Transitioning Your Health Care

Helping You Make Wise Decisions

This Guide was Created by the the Governor's Advisory Council for Exceptional Citizens (GACEC) of Delaware

Table of Contents

Health Care & Dental Transition at Nemours/ A.I DuPont & ChristianaCare

Around age 18 families should set up a meeting with the Transition of Care Department at Nemours/Alfred I. DuPont Hospital for Children in Wilmington, DE. By their 21st birthday, all patients treated at AIDIHC, must transition to adult health care. Since many transitions occur between the ages of 18 and 30, families often aren't adequately prepared.

The Transition of Care program is a clinical consultation service designed to help teenage and young adult patients (particularly those with special health care needs) and their families transition as smoothly as possible from pediatrics into adult health care. They address both the medical and non-medical issues during the transition (educational, vocational, legal guardianship, residential options, etc.). They are experienced in covering chronic and complex conditions involving the full range of medical specialties.

The Center for Special Health Care Needs at ChristianaCare serves young adults 18+ with medically and socially complex conditions.

How to Find an Adult Provider

It is crucial to find your adult doctors early. You may have a family doctor you can keep. If not, you should begin seeing an adult doctor around age 18 to 21. If possible, have your first appointments and send your records to your new doctors while you are still being seen by your old doctors in case there are questions about your condition or treatment.

Ask your current doctor for a referral

Ask your care coordinator or case manager

Consider asking your parents doctor for suggestions

Call your insurance company

Ask friends for a suggestion

Check with your local support group

Call a large medical or specialty rehab center

It is vital to find a doctor who makes you feel comfortable and can meet your needs. Before you choose your new doctor, call his/her office and ask to speak with a staff member who has time to answer your questions, or make an appointment to meet the doctor and staff in person.

Questions You Need to Ask

Ask Staff at the Dr's Office:

1. Does the doctor accept your insurance coverage? Is he/she taking new patients?
2. Is the office accessible (easy to reach and easy to get around inside the building or clinic area)?
3. What are the office hours? Can the doctor be reached after hours?
4. How will the doctor exchange information with your specialists?
5. Will the office be flexible to meet your health needs (allow service dog, schedule visits so you will not miss a meal, or schedule at quiet times if you are sensitive to noise)?
6. What is the average wait time?
7. Are basic lab tests offered at the office?

Questions to Ask A New Doctor:

1. Would you discuss my health history and special needs with my pediatric doctor?
2. Do you currently see patients with health conditions similar to mine?
3. At what hospital do you schedule procedures?
4. Where did tyou get your medical school and specialty training? Are you board certified?
5. Do you have any special interests or advanced training?
6. Have you worked with people with my disability before?
7. Will you allow my caregiver, advocate or supported decision maker in the room with me?

Questions for You:

1. Does the doctor or office staff listen to your questions, or is he/she continually interrupting you?
2. Can the doctor or office staff explain information so that you can understand it?
3. Does the doctor or office staff take enough time to answer your questions?
4. Does the doctor or office staff treat you with respect?
5. How did you feel after speaking with the office staff or doctor?

Calling In a Prescription

When your doctor wants you to take medication, the prescription may be called into a pharmacy by the doctor's office and you will have to pick it up. If the doctor gives you a written prescription, you will have to take it to a pharmacy to get it filled with the proper medicine.

If your prescription has refills, when you have about a weeks' worth of medication left, you will have to call the pharmacy to get it refilled so you do not run out of your medicine.

When you call the pharmacy, you may get a phone answering system that asks you questions. You can respond by pushing the numbers you need to or wait for the instructions to speak to a person. Make sure you have the bottle in your hand when you make the call or write down the information from the bottle in the blanks below before you make the call.

What is the phone number of the pharmacy?_____

What is the prescription number? _____

What to say:

Hello, My name is _____

I need a prescription filled.

The prescription number is _____

When will it be ready? _____

Do you deliver?_____ If yes, when?_____

If there is a co-pay, how much money will I need ?_____

Thank you for your help.

Supported Decision-Making and Health Care

Transitioning to adulthood is an emotional and exciting time of life. Individuals with intellectual disabilities can use supported decision-making (SDM) by getting supporters to help them make complicated decisions. The supporters can be family members, friends, or a trusted person that helps communicate a decision clearly. For individuals with intellectual, developmental or other disabilities, supported decision making offers an alternative to guardianship or conservatorship.

Using supported decision-making for health care or medical decisions allows the individual with a disability the freedom to live and make important life decisions with assistance from their chosen supporter. The person with the disability ultimately makes the final decision about health care under SDM.

The National Resource Center for Supported Decision-Making brings together leaders and partners who are experienced in SDM. On their website (www.supporteddecisionmaking.org) you will find the laws in each state regarding supported decision making any court orders, resources and information. If you are planning to move to another state, it is good to know the laws before you relocate. The Delaware section is a helpful place to look to understand the SDM laws of Delaware since 2015.

If you take your supporter to the doctor's office with you, they may have to sign a Health Insurance Portability and Accountability Act (HIPPA) waiver to learn about your personal information. To learn more about HIPPA visit the DHSS website. They can accompany you and sit in and listen while the doctor speaks to you about your medical care.

Make sure you let your doctor's office know that you use a supporter to help you make decisions.

What Your SDM Supporter Can Do For You

Help you understand forms you need adn what they mean.

They can remind you to take your medicines.

Explain what doctors and nurses say to make it easier to understand.

Give the doctor's office your decisions.

Help you remember your health care issues and symptoms.

Help you decide to be seen by a doctor and which doctor to see.

Assist in understanding and getting copies of your medical records.

Explain health insurance terms and discuss your co-pay if you have one.

Discuss the benefits and/or side effects of your prescriptions.

Help you weigh the decision to have surgery or health related treatments.

Help you locate alternative treatments.

Help you decide if you need a second opinion.

Help with transportation arrangements or take you to the doctor.

Helping Your Supported Decision Maker Help You

You may want to write down what you expect from your supporter. This way their role is clearly defined so there is no confusion as to what you expect them to do.

Creating a supported decision-making agreement between you and your supporter or supporters if you have more than one defines their role in your life. You can also give the agreement to your doctor so they know the involvement of the supporter in your life.

If you do not have a guardian or conservator, supported decision-making is a way for you to keep your independence regarding decisions about your life. The National Resource Center for Supported Decision-Making has a number of model agreements that you can alter depending upon your needs.

Here is a link with the example on the following pages Supported Decision-Making Agreement from Delaware Health and Social Services (DHSS).

Supported Decision-Making Agreement

Delaware Code Title 16, Chapter 94A, Section 9401A

This form is to be read aloud or otherwise communicated, in the presence of the witnesses and parties to the agreement. The form of communication shall be appropriate to the needs of the individual with the disability, that individual's language (an interpreter must be present for foreign languages and alternative forms of communication) and sensory processing wants or needs.

This form is to be used for the appointment of a person(s) to help me make decisions. A Supported Decision-Making Agreement is a written agreement between me and my appointed person(s). The person(s) I appoint helps me make decisions. My appointed person(s) does not make decisions for me. A Supported Decision-Making Agreement is effective if I am at least 18 years of age and able to understand the nature and effect of this agreement. I can revoke this agreement at any time and with notice to the appointed Supported Decision-Maker(s). This agreement takes effect as soon as it is signed by all the required individuals. This agreement supersedes any other Supported Decision-Making Agreement made by me. This agreement is not durable and would not survive a determination of incapacity under Delaware Code.

This is the Supported Decision-Making Agreement of:

1. Name_____ Date of Birth_____
Address_____
Phone_____
Email_____

2. **My Supported Decision-Maker**
I appoint the following person(s) to be my Supported Decision-Maker(s):
Supported Decision-Maker:
Name_____
Address_____
Phone (wk)_____ (hm)_____(cell)_____
Email_____

3. Alternate Supported Decision-Maker (Optional) – **if there is no Alternate, please cross out this section.**
If my Supported Decision-Maker named above declines to help me or is unable or unavailable to help me within a reasonable time period, I want the following person to help me as my Supported Decision-Maker:
Name_____
Address_____
Phone (wk)_____ (hm)_____(cell)_____
Email_____

4. **Areas I Want My Supported Decision-Maker to Help Me**
I want my Supported Decision-Maker(s) to help me make decisions in the following areas:

a) **Health Affairs** _____initials
Access or obtain any information that will help me make decisions. Help me make appointments with health care providers. Help me keep track of information about my health care, including my medicalrecords and help me with creating my health care plan and activities of daily living. Help me understand information about health care decisions I have to make, now or in the future, so that I can make my own decisions about my health care. Communicate or assist me in communicating my decision to other persons.

My Supporter may see my private health information under the Health Insurance Portability and Accountability Act of 1996, and I will provide a signed release.
Add any additional information:
_____

_____

_____

b) **Supportive Services** _____initials
Defined as a coordinated system of social and others services supplied by private, state, institutional, or community providers designed to help maintain the independence of an adult.
Communicate or assist me in communicating my decision to other persons. For more specifics see DE Code, Title 16, Ch. 94A. Access or obtain any information that will help me make decisions. My Supporter may see my educational records under the Family Education Rights and Privacy Act of 1974 (20 U.S.C. Section 1232g), and I will provide a signed release.
Add any additional information:

_____

_____

_____

c) **Financial Affairs** _____initials
Access or obtain any information that will help me make decisions. Help me obtain information
and understand information about financial affairs, including but not limited to assets and resources and
their use and management for my clothing, support, care, comfort, education, health care and shelter.
Communicate or assist me in communicating my decision to other persons.
Add any additional information:

_____

_____

_____

5. **Areas I DO NOT Want My Supported Decision-Maker(s) To Help Me (if any)**
I do not want my Supported Decision-Maker(s) to help me in making these kinds of decisions:

_____

_____

_____

6. **Signatures (me, my Supported Decision-Maker(s) and the witnesses must sign together at the same time)**

Adult
I am at least 18 years of age and I understand the nature and effect of this agreement.

_____	_____	_____
Print Name	Signature	Date

Supported Decision-Maker #1

_____	_____	_____
Print Name	Signature	Date

Alternate Supported Decision-Maker (optional) - if there is no Alternate, please cross out this section.

_____	_____	_____
Print Name	Signature	Date

Witnesses
Two adults must witness my signature and the signature(s) of my Supported Decision-Maker(s) and sign together in my presence. The witnesses CANNOT be a Supported Decision-Maker of the adult. They also CANNOT be an employee or an agent of the Supported Decision-Maker. As well, they CANNOT be a spouse, child or parent of the Supported Decision-Maker or an employee of the Supported Decision-Maker.

_____	_____	_____
Print Name	Witness Signature	Date

_____	_____	_____
Print Name	Witness Signature	Date

Concerns about adults who may be in need of protective services should be evaluated and reported in accordance with Title 31 chapter 39.A person, who in good faith acts in reliance on an authorization in a supported decision-making agreement, or who in good faith declines to honor an authorization in a supported decision-making agreement, is not subject to civil or criminal liability or to discipline for unprofessional conduct. For further guidance please see Title 16, chapter 94A.

Supported Decision-Making Agreement Declaration

My relationship to the Adult is:

_____

I am willing to act as a supporter.

I acknowledge the duties of a supporter under DE Code Title 16, Chapter 94A.

Supported Decision-Maker #1

_____ _____ _____
Print Name Signature Date

Alternate Supported Decision-Maker (optional) <u>if there is no Alternate, please cross out this section.</u>

_____ _____ _____
Print Name Signature Date

Legally Protecting Your Health Care Rights

If you were injured or too ill to express yourself having legal documents to represent your wishes is very important. They make you prepared for the known and unknown situations that arise in life.

An **Advance Health Care Directive** is a guide for family members, friends and healthcare professionals which relieves them of the duty of making decisions for you in emergency situations. This is the same as a Living Will or Medical Power of Attorney (POA). They only become effective when a person lacks capacity to make their own decisions.

Delaware Medical Orders for Scope of Treatment (DMOST) is based on communication between patient, health care agent or other designated decision-maker and health care professionals that honor the patients medical preferences that will die within a year. They are an actionable medical order used in all health care settings.

A **Durable Power of Attorney** names a proxy or a person that you trust to make wise health, financial, business,and legal decisions for you or enforce the ones you want followed if you cannot make your own decisions. It is stronger than a regular power of attorney because it is “durable” in other words, does not end at death.

When your documents are completed and witnessed or notarized:

1. Keep the originals in a safe place that is easily accessible.

2, Keep a copy with you when traveling.

3. Give a copy to your doctor.

4. Give a copy to your medical power of attorney if you have one or the person who will make decisions for you.

5. Keep a record of who has one with the original.

6. Talk to important people in your life about your advanced care directives.

7. Carry a card in your wallet mentioning you have advance care directives.

Advance Health Care Directive

This form was developed by the Committee on Law and the Elderly of the Delaware Bar Association and approved for use by the Office of the Attorney General of the State of Delaware. Please use an attorney when filling out this document. (Used with permission)

GENERAL INSTRUCTIONS

You should read this form carefully before filling it in. You should fill it in completely. If there are health care decisions you do not want to make, you should strike the wording of that decision rather than leave it blank. You may not change the qualifications for witnesses or agents, even if you cross out the wording. You should write legibly.

After you have filled out the form completely, you should sign the form before a notary public. Although signing before a notary public is not legally required, it is advisable. It is advisable because the notary, as well as your witnesses, can testify as to your competence when you sign the directive, if your competence becomes an issue. Notaries, who are registered with the State, are often easier to locate later than witnesses.

You should retain your original Advance Health care Directive, and give copies to your doctor, agent, spouse, family members, and close friends, if you desire. You should explain to each person who receives a copy of your health care directive what choices you made on the form, and why. This will help if, while you lack competence, there arises a need to make a health care decision that is not explicitly set forth on your advance health care directive form.

This form does not contain all of the types of health care decisions you are legally entitled to make. For example, the form does not give you the opportunity to nominate a guardian, in the event you become incompetent and need one. Also, the form does not give you the opportunity to designate a primary care physician, or another person, to certify that you lack the capacity to make your own decisions on health care. Finally, the form does not include a provision that accommodates a person's religious or moral beliefs. If you would like to exercise these options, you should talk to an attorney. If anything on the form conflicts with your religious beliefs, you should contact your clergy.

PART I. INSTRUCTIONS FOR HEALTH CARE DECISIONS

If you are an adult who is mentally competent, you have the right to accept or refuse medical or surgical treatment, if such refusal is not contrary to existing public health laws. You may give advance instructions for medical or surgical treatment that you want or do not want. These instructions will become effective if you lose the capacity to accept or refuse medical or surgical treatment. You may limit your instructions to take effect only if you are in a specified medical condition. If you give an instruction that you do not want your life prolonged, that instruction will only take effect if you are in a "qualifying condition." A "qualifying condition" is either a terminal condition or permanent unconsciousness.

If you want to give instructions to accept or refuse medical or surgical treatment, you should fill in the spaces on the following page. You may cross out any wording you do not want.

A. END OF LIFE INSTRUCTIONS

1. **Choice To Prolong Life**

_____I want my life to be prolonged as long as possible within the limits of generally accepted health care standards.

OR

2. **Choice Not To Prolong Life**

I do not want my life to be prolonged if (please check all that apply)

____ (i) I have a terminal condition (an incurable condition from which there is no reasonable medical expectation of recovery and which will cause my death, regardless of the use of life-sustaining treatment). In this case, I give the specific directions indicated:

	I want used	I do not want used
Artificial nutrition through a conduit	_____	_____
Hydration through a conduit	_____	_____
Cardiopulmonary resuscitation	_____	_____
Mechanical respiration	_____	_____
Other (explain) _____	_____	_____

_____ (ii) I become permanently unconscious (a medical condition that has existed at least four (4) weeks and has been diagnosed in accordance with currently accepted medical standards and with reasonable medical certainty as total and irreversible loss of
consciousness and capacity for interaction with the environment. The term includes, without limitation, a persistent vegetative state or irreversible coma) and regarding the following, I give the specific directions indicated:

	I want used I	do not want used
Artificial nutrition through a conduit	_____	_____
Hydration through a conduit	_____	_____
Cardiopulmonary resuscitation	_____	_____
Mechanical respiration	_____	_____
Other (explain) _____	_____	_____

B. **RELIEF FROM PAIN**: Whether I choose A.1 or A.2, or neither, I direct that in all cases I
be given all medically appropriate care necessary to make me comfortable and alleviate pain.

C. **OTHER MEDICAL INSTRUCTION**: If you wish to add to the instructions you have given above, you may do so here. (use additional sheets of paper if necessary)

_____

PART II: POWER OF ATTORNEY FOR HEALTH CARE

Your agent may make any health care decision that you could have made while you had the capacity to make health care decisions. You may appoint an alternate agent to make health care decisions for you if your first agent is not willing, able and reasonably available to make decisions for you. Unless the persons you name as agent and alternate agent are related to you by blood, neither may own, operate or be employed by any residential long-term care institution where you are receiving care.

If you wish to appoint an agent to make health care decisions for you under these circumstances and conditions, you must fill out the section below. You may cross out any wording you do not want.

A. **DESIGNATION OF AGENT:** I designate _____ as my agent to make health care decisions for me. If he/she is not living, willing or able, or reasonably available, to make health care decisions for me, then I designate _____ _____ as my agent to make health care decisions for me.

_____

(name of individual you choose as agent)

_____

(address) (city) (state) (zip code)

_____

(home phone) (work phone)

_____

(name of individual you choose as alternate agent)

_____

(address) (city) (state) (zip code)

_____

(home phone) (work phone)

B. **AGENT'S AUTHORITY:** I grant to my agent full authority to make decisions for me regarding my health care; provided that, in exercising this authority, my agent shall follow my desires as stated in this document or otherwise known to my agent. Accordingly, my agent is authorized as follows:

1. To consent to, refuse, or withdraw consent to any and all types of medical care, treatment, surgical procedures, diagnostic procedures, medication, and the use of mechanical or other procedures that affect any bodily function;
2. To have access to medical records and information to the same extent that I am entitled to, including the right to disclose the contents to others;
3. To authorize my admission to or discharge from any hospital, nursing home, residential care, assisted living or similar facility or service;
4. To contract for any health care related service or facility on my behalf, without my agent incurring personal financial liability for such contracts;
5. To hire and fire medical, social service, and other support personnel responsible for my care; and

6. To authorize, or refuse to authorize, any medication or procedure intended to relieve pain, even though such use may lead to physical damage, addiction, or hasten the moment of (but not intentionally cause) my death.

C. WHEN AGENT'S AUTHORITY BECOMES EFFECTIVE: My agent's authority becomes effective when my attending physician determines I lack the capacity to make my own health care decisions.

D. **AGENT'S OBLIGATION:** My agent shall make health care decisions for me in accordance with this power of attorney for health care, any instructions I give in Part I of this form, and my other wishes to the extent known to my agent. To the extent my wishes are unknown, health care decisions by my agent shall conform as closely as possible to what I would have done or intended under the circumstances. If my agent is unable to determine what I would have done or intended under the circumstances, my agent will make health care decisions for me in accordance with what my agent determines to be my best interest. In determining my best interest, my agent shall consider my personal values to the extent known to my agent.

PART III. ANATOMICAL GIFT DECLARATION (Optional)

I hereby make the following anatomical gift(s) to take effect upon my death. The marks in the appropriate squares and words filled into the blanks below indicate my desires:

I give [ ] my body; [ ] any needed organs or parts;
[ ] the following organs or parts _____

to [ ] the physician in attendance at my death; [ ] the hospital in which I die;
[ ] the following named physician, hospital, storage bank or other medical institution
_____

for the following purpose(s):
[ ] any purpose authorized by law; [ ] transplantation;
[ ] therapy; [ ] research;
[ ] medical education.

EFFECT OF COPY: A copy of this form has the same effect as the original.
I understand the purpose and effect of this document.

_____ _____
(date) (sign your name)

_____
(print your name)

_____
(address)

_____
(city) (state) (zip code)

STATEMENT OF WITNESSES

SIGNED AND DECLARED by the above-named declarant as and for his/her written declaration under 16 Del.C. §§ 2502, 2503, in our presence, who in his/her presence, at his/

request, and in the presence of each other, have hereunto subscribed our names as witnesses, and state:

A. The Declarant is mentally competent.
B. That neither of us is prohibited by §2503 of Title 16 of the Delaware Code from being a witness. Neither of us:

1. Is related to the declarant by blood, marriage or adoption;
2. Is entitled to any portion of the estate of the declarant under any will of the declarant or codicil thereto then existing nor, at the time of the executing of the advance health care directive, is so entitled by operation of law then existing;
3. Has, at the time of the execution of the advance health care directive, a present or inchoate claim against any portion of the estate of the declarant;
4. Has a direct financial responsibility for the declarant's medical care;
5. Has a controlling interest in or is an operator or an employee of a health care institution in which the declarant is a patient or resident; or
6. Is under eighteen years of age.

C. That if the declarant is a resident of a sanitarium, rest home, nursing home, boarding home or related institution, one of the witnesses, _____ _____, is at the time of the execution of the advance health care directive, a patient advocate or ombudsman designated by the Division of Services for Aging and Adults with Physical Disabilities or the Public Guardian.

Witness	Witness
_____	_____
(print name)	(print name)
_____	_____
(address)	(address)
_____	_____
(city, state, zip code)	(city, state, zip code)
_____	_____
(signature of witness) (date)	(signature of witness) (date)

(Optional)

Sworn and subscribed to me this _____ day of _____.

My term expires: _____ _____
(Notary)

Health Insurance and Resources

The government offers people with disabilities a number of options for health coverage. To find out more visit https://usa.gov/disability-services

Medicaid gives free or low-cost medical benefits to people with disabilities whose income is insufficient to meet the cost of medical services. There are two ways to apply/contact your state Medicaid agency or fill out the Health Insurance Marketplace application.

Delaware ASSIST is a fast and easy way to apply for benefits with their online application. Delaware Department of Health and Social Services over sees the ASSIST program that offers a variety of State services.

Medicare helps by providing people with certain disabilities medical health insurance.

The Affordable Health Care Act Marketplace gives people options if they do not qualify for disability benefits.

In Delaware you can visit the Delaware Department of Insurance Consumer Listing website to view many insurance related topics. The Delaware Insurance Commissioner heads up the Department of Insurance and takes the lead in protecting Delawareans by handling your insurance complaints.