Assisting at the End of Life

One of the most meaningful times to help a person with I/DD to lead a full life is to assist at the end of his or her life. However, this can also be an emotionally challenging time. This white paper is intended to help you to support the individuals and their guardians to find resources that will help this time to be less stressful for everyone.

Ideally, persons in the DD Waiver and their guardians are supported to make decisions during this transition by their physicians and DD Waiver providers. The differences in guardian, family and staff experiences, ideas, knowledge and emotional connection may increase the difficulty in having discussions and making decisions. Everyone has a right to make decisions regarding their health care and how they wish to be cared for at the end of life.

This information is provided to you to support you in having discussions with individuals and families. It is also very important to understand what you need to remember in working with palliative care or hospice teams or the impact of some health care decisions on the care that is provided.

Plan in advance. At the annual ISP meeting, the presence of advanced directives is reviewed. When a general health decline, new serious illness or condition occurs or when a known illness or condition advances, previous decisions should be reviewed and individuals, parents/guardians may be offered information or support to make decisions. Health care providers, hospitals, etc. should be made aware of an individual’s concerns and desires about their condition so that they can honor those decisions.

Health care decisions are decisions about any care, treatment, service or procedure to maintain, diagnose, or otherwise affect an individual’s physical or mental condition. They include decisions about choosing and changing health-care providers and facilities; approval or disapproval of diagnostic test, surgical procedures, programs of medication; orders not to resuscitate ("DNRs") and directions about providing, withholding, or withdrawing life sustaining treatment, nutrition, hydration, and life support.

Decision Consultation
The Decision Consultation process is used when a person or their guardian/health care decision maker has concerns, needs more information about health-related issues, or has decided not to follow all or part of an order, recommendation, or suggestion. This includes:

- Medical orders or recommendations from the Primary Care Practitioner (PCP), Specialists or other licensed medical or healthcare practitioners such as a Nurse Practitioner (NP or CNP), Physician Assistants (PA) or Dentists;
- Clinical recommendations made by registered/licensed clinicians who are either members of the IDT or clinicians who have performed an evaluation such as a video-fluoroscopy;
- Health related recommendations or suggestions from oversight activities such as the Jackson Individual Quality Review or other DOH review or oversight activities.
The Decision Consultation process is designed to be sure that enough information has been provided for the individual and/or guardian to make an informed decision about not following a recommendation or order.

**Advanced directives**

Advanced directives are tools for an individual to give instructions for health care. They are made by an individual when he or she has the capacity to decide. Advance directives include both "individual instructions," which can be made in writing or can be made orally to the individual’s health care provider, and a "power of attorney for health care," which must be made in writing. Advance directives for health care decisions can govern both who should make health care decisions for the individual and what decisions should be made. If an individual has made an advance directive, it must be honored by whomever is later appointed to make decisions for the individual, including a guardian, unless a court expressly directs otherwise.

Making decisions for an incapacitated person can be aided by considering what the individual is typically able to do and what the person enjoys. Guidance for guardians is available in the “Handbook for Guardians & Conservators A practical guide to New Mexico Law” available at: [http://www.nmddpc.com/laws_-_uniform_health_care_decisions](http://www.nmddpc.com/laws_-_uniform_health_care_decisions).

**Palliative Care**

Palliative care (pronounced pal-lee-uh-tiv) is specialized medical care for people with serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve or maintain quality of life for both the patient and the family. Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. Palliative care can be provided in a clinic, a hospital or in the home. It is appropriate at any age and at any stage in a serious illness. It may be given when the illness is diagnosed, throughout treatment and follow-up and at the end of life.

Palliative care may be offered to persons with illnesses such as: cancer, heart disease, lung diseases, kidney failure, dementia, or other progressive illness. Palliative care treats physical or emotional problems such as, pain, depression, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping, anxiety, depression and other symptoms that may cause stress or discomfort during illness or treatment. Individuals on palliative care often have Do Not Resuscitate (DNR) orders.

A doctor can make a referral to palliative care. It is a benefit under Medicare Hospice, Medicaid and some insurance. Please check for current benefits. Additional resources are available at: [https://www.nhpco.org/](https://www.nhpco.org/).

**What to remember when working with a palliative care team.**

- It is important to let the palliative care provider know what bothers or concerns the individual most.
- Physicians and palliative care providers need to know about advance directives and the presence of a DNR.
• Determine if the palliative care team is available 24/7 and when and how to contact them.
• Share information about the individual’s communication and their communication needs.
• Share the individual’s unique signs of distress and subtle signs of illness.
• Discuss the palliative care plan with the provider. Provide information about the waiver protocols and care. Align plans, communication and tasks so that all know who is responsible for what tasks.
• Usually there are changes in the medication orders. It is very important to provide feedback to the palliative care team regarding the individual’s response to medication or treatment changes.
• Share and discuss health care plans and MERPs. Update with additional information and contact information as necessary. Ensure that direct care staff are kept well informed.
• Discuss changes in health care plans and MERPs with staff and educate as necessary.
• Spend quality time with the individual.

Notes to the Direct Care Staff
• Direct Care Staff are essential to effective communication of changes in behavior or condition to the nurse or palliative care staff.
• IDT meetings, discussion and training will help you to establish who does what tasks and how to communicate with the palliative care team. Communicate your understanding of the plan or need for clarification.
• Please request the information or support that you need, so that you can care for the waiver participant.
• Know what changes to expect in the individual’s condition. Be aware of non-verbal signs of pain. What does comfort or discomfort look like? Should you expect a change in eating or drinking? What might you see if there is an emergent situation?
• Know who to call and what to do. Place newly updated health care plans and MERPs in a place that is known and readily accessible. Look for changes in medications as this usually occurs.
• Individuals on palliative care often have Do Not Resuscitate (DNR) orders, which means CPR will not be given.
• When palliative care is in place, an individual may pass way. It is okay to grieve. Your agency will support you if you let them know how you are feeling. The palliative care team may also be of support.
• Spend quality time with the individual.

Hospice
Hospice care is specialized medical care for people with serious illness at the last stages of life. Hospice provides medical services, emotional support, and spiritual resources to increase comfort and improve quality of life. The goal is to keep the individual comfortable and improve their quality of life all the way to the end of life. Hospice is usually offered in the home, but may also occur in nursing homes, long-term care facilities, hospitals or a hospice center. Emotional support is a central element and is offered to the patient, their family, and provider staff.

Hospice care is provided by a hospice doctor and a specially-trained team of nurses and other specialists who work together according to a plan of care. Members of the hospice staff make
regular visits to assess the patient and provide additional care or other services. Hospice staff is on-call 24 hours a day, seven days a week.

Hospice care treats physical or emotional and spiritual problems such as pain, nausea, difficulty sleeping, anxiety and depression that may cause stress or discomfort for those that are terminally ill and are not seeking curative treatment. It may include coverage for medications, durable medical equipment, spiritual counseling and bereavement services. It will not address or cover medical services for illnesses or conditions that are not related to the terminal illness.

A doctor can make a referral to hospice for persons with a terminal illness with a life expectancy of 6 months or less. If a person’s condition goes into remission, improves or they no longer wish to be on hospice, the hospice care may be discontinued. If a person lives past 6 months, hospice services may be extended. Hospice is a benefit under Medicare, Medicaid and most insurance. Please check for current benefits. Information is available at: https://www.nhpc.org/.

What to remember when working with a hospice care team.
- It is important to let the hospice care provider know what bothers or concerns the individual most.
- Physicians and hospice care providers need to know about advance directives and the presence of a DNR.
- Determine if the hospice care team is available 24/7 and when and how to contact them.
- Share information about the individual’s communication and their communication needs.
- Share the individual’s unique signs of distress and subtle signs of illness.
- Discuss the hospice care plan with the provider. Provide information about the waiver protocols and care. Align plans, communication and tasks so that all know who is responsible for what tasks.
- Share and discuss health care plans and MERPs. Update with additional information and contact information as necessary. Not who is to be contacted for PRN medication use.
- Discuss changes in health care plans and MERPs with staff and educate as necessary.
- Spend quality time with the individual.

Notes to the Direct Care Staff
- Whether hospice is involved or not, you should have support for caring for individuals at the end of life. Please request the information or support that you need, so that you can care for the waiver participant.
- Know what changes to expect in the individual’s condition. You may see changes in eating, drinking or activity. There may be a loss of weight, change of breathing or alertness. If you have questions, call the nurse.
- Expect a change in medication orders. Know who to call for PRN medication use.
- IDT meetings, discussion and training will help you to establish who does what tasks and how to communicate with hospice. Communicate your understanding of the plan or need for clarification.
- Know who to call, what to do and place newly updated health care plans and MERPs in a place that is known and readily accessible.
• *Individuals on hospice care usually have Do Not Resuscitate (DNR) orders, which means CPR will not be given.*

• *It is okay to grieve the passing of an individual you have cared for. This is a large event for everyone. If you have worked with the individual for any length of time, you may experience significant grief when they pass. This is normal, and it can be helpful to get support for yourself. Hospice staff, family, friends and clergy may be helpful to support you. When you have the support that you need, you will also be able to provide comfort and support to the waiver participant.*

• *Spend quality time with the individual. This will be meaningful for you as well as providing the support and companionship that the person needs.*