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## MENTAL HEALTH ADVANCE DIRECTIVES: USING HEALTH CARE PROXIES & ADVANCE DIRECTIVES FOR MENTAL HEALTH TREATMENT

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### WHAT ARE HEALTH CARE PROXIES AND ADVANCE DIRECTIVES?

Health care proxies and advance directives are legal documents you use to take more control over your future health care if you become unable to make your own decisions.

In a health care proxy you pick someone to be your health care “agent.” Your agent will have legal authority to make health care decisions for you, including decisions about your mental health treatment, if you lose “capacity” to decide for yourself.

Usually, as an adult, you have the legal right to say “yes” or “no” or “enough, stop” to any health care, including mental health care. This is true even if you have a mental health diagnosis and even if you are in a hospital.

However, sometimes a doctor will decide that you have lost “capacity” to make your own decisions. If you lose your capacity to decide and a decision must be made, your agent will step in. In a health care proxy you may give your agent instructions on how to make decisions for you. If you give instructions, your agent must follow them.

Health care proxies are covered by a New York State Law which describes the process for making a valid health care proxy and how providers must follow your agent’s decisions. The basic rule for providers is, “A health care provider shall comply with ... decisions made by an agent ... under a ... health care proxy ...” NY Public Health Law 2984(2).

In an advance directive, you give instructions about your future care, in case you lose capacity, but you do not name an agent. Properly done advance directives are binding on providers, which means they must be followed. Advance directives are often used to state what care people want and do not want at the end of their lives. These kinds of advance directives are called “living wills.”

A health care proxy is the more powerful tool, because you are selecting an agent to speak for you, but an advance directive is also valuable. If you do not have someone to be your agent, your advance directive will convey your choices about treatment whenever you lose capacity to make health care decisions.

## ARE HEALTH CARE PROXIES AND ADVANCE DIRECTIVES THE SAME AS WELLNESS RECOVERY ACTION PLANS?

No. Wellness recovery action plans (WRAPs) do not legally appoint an agent and may not be binding on providers. However, WRAPs are important for managing crises before you have to go to a hospital. WRAPs also cover important practical topics that health care proxies and advance directives do not. Ideally, you would have a health care proxy or advance directive, and a WRAP.

## WHY SHOULD YOU PREPARE HEALTH CARE PROXIES AND ADVANCE DIRECTIVES?

An agent has a legally recognized role to express your choices, and to advocate for them, when you cannot speak for yourself. Preparing a health care proxy or advance directive gives you a chance to think about and discuss your treatment preferences and plan ahead. You decide when to discuss these matters and with whom. You can use your knowledge and experience about what treatments worked well for you in the past, and what did not.

A provider who sees your health care proxy or advance directive will know your choices and your experiences with treatment. Providers are obligated to honor your agent's decisions to refuse a treatment. Even if you cannot always get your preferred treatment, your instructions will may have an important influence on your care.

You can write what will help you avoid a crisis and what you want a hospital to try before restraint or seclusion. This may help avoid restraint, seclusion and emergency medications. The hospital will honor your wishes if possible.

You can state your choices about medications to use in emergency circumstances in a psychiatric hospital. This may include using the types of medication that you would choose if necessary, and which to avoid. Again, if it is possible, the hospital will honor your wishes.

A hospital is less likely to go to court to ask for an order for mental health treatment over your objection, if you have a health care proxy. If there is a court hearing, your health care proxy may help persuade the court that you should not be treated over your objection.

If you have an advance directive that says "no" to certain treatment, it may also persuade a court not to order that treatment over your objection.

In a Kendra's Law (Assisted Outpatient Treatment, or "AOT") case, the doctor who prepares your written treatment plan must consider your choices in your health care proxy.

The agent you pick in a health care proxy should remain in charge of your health care even if a judge later appoints a guardian for your personal needs. Also, preferences in your advance directive must be considered by a guardian who is appointed to handle your health care.

Having a health care proxy or advance directive in place can also give you peace of mind. You will have taken powerful steps to take good care of yourself in case there is a crisis.

## ARE THERE LIMITS ON WHAT HEALTH CARE PROXIES AND ADVANCE DIRECTIVES CAN DO FOR ME?

Yes. Health care proxies and advance directives cannot prevent civil commitment for mental health care. They cannot legally prevent you from being committed to a hospital you do not like. However, they might help guide your providers or help you or your agent advocate for a hospital that you prefer.

Health care proxies and advance directives cannot legally prevent restraint, seclusion or forced medication in an emergency situation involving imminent threat of serious injury to self or others in a hospital. However, they can help communicate what may help you stay calm and avoid these measures.

## OUR FORM

Disability Rights New York (DRNY) has developed a health care proxy form that you can use. The form is designed to help you lay out your choices about mental health treatment. The form also includes a link to another document that you can use to express your decisions about end-of-life treatment, if you wish.

You can create a limited health care proxy that simply appoints an agent by completing Parts A and C of DRNY's form. You can also complete Part B to give instructions to your agent.

Alternatively, you can create an advance directive using only Parts A and C of DRNY's form, if you do not have an agent.

You can find the form here: <http://bit.ly/NY-HealthCareProxy-MH>

You may want to work with someone who has had training on completing health care proxies or advance directives, such as a trained peer specialist. Your social worker or case manager, if you have one, may also be helpful.

## WHEN SHOULD I DO A HEALTH CARE PROXY OR ADVANCE DIRECTIVE?

You must be at least 18 years of age and legally competent to sign the form. In other words, you must be able to make health care decisions. Health care proxies and advance directives cover important decisions. Do them when you are well and at your best. Do not wait for a crisis. Plan ahead.

## HOW LONG WILL IT TAKE TO WRITE A PROXY OR ADVANCE DIRECTIVE?

You may need to think about and discuss the information required over a period of time. For some people developing a health care proxy or advance directive is more of a process than an event.

You may need to get used to having some control over your own care, and to planning for a situation you do not want to happen. There may be painful memories. It may help to have peer support as you prepare your health care proxy or advance directive.

It may also take time to find a good and willing agent. You will need to line up witnesses for signing. A trained peer specialist may help with critical practical details.

## WHAT AUTHORITY WILL MY AGENT HAVE?

**Authority to Make Decisions?** Your agent will be able to make decisions only if you lose capacity to make decisions for yourself. The agent's decision-making power ends when you regain capacity.

**Authority to Access to Your Records?** To make decisions for you, your agent will have access to your confidential medical and mental health information.

**Authority over what Health Care?** Unless your proxy says otherwise, your agent will have authority to make "any and all" health care decisions you could have made. This includes medical and mental health care. Your agent will have the authority to agree to or refuse treatment on your behalf. Your agent may also agree to treatment under certain conditions. See the next section for how your agent is to make decisions. Your agent cannot demand a particular provider or treatment, but may have influence.

Your agent's authority includes life-sustaining treatment in case you become gravely ill. For example, treatment that may include CPR, respirator, and dialysis. Treatment decisions may include organ donation in the event you pass away.

**Any Limitation on Your Agent's Authority?** You can limit your agent's authority in any way you want. You can limit your agent from admitting you "voluntarily" to a hospital. If you use DRNY's form your agent will be prohibited from admitting you voluntarily, because the form includes this limitation.

You can limit your agent through providing specific instructions. For example, you can list treatments that you do not want, under any circumstances; or, you can list conditions under which you will accept certain treatments.

For more information about instructions, see HOW DO I GIVE INSTRUCTIONS TO MY AGENT, OR IN AN ADVANCE DIRECTIVE? below.

## HOW MUST MY AGENT DECIDE?

Your agent is to follow your wishes, if your agent knows them or can reasonably figure them out. Your agent must do what you would do. Make sure your agent knows your wishes, values and beliefs very well. Discuss them with your agent. Also, write them as instructions in your health care proxy.

You do not have to try to cover every specific future possibility in the instructions. Cover what matters most to you. DRNY's form gives many possibilities in Part II. You can also give general principles to guide your agent in situations you did not expect.

Unless you limit your agent, when your agent cannot figure out what you would do, your agent will decide what is in your "best interest." This means your agent is to weigh the pros and cons of the proposed treatment, and any other options.

Your agent would normally consult with the treating doctor. You can instruct your agent to consult with other people you trust, but still leave the final say to your agent.

## HOW DO I GIVE INSTRUCTIONS TO MY AGENT, OR IN AN ADVANCE DIRECTIVE?

You can give instructions orally or in writing to your agent. It is best to do both. Write your instructions as clearly as possible and discuss them with your agent to make sure your agent understands.

There are many options for instructions on mental health care in Part II of DRNY's form. You can fill out as many or as few as you want. You can use the form to say "yes" or "no," or "yes but only if ...." You can use "yes but only if" to set conditions for a treatment you dislike but may need to receive in order to recover.

You can also state general priorities you want your agent to follow when your specific instructions do not cover a situation.

Be as specific as possible about treatments you do not want, or want only under certain conditions. Giving reasons which explain your choices to your agent and providers can help avoid or overcome challenges to your proxy or AD.

## WHAT ABOUT END-OF-LIFE SITUATIONS?

Many people use health care proxies or advance directives to say what medical care they want or do not want or to keep them alive if they become gravely ill or injured – such as CPR, respirators, or tube feeding. You can give instructions on these medical treatments whether or not you have an agent. If you do not have an agent, you can complete a form called a "living will" for end-of-life decisions.

Your agent may decide about life-sustaining treatments, unless you limited your agent's authority to do so. Your agent must make decisions according to your wishes, including your religious and moral beliefs, if known to your agent or if your agent can reasonably figure them out. If your agent does not know what you would do, your agent must decide in your "best interest." There is only one exception, the use of a tube or IV food and water, when your agent must know or be able to figure out your wishes to make a decision.

DRNY's form focuses on mental health treatment and does not offer choices for end-of-life decisions, but there is a link to another form you may use for these choices. If you wish to do both, click on the link to the second form, print it out and complete it along with DRNY's form. If you complete and execute our form without completing the end-of-life instructions, you can still complete the

instructions at a later time. Just be sure to give the end-of-life instructions to your agent if you have one, and to the providers and other people you gave your health care proxy or advance directive.

It is important that you name the same person to be your agent for end-of-life decisions, as your agent for mental health treatment. Legally, you can have only one agent at a time.

## WHAT DOES IT MEAN TO LACK CAPACITY TO MAKE MY OWN HEALTH CARE DECISIONS, AND WHO DECIDES?

Your treating doctor decides whether you have lost capacity. If you have a health care proxy, the doctor must record this decision in your medical record, including the reasons for incapacity and how long it is expected to last.

You must get oral and written notice of the doctor's decision, with limited exceptions. Your agent must also get notice. Both of you should be able to see the decision in your record. Even if you have no health care proxy, the decision that you lack capacity will be in your record and the record must be made available to you, with limited exceptions.

## CAN I OBJECT TO THE DECISION THAT I HAVE LOST CAPACITY? AND WHAT IF I OBJECT TO TREATMENT, OR TO MY AGENT'S DECISIONS?

Under New York's health care proxy law, you can object to the doctor's decision that you have lost capacity. If you object, you are still in charge, unless a court decides you have lost capacity. You also can object to treatment decisions made by your agent. Unless a court decides you have lost capacity, your decision must prevail.

If you are involuntarily committed to a psychiatric hospital, you can still object to treatment whether or not you have a health care proxy. This includes major medical treatment, as well as mental health treatment. Your Mental Hygiene Legal Service attorney can advise you about your rights, and you will have the right to representation by Mental Hygiene Legal Service in such matters.

## HOW DO I PICK AN AGENT?

Your agent -

- must be at least 18 years of age and competent to serve;
- can be a doctor, but not your current treating doctor; and
- cannot be the operator, administrator or an employee of an Office of Mental Health (OMH) or Office of Persons With Developmental Disabilities' (OPWDD) licensed residence or of a hospital or nursing home that you are in, unless they are related to you.

You should pick an agent -

- you trust;

- who can and will stand up for your wishes and best interests;
- who knows you well and understands your condition;
- who has good judgment;
- who lives in your area, if possible; and
- who actually will be able, willing and available to serve.

Also, pick an alternate agent if possible, in case your first choice is unable to serve for any reason.

If you name your spouse as your agent, s/he is automatically removed if you get divorced or legally separated - unless your health care proxy says otherwise.

*Always ask the individual for permission before you name them as your agent!*

## WHAT ABOUT WITNESSES?

You must have witnesses follow the below instructions for your health care proxy to be valid in New York. It is best to have witnesses follow the same instructions for an advance directive.

Sign and date the form in front of two witnesses. The witnesses must be at least 18 years of age, and they must be willing to say you are of sound mind.

Your agent cannot be a witness. Also, do not ask your alternate agent to be a witness.

One witness must be a psychiatrist if you are a patient in a psychiatric hospital. Even if you are not, you can ask your psychiatrist, therapist or physician to be a witness, but this is not required. If you do have your psychiatrist witness the document, this will give additional weight to the document if there is ever a question about your competence to prepare the document.

If you are in an OMH or OPWDD licensed residence or a psychiatric hospital, one witness must be unaffiliated with the facility. This could be a friend or family member. If you are in a hospital, try to ask someone other than another patient.

## HOW DO I MAKE MY HEALTH CARE PROXY OR ADVANCE DIRECTIVE KNOWN?

You cannot keep the health care proxy or advance directive to yourself, or it will not work.

Make sure that you have enough copies to distribute to the people listed below.

Your health care proxy or advance directive should go to the following: 1) your agent and alternate; 2) your health care providers; 3) hospitals where you have been a patient; 4) your case manager, if you have one; and 5) family members and friends you think should know about your health care proxy or advance directive.

You can sign and have witnessed more than one original, so that you can give one to your agent and keep one for yourself in a safe place. You should keep another copy with your emergency papers that can easily be found. Keep extra copies for others who may need them later on.

If you completed a form on life-sustaining treatment, attach a copy of that form to all originals and copies of your health care proxy or advance directive.

Follow the same steps if you replace your health care proxy or advance directive with a new one, or add instructions.

Fill out and carry the wallet card, which is attached to DRNY's form. Staple or tape the wallet card to your insurance card. Hospitals will find your insurance card.

If you are hospitalized, try to tell your agent right away, and tell the hospital staff and Mental Hygiene Legal Service about your health care proxy or advance directive.

## CAN I CHANGE MY MIND ABOUT MY AGENT, OR MY INSTRUCTIONS?

You can revoke your health care proxy, unless a court decides you lack capacity to do. This will cancel the entire document.

You can object to a decision your agent made, even if your agent was following your instructions. The provider must accept your decision, unless a court decides you lack capacity.

You can change or add instructions to an existing health care proxy or advance directive by putting instructions in another document. Distribute these documents to the same people and hospitals who have your original health care proxy or advance directive.

## HOW DO I REVOKE MY HEALTH CARE PROXY OR ADVANCE DIRECTIVE?

You can revoke the health care proxy orally or in writing, to your agent or to a provider. You may also revoke your health care proxy by actions clearly showing you mean to revoke it, like tearing it up.

It is best to revoke the health care proxy in writing and get back copies you gave to others. Revoking removes your agent and alternate, and cancels any choices you wrote in the health care proxy.

A new health care proxy that is properly signed and witnessed automatically revokes any earlier one. Do not complete a new health care proxy form – for example, when you go to a hospital - if you want to keep the health care proxy you already have.

If you already have a health care proxy covering some things and want to keep the choices you made in it, copy them into your new health care proxy.

You should revoke an advance directive the same way as a health care proxy.

You might get pressure to revoke a health care proxy or change your instructions. You might find support to stand your ground from your network – for example, from your agent, peer specialist, or social worker.

## HOW LONG WILL MY HEALTH CARE PROXY OR ADVANCE DIRECTIVE LAST?

You can choose for the health care proxy or advance directive to last indefinitely, only until a certain date, or only until a certain condition that you name is met.

Usually it is better to pick “indefinitely,” but then you need to update the proxy when things change. Review it at least every year.

## CAN COURTS DECIDE DISPUTES ABOUT PROXIES AND ADVANCE DIRECTIVES?

Not many disputes about health care proxies and advance directives get to court, but courts can decide disputes about these documents. If you are in a psychiatric hospital, Mental Hygiene Legal Services may be able to represent you in disputes about these documents.

## IS THIS Q&A DOCUMENT LEGAL ADVICE?

No, this document is not legal advice. It is a public education tool. If you have questions about how the law applies to your situation, get legal advice. If you are in a psychiatric hospital, Mental Hygiene Legal Services may be able to advise you. You can also try contacting us for advice or assistance.

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