

This form lets you have a say about how you want to be treated if you get sick.

If you need help filling it out you may want to tell someone what you want to write and what to check off.

This form has 3 parts. It tells you how to:

Part 1 **Choose a health care agent**

A health care agent is a person you trust who can make medical decisions or help make them for you if you are not able to make them yourself

Part 2 **Make your own health care choices or tell your health care agent what you want.**

This form lets you choose the kind of health care you want. This way, those who care for you will not have to guess what you want if you are too sick to tell them. yourself.

Part 3 **Sign the form**

It must be signed before it can be used.

You can fill out **Part 1**, **Part 2**, or both.

Fill out <u>ONLY</u> the parts you want.

<u>ALWAYS</u> sign the form in **Part 3**

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If you only want a health care agent go to Part 1 on page 4.

If you only want to make your own health care choices go to Part 2 on page 7.

If you want both then fill out Part 1 and Part 2

What do I do with the form after I fill it out?

Share the form with those who care about you:

- doctors
- nurses
- social workers

What if I change my mind?

- Change the form
- Tell those that care about you about your changes
- Tell your doctor or nurse that you don't want your agent to make decisions for you anymore.

What if I have questions about the form?

Bring it to your doctors, nurses, direct support staff, social workers, family or friends to answer your questions.

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Part 1

The person who can make medical decisions for you if you are too sick to make them yourself

Who should I choose to be my health care agent?

A family member or friend who:

- Is at least 18 years old
- Knows you well and knows what health care you want
- Is willing to be your health care agent and can be there for you when you need them
- You trust to do what is best for you
- Can tell your doctors about the decisions you made on this form

If you have a legal guardian, you should make that person your agent or at least talk to your guardian about this form. Your agent CANNOT be your doctor or someone who works at your community residence, hospital, or clinic unless they are a family member.

What will happen if I do not choose a health care agent?

Maybe someone else will be able to make decisions for you, but they might not know what you want or even know you at all. When you decide who you want your agent to be you must write his or her name on the form on page 5. You can also choose another person to be your agent if the first person might not be able to be nearby at all times. **If you don't state your wishes someone else may decide what's in your best interest.**

What kind of decisions can my health care agent make?

With your agreement, your agent can consent to any medical treatment that your doctor thinks will help you like

- medications
- medical tests
- surgery/operations

REMEMBER YOU CAN FIRE YOUR AGENT AT ANY TIME OR DISAGREE WITH YOUR AGENT'S DECISIONS.

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Life support treatments **-** medical care to try to help you stay alive longer

- CPR or cardiopulmonary resuscitation

cardio = heart pulmonary = lungs resuscitation = to bring back

This may involve:

- Pressing very hard on your chest again and again to keep your blood pumping
- Electrical shocks to jump start your heart
- Medicines in your veins
- Putting breathing tubes down your throat

- Breathing machine or ventilator

The machine pumps air into your lungs and breathes for you. You are not able to talk when you are on the machine.

- Dialysis

A machine that cleans your blood if your kidneys stop working.

- Artificial nutrition and hydration

If you can't chew or swallow you might be able to eat and drink through a plastic tube. The tube might go down your throat or it might be placed by surgery to go straight into your stomach. Unless you tell your health care agent that you don't want food and water to be provided by tubes, you will get fed by tube when your doctor believes you need that.

- Blood transfusions

To put blood in your veins.

- Surgery
- Medicines

End of life care - if you might die soon your health agent can:

- call a pastor, rabbi, priest or other religious leader
- decide if you die at home or in the hospital
- consent to hospice

Show your health care agent this form.
Tell your agent what kind of medical care you want.

Part 1: Choose your health care agent

Your Health Care Agent

I want this person to help make my medical decisions:

_____
first name last name

_____
street address city state zip code

_(_____)_____(_____)_____
home phone number work phone number

If the first person cannot do it, then I want this person to help make my medical decisions:

_____
first name last name

_____
street address city state zip code

_(_____)_____(_____)_____
home phone number work phone number

Put a check mark in the box if you agree with the following sentence:

❑ I have talked about artificial nutrition and hydration (tube feeding) with my health care agent and that person knows what I want.

If you trust your health care agent to make the best decisions for you and you do not want to give specific instructions go to Part 3 on Page 10 and sign this form. If you wish to give special instructions as to your health care choices go to Part 2 on the next page.

Name:_____

Date_____

Part 2

Make your own health care choices or tell your health care agent what you want.
Write down your choices so those who care for you will not have to guess.

Think about what you enjoy most in life.

Here are some things that are very important to me in my life (things like being with my friends, familiar staff, my residence, things I do for fun)

_____

_____

_____

Here are some things that I wouldn't want to have in my life (like not being able to eat or drink, being hooked up to a machine to help me breathe, Not being able to live in my home).

_____

_____

_____

If I am dying, I would rather be:

❑ at home ❑ in the hospital ❑ I am not sure

Is religion or spirituality important to you?

❑ Yes ❑ No

What should your doctors know about your religion or spirituality?

_____

_____

❑ If I am so sick that I am expected to die soon, I do not want a permanent feeding tube for food and water and I know if I don't ☑ check this, I will be fed by a tube if my doctor believes it will help me

If you are sick, your doctors and nurses will always try to keep you comfortable and free from pain.

Name:_____

Date_____

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Part 2: Make your own health care choices
or tell your health care agent what you want

Life support treatments are used to try to keep you alive. These can be CPR, a breathing machine, feeding tubes, dialysis, blood transfusions, or medicine.

Please read this whole page and then put an X in the box next to the sentences that you most agree with.

➲ ***If I am so sick that I am expected to die soon:***

❑ I want my HEALTH CARE AGENT to decide for me based upon what he or she knows about me and thinks is best for me

➲ ***If I am so sick that I am expected to die soon, I want to:***

❑ Try all life support treatments that my doctor think might help

If the treatments DO NOT WORK and there is little hope of getting better, I DO NOT WANT TO STAY on life support machines.

If I am so sick that I am expected to die soon, I want to:

_____

_____

_____

_____

_____

_____

❑ If I am so sick that my heart stops beating or I stop breathing, I DO NOT want CPR

Name:_____

Date_____

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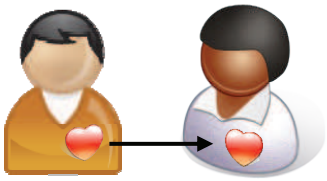
Part 2: Make your own health care choices

Your doctors may ask about organ donation and autopsy after you die. Please tell them your wishes. If you don't make a choice about organ donation, another family member or friend may be allowed by law to choose to donate your organs after you die.

Put an X next to the sentences that you most agree with:

➲ ***Donating (giving) your organs can help save lives.***



❑ I WANT to donate my organs

Which organs do you want to donate?

❍ Any organs

❍ Only _____

❑ I DO NOT want to donate my organs

❑ I want my HEALTH CARE AGENT to decide

❑ I want my family to decide

➲ ***What should your doctors know about how you want your body to be treated after you die?***

_____

_____

_____

Name:_____

Date_____

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Part 3

Sign the form

Write down your choices so those who care for you will not have to guess

➲ ***Before this form can be used, you must:***

- sign this form
- if you are not able to sign the form, you can tell someone else to sign it for you while you and your witnesses are present
- have two witnesses sign the form

➲ ***Your witnesses must:***

- be 18 years of age or older
- see you sign this form

➲ ***Your witnesses cannot be your health care agent, doctor, nurse, or social worker***

➲ ***Right to Revoke***

You have the right to fire your agent at any time by telling him or her or telling your doctor that you don't want your agent to make decisions with or for you. AND, if you and your agent <u>disagree</u> about a decision, <u>your</u> decision will be the one the doctor must follow.

➲ ***Give this form to your Community Residence Director <u>ONLY</u> if you live in an OPWDD-type facility.***

For people who live in an OPWDD operated or certified residence at least one witness must be a person <u>NOT</u> affiliated with the residence and one witness must be either a medical doctor or psychologist with significant experience in caring for people who have developmental disabilities (refer to Public Health Law Section 2981 and 14 NYCRR 633.20 (a) (2) (ii)).

Also, your ***Community Residence Director*** should review 14 NYCRR 633.20, and his or her duties. If you have a guardian, you and your Community Residence Director should discuss this form and your wishes with him or her.

You and your witnesses need to sign their names on page 11.

Name:_____

Date_____

Part 3: Sign the Form

Sign your name and have your witnesses sign their names and write the date

Sign your name and write the date

_____/_____/_____
sign your name date

Witness #1

_____/_____/_____ __
sign your name date

_____
print your first name print your last name

_____
address city state zip code

Witness #2

_____/_____/_____
sign your name date

_____
print your first name print your last name

_____
address city state zip code

You are now done with this form. Share this form with your doctors, nurses, social workers, friends, and your family. Talk with them about your choices.

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For New York State OPWDD Community Residences Residents <u>ONLY</u>

➲ *Directors of OPWDD facilities are under an obligation to:*

- establish procedures to inform adult residents of their right to designate a health care agent and of their right to tell the agent what health care they want;
- to help adult residents understand how to write a ***Health Care Proxy***, *how to revoke it, and what he or she can say about what they want;*
- to make sure that the writing of a health Care Proxy is ***VOLUNTARY***;
- to tell any other people who support or care for the resident who his or her health care agent is; and
- to give every resident and his or her family when they come to live at the home, a printed statement of these rights and duties. [14 NYCRR 633.20 (a) (20) and (23)].

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For more information contact

NYSARC Inc. Established 1949

393 Delaware Avenue
Delmar, New York 12054
Phone: 518-439-8311
Fax: 518-439-1893
www.nysarc.org