



COMMONWEALTH of VIRGINIA

Nelson Smith
Commissioner

**DEPARTMENT OF
BEHAVIORAL HEALTH AND DEVELOPMENTAL SERVICES**
Post Office Box 1797
Richmond, Virginia 23218-1797

Telephone (804) 786-3921
Fax (804) 371-6638
www.dbhds.virginia.gov

Office of Integrated Health Supports Network Health & Safety Information

End-of-Life Planning for Individuals with Intellectual and Developmental Disabilities Health & Safety Alert

Introduction

End-of-life planning is never easy. These emotionally difficult and often complicated conversations can be intensified when an individual has an intellectual or developmental disability (IDD). However, having a clear understanding of an individual's wishes for their care is important (17).

These discussions should include not only the individual but their family, loved ones, support/treatment team and healthcare professionals. Making a will, specific to what end-of-life care will look like, deciding whether to donate organs or not, and funeral arrangements, are all part of end-of-life planning (17).

Individuals with IDD deserve the same basic human rights as everyone else. With assistance, many individuals are capable of making their own major life decisions about where they want to live and with whom, if they want to work or not, their education, personal relationships, as well as end-of-life care (29).

Persons with IDD are often not even asked about their choices or afforded the opportunity to participate in conversations about their end-of-life plan. They should be given the opportunity to ask questions along with expressing their thoughts and feelings on the topic if they are capable (29).

If the individual does not have the mental capacity to make their own decisions the person authorized to consent on the individual's behalf will be required to do so specifically for Durable Do Not Resuscitate Orders. Please see [Virginia Code § 54.1-2987.1](#) for more information.

In Virginia, one tool which can be used to help individuals communicate end-of-life decisions to others is an Advance Directive (AD). Virginia law supports the rights of people to have their AD honored in all healthcare venues ([54.1-2983 Virginia Code](#); [22VAC40-73-720](#)).

Do Not Resuscitate (DNR) and Durable Do Not Resuscitate (DDNR) Orders

DNR means 'Do Not Resuscitate' (16). DDNR means 'Durable Do Not Resuscitate' (25).

Resuscitate is a medical term commonly referred to as cardiopulmonary resuscitation or CPR. Basically, resuscitation is providing mechanical air flow (breathing) and/or artificial heart contractions (heart beats) (3).

Each state has different laws regarding the terms for resuscitation orders. For example, some states do not use the term 'durable do not resuscitate'. Instead, they may use the term 'portable do not resuscitate' (19).

Essentially, both portable and durable DNR orders mean an order to withhold resuscitation. Both travel with the person regardless of the institution providing care (18) (19). Durable DNR (DDNR) orders are specific to the state of Virginia.

In the Commonwealth of Virginia, ““Durable Do Not Resuscitate Order” means a written physician’s order issued pursuant to Virginia Code [§54.1-2987.1](#) to withhold cardiopulmonary resuscitation from a particular patient in the event of a cardiac or respiratory arrest.

For purposes of this Health & Safety Alert, cardiopulmonary resuscitation shall include cardiac compression, endotracheal intubation and other advanced airway management, artificial ventilation, defibrillation and related procedures. (25).

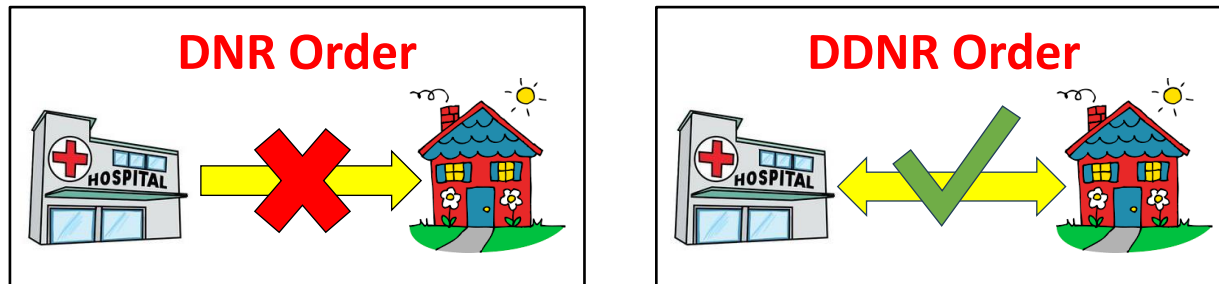
The Differences Between a DNR and a DDNR

While on the surface these two acronyms are similar, there are critical distinctions between the two. Withholding CPR may lead to a person’s death. For this reason, an individual (or their legally appointed decision maker) must discuss the plan for a DNR/DDNR with a physician (in detail), before making any decisions.

Individuals who have been diagnosed with a terminal illness and/or have serious medical conditions might choose to ask their primary care provider (PCP) about completing a DNR or DDNR. A physician can then write an order to withhold resuscitation efforts in the event the individual’s heart stops beating and/or they stop breathing.

This is where the key differences in a DNR and DDNR are noted. Both require a physician’s order, and both are legal instructions. However, in general, a DNR order is not transferable from facility to facility.

Meaning, if a physician orders a DNR for a person while they are in one hospital, that DNR usually **cannot** be used at any other hospital, healthcare facility or residence after they are discharged from the hospital where it was initially ordered. Hospitals in the United



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House image courtesy: http://clipartbarn.com/clipart-house_39822/

States accredited by the Joint Commission are required to have a Do Not Resuscitate (DNR) policy in place. However, there is no accepted standard for **all** hospitals.

Meaning DNR forms vary greatly from one hospital or healthcare facility to the other. In addition, the way one hospital defines a “Code” can also vary greatly from the way another hospital or healthcare facility defines one. Due to this, most hospitals will not accept a DNR from another hospital and it is not best practice due to those variations in hospital policy (7).

A DNR order initiated at a healthcare facility (usually a hospital) does not require the signature of the recipient of the DNR order or the signature of the person authorized to consent on the individual’s behalf. Most hospitals only require the signature of the attending physician on a DNR order. In fact, the attending physician can give a verbal order for staff to end resuscitation efforts, but the physician must be physically present as specified in Virginia law ([12VAC5-66-60 Virginia Code](#)).

In addition, the American Medical Association’s ethical guidelines imply that only an attending physician can write a DNR order and there is a strict set of recommended ethical guidelines (4) physicians should follow.

However, a DDNR order does require the signature of the person (or a legally appointed decision maker) on the order form ([12VAC5-66-40 Virginia Code](#)). A DDNR in Virginia must be on [Virginia’s authorized, standardized, state-approved DDNR form](#).

DNR orders are typically used in healthcare settings like hospitals.
DDNR orders are commonly used in community and residential service settings.

Some of the Ethical Considerations

As stated, both DNR and DDNR are physician orders to withhold cardiopulmonary resuscitation from a person if the person's heart stops beating or the person stops breathing independently. This means if a person stops breathing independently or a person's heart stops beating independently, chest compressions and/or rescue breaths would not be given.

As previously mentioned, healthcare facilities have differing policies and procedures regarding the implementation of DNR orders. Similarly, Emergency Medical Technicians (EMTs) and other rescue agencies may also have differing policies regarding interpretation and implementation of DNRs too.

This means no one healthcare center or rescue agency is likely to have the exact same interpretation of resuscitation as any another healthcare facility or rescue agency.

Discussion regarding DNR orders should be comprehensive and part of an end-of-life plan for individuals (28). Development of a DNR can cause confusion and complicate medical care if appropriate discussions and understandings of treatment plans has not been thoroughly examined.

Revocation of a DDNR

In Virginia, a Durable Do Not Resuscitate (DDNR) order can be revoked at any time by the individual themselves, by verbally expressing their desire to be resuscitated to a healthcare provider, or by an authorized decision-maker designated by the patient; this can be done by destroying the DDNR form, removing their DDNR bracelet, or verbally withdrawing the order to their physician (25).

Key points from the Virginia Code:

- **Patient's ability to revoke:** A patient can revoke their DDNR by simply expressing their desire to be resuscitated to a healthcare provider.
- **Authorized decision-maker:** If a patient is unable to make decisions, their designated authorized decision-maker can revoke the DDNR.
- **No third-party revocation:** Only the patient or their authorized decision-maker can revoke a DDNR.

For more information, please see the [Virginia Department of Health's Authorized Durable Do Not Resuscitate Order Form](#) and/or [Virginia Code 12VAC5-66-40. The Durable Do Not Resuscitate Order Form.](#)

Studies Aimed at Examining How DNRs Impact Care

Some research studies showed the enactment of a DNR order negatively impacted the carrying out of additional treatments for acute and chronic diseases (6).

The Kolli et al. study (2017) revealed the interpretation of DNR orders among patients seemed to be loosely related to each hospital's cultural differences, which included factors such as how aggressively the patients were treated, care limitations and the doctor-patient relationship (14).

A study done at Taipei Veterans General Hospital between 1 February 2018 to 31 January 2020 revealed patients who had DNR orders had increased risk of death when admitted into the emergency department (ED) compared to those patients who had no DNR orders (8).

Another study (15) revealed some healthcare providers may interpret a DNR order as a 'do not treat' order as well as a 'do not resuscitate' order. The eight-year study conducted from 2010-2018 using the California Patient Discharge Database revealed that a DNR order impacted resource allocation within the hospital significantly. The study found healthcare professionals wrongly assumed that patients with do not resuscitate (DNR) orders did not want any lifesaving measures whatsoever. In many instances, advanced therapies and treatments which may have saved the patient's life were not used or even tried (e.g. ICU transfer, surgical consultations, etc.) (15).

Research also indicates the culture and policies within a specific healthcare institution significantly impacts how physicians interpret DNR orders, regardless of whether the resuscitation efforts were clinically appropriate or not (10) (11). One physician may not interpret a particular DNR order to mean exactly the same thing as another physician would (20) (5).

Varying interpretations of DNR and DNI (do not intubate) orders has also been found among nurses, sometimes resulting in unintended consequences (12) (13). Engels et al. (2020) found that a nurse's response was negatively impacted by the patient's code status. The study surveyed responses of medical-surgical nurses at two large academic hospitals. The nurses' responses indicated they responded differently to patients based on their code status. Specifically, nurses said they were less likely to call rapid response (or a physician) if a patient developed tachypnea (fast breathing), tachycardia (fast heartrate), or a change in mental status (decreased alertness, confusion, etc.) if a patient had a code status of DNR or DNI.

The research clearly indicates misinterpretation of DNRs is systemic (throughout healthcare systems, healthcare venues, healthcare professionals, etc.) and indicates the person receiving services and their advocates, their legal guardians, their family

members, their healthcare team, and their physician, must all have a clear understanding of the individual's wishes regarding end-of-life care (1).

More specifically, it may mean a detailed list of instructions be provided to healthcare professionals which outline specific boundaries of when the person wants care and treatment (including what treatment they want) and when they do not want treatment or care (1). Advanced Directives can be extremely helpful tools for communicating this information.

It is never acceptable for healthcare professionals to assume that just because a person has a DNR order they are opting to not receive any care whatsoever.

Understanding the boundaries of the DNR order (in each treatment venue) and initiation of a detailed discussion on all end-of-life plans should be clearly defined and understood by all members of the Care Team. Ethical discussions about issuing DNR orders should be discussed with all healthcare professionals who are participating in the person's care.

It is imperative that all healthcare professionals treating the individual regularly be included in these discussions. Their interpretation of a particular individual's DNR/DDNR orders should be explored in-depth, so the individual and their legally appointed decision makers have:

- A full understanding of all DNR/DDNR orders.
- How said orders will be interpreted.
- An understanding of the impact to the individual's care moving forward in all venues, and in relation to all treatments, medicine, diagnostic tests, etc.

Individuals and their legally appointed decision makers must clearly understand a particular institution's interpretation of a DNR and work with healthcare professionals to better align the hospital's interpretations with the individual's own choices.

The person drives their care...not healthcare professionals.

Matters of life and death, such as in the case of DNR/DDNR orders, must be detailed, and must be written with extreme clarity so there are no misunderstandings, in order to protect an individual's right-to-life, as well as their end-of-life decisions.

These can be difficult conversations to have with individuals, but they are necessary ones and should be encouraged by all members of the Care Team, including the individual receiving services.

Other Considerations

It is important to understand either order (DNR or DDNR) **does not exclude a person from receiving other medical interventions**. Examples of other medical interventions may include:

- Transfer to an intensive care unit (ICU).
- Oxygen administration.
- Laboratory tests.
- Diagnostic studies.
- IV medications; and/or
- The administration of other medications to treat an emergent, acute or a chronic condition.

Essentially, any intervention can (and/or should) continue, so long as it does not involve **mechanical cardiac or pulmonary resuscitation** (19).

Since withholding CPR (as a result of either order), will likely lead to an individual's death, it is important for staff to:

- Have a full understanding of their agency's policies and procedures relating to this topic.
- Be encouraged to adhere to agency policies and procedures.
- Feel comfortable asking any questions they may have relating to ethical and medical decision-making and end-of-life planning.
- Know that if they suspect an individual needs more care than staff can provide, they should call 911 and have the individual assessed by licensed medical personnel promptly. (For more information on calling 911 see the DBHDS, OIH Health and Safety Alert, "The Importance of Calling 911").

Supported Decision-Making Agreements

Virginia now formally recognizes Supported Decision-Making Agreements as an alternative to legal guardianships ([Virginia Code § 37.2-314.3](#)) which are more restrictive.

Supported Decision-Making Agreements are a way for adults with developmental disabilities living in Virginia to communicate and document when they want to receive support with making decisions, how they want to receive support, and who they want to help them, while still retaining all of their rights, including the right to make their own decisions regarding end-of-life choices, as well as others (26).

Links to some of the DBHDS Office of Human Rights' resources about Supported Decision Making (in both English and Spanish) are shown below in the Resources section.

Resources

DBHDS resources for Supported Decision-Making and Supported Decision-Making Agreements.

- [Supported Decision-Making Quick Reference Document](#)
- [Supported Decision-Making FAQ \(Plain Language\)- UPDATED](#)
- [Supported Decision-Making FAQ- UPDATED](#)

Virginia's Supported Decision-Making Agreement template and Instructions

- [Instructions for Completing Your Supported Decision-Making Agreement](#)
- [Virginia's Supported Decision-Making Agreement template \(Word\)](#)
- [Virginia's Supported Decision-Making Agreement template \(PDF\)](#)

Tool Kit: *Discovery Tools and forms you can use to help you create your Supported Decision-Making Agreement or to use on their own.*

- [Discovery Tool- When Do I Want Support \(Word\)](#)
- [Discovery Tool- When Do I Want Support \(PDF\)](#)
- [Discovery Tool- What Kind of Support Do I Want \(Word\)](#)
- [Discovery Tool- What Kind of Support Do I Want \(PDF\)](#)
- [Discovery Tool- Relationship Map \(Word\)](#)
- [Discovery Tool- Relationship Map \(PDF\)](#)
- [Who Do I Want to be My Supporters \(Word\)](#)
- [Who Do I Want to be My Supports \(PDF\)](#)
- [Who has a copy of my Supported Decision-Making Agreement tracker \(Word\)](#)
- [Who has a copy of my Supported Decision-Making Agreement tracker \(PDF\)](#)

Release of information forms for school and doctor's offices written in plain language.

- [Educational Release of Information Form](#)
- [Medical Release of Information Form](#)

Examples of completed Discovery Tools and Supported Decision-Making Agreements.

- [Completed Supported Decision-Making Agreement Example: Sam](#)
- [Completed Supported Decision-Making Agreement Example: Maria](#)

Español

Preguntas frecuentes

- [Preguntas frecuentes \(Lenguaje sencillo\)](#)
- [Preguntas frecuentes](#)

Acuerdo e instrucciones para la toma de decisiones con apoyo

- [Cómo completo mi acuerdo de toma de decisiones con apoyo](#)
- [Mancomunidad de Virginia- Acuerdo de toma de decisiones con apoyo \(Documento de Microsoft Word\)](#)
- [Mancomunidad de Virginia- Acuerdo de toma de decisiones con apoyo \(Formularios PDF rellenables\)](#)

Herramientas

- [Herramienta- Cuándo quiero el apoyo \(Documento de Microsoft Word\)](#)
- [Herramienta- Cuándo quiero el apoyo \(Formularios PDF rellenables\)](#)
- [Herramienta- Qué tipo de apoyo quiero \(Documento de Microsoft Word\)](#)
- [Herramienta- Qué tipo de apoyo quiero \(Formularios PDF rellenables\)](#)
- [Herramienta- Mapa relacional \(Documento de Microsoft Word\)](#)
- [Herramienta- Mapa relacional \(Formularios PDF rellenables\)](#)

Formularios de liberación de información

- [Suministro de información escolar](#)
- [Brindar mi información médica](#)

Modelo

- [Muestra del acuerdo de toma de decisiones con apoyo- Sam](#)

For questions regarding Supported Decision-Making and/or Supported Decision-Making Agreements please contact Sara Thompson at Sara.Thompson@dbhds.virginia.gov

Many additional resources relating to an individual's human rights and resources for decision-making can be found on the [DBHDS Office of Human Rights Webpage](#) and their [Supported Decision-Making webpage](#)

Virginia End-of-Life Planning Resources:

Durable DNR Forms

As of July 20, 2011, the authorized Durable DNR has changed to a downloadable form. The previous authorized yellow DNR form may still be honored. Click below to download and print the new Durable DNR Form and its instructions.

[AuthorizedDurableDNRForm-2017_508c](#)

[How-to-Purchase-DDNR-Bracelets-or-Necklaces 508c](#)

What you need to know about DDNR and POLST

- [DDNR-FACT-SHEET-2017 508c](#)
- [The Code of Virginia and Durable DNR](#)
- [National POLST](#)
- [Virginia POLST](#)
- [Virginia POLST – Announcement](#)
- [National POLST Fillable Form](#)
- [2022 DDNR Update – Symposium Presentation](#)

Questions about the Durable DNR Program? Please contact (804) 888-9131.

Guidance Documents relating to DDNR: [Authority-of-Licensed-Nurse-Practitioners-to-write-Do-Not-Resuscitate-Orders 508c](#)

[Authority of Physicians Assistants to write Do Not Resuscitate Orders \(DNR Orders\)-85-8-PA 508c](#)

Guidance Memorandum: [Other-DDNR-Guidance-Doc-03182022-1 508c](#) (March 18, 2022) NEW

Virginia Code Regarding DDNR orders (2019):

<https://law.lis.virginia.gov/vacode/title54.1/chapter29/section54.1-2987.1/>

[Virginia Advanced Directives \(2019\):](#)

<http://www.virginiaadvanceddirectives.org/home.html>

Supported Decision-Making in Virginia: <https://dbhds.virginia.gov/supported-decision-making-supported-decision-making-agreements/>

Other Resources:

- National POLST (portable medical orders or medical orders that travel with the patient) paradigm (2019): <https://polst.org/>
- Coalition for Compassionate Care of California (2019):
<https://coalitionccc.org/CCCC/Resources/People-With-Developmental-Disabilities-Resources.aspx>
- American Association on Intellectual and Developmental Disabilities (2019):
<https://aaidd.org/news-policy/policy/position-statements/caring-at-the-end-of-life>
- Five Wishes: <https://www.fivewishes.org/>

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**DEPARTMENT OF
BEHAVIORAL HEALTH AND DEVELOPMENTAL SERVICES**

Post Office Box 1797
Richmond, Virginia 23218-1797

Telephone (804) 786-3921
Fax (804) 371-6638
www.dbhds.virginia.gov

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To the best of the OIHSN Nursing Team's knowledge the information contained within this alert is current and accurate. If the reader discovers any broken or inactive hyperlinks, typographical errors, or out-of-date content please send email to communitynursing@dbhds.virginia.gov to include the title of the Health & Safety alert with specific details of concern.