

Dear Caregiver:

Thank you for choosing Kids Path of Mountain Valley Hospice & Palliative Care. All children with life threatening conditions deserve access to excellent pediatric palliative care, either as the primary treatment, or concurrent with disease-modifying or curative therapies. Children with potentially life limiting illness or limited life expectancy are served through Kids Path, a comprehensive and specialized children's program.

The goal of Kids Path is to enhance the quality of life for children, and those who share their lives, by helping them manage and adjust, while regaining a sense of normalcy to their lives. We follow Standards of Practice for Pediatric Palliative Care and Hospice from the National Hospice and Palliative Care Organization.

In addition, grief support services are available for families and children dealing with loss by death or illness of a loved one. Care is available regardless of gender, nationality, race, creed, sexual orientation, disability, ability to pay, diagnosis, do not resuscitate status, or religion.

Sincerely,

Denise Watson, MSN, MBA/HC

Denise Watson, MSN, MBA/HC

Executive Director

Kids Path

Mount Airy Office

401 Technology Lane
Suite 200
Mount Airy, NC 27030
Phone: 336-789-2922

Elkin Office

688 North Bridge Street
Elkin, NC 28621
Phone: 336-526-2650

Pilot Mountain Office

129 Veterans Drive
Pilot Mountain, NC 27041
Phone: 336-368-1260

Yadkinville Office

320 West Maple Street
P.O. Box 1267
Yadkinville, NC 27055
Phone: 336-679-2466

Joan & Howard

Woltz Hospice Home

945 Zephyr Road
Dobson, NC 27017
Phone: 336-356-5000

Hillsville Office

1477 Carrollton Pike
Hillsville, VA 24343
Phone: 276-728-1030

Martinsville Office

730 East Church Street
Suite 13
Martinsville, VA 24112
Phone: 276-403-4764

Stuart Office

18981 Jeb Stuart Hwy
Stuart, VA 24171
Phone: 276-694-4416



ACCREDITED

MVHPC is certified by the Centers for Medicare and Medicaid Services and is accredited by Accreditation Commission for Healthcare.

Mountain Valley Hospice & Palliative Care is an Approved Provider of continuing nursing education by North Carolina Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.

Our Mission: *We are committed to...*

- Improving the quality of life for children with a limited life expectancy and their families

Our Vision: *We will be recognized as...*

- Expert providers of pediatric Hospice care, Pediatric Palliative Care, management of advanced disease, and grief support; and to be the agency of choice for the provision of pediatric Hospice care and services
- Leaders in all aspects of end of life care and resources to influence perceptions within the community and among medical professionals so that end of life is accepted as a meaningful component of the human experience

Our Values: *We believe...*

- That death is a natural part of life's journey
- That honesty and integrity must be ever present
- In providing compassion to those we serve and to each other
- In hiring professional, competent, and motivated staff
- Being responsible stewards of our resources
- In providing ongoing education to families and communities about care options and resources, to empower them to make decisions regarding their care
- Teamwork will help to achieve our vision and mission

Our services are primarily provided in your home. Our staff will make visits based on a schedule that is established with you and your family. The frequency of these scheduled visits will depend upon your specific needs.

Hospice accepts patients without regard to race, pregnancy, religion, national origin, lifestyle, sexual orientation, age, gender, handicap, gender identity, sex stereotyping, or ability to pay.

Surveys

Kids Path is committed to providing **excellent** care to our patients and families. We care about what you have to say about the care you received. An important part of our program is the evaluation of how well we are meeting the needs of those we serve. We value your honest feedback about our performance and your overall Hospice experience.

Your responses are important in assisting us with continual improvement of our services. Participation in any survey is voluntary and will not affect the services you receive. If you have any concerns about the care being provided or suggestions about how we can better meet your need, please contact your nurse or an Administrator. If at any time your experience is anything less than **EXCELLENT**, please contact Tracey Dobson, Chief Clinical Operations Officer at (336) 789-2922.

Patient/Family Rights and Responsibilities

Patients of this agency possess basic rights. You have the right to be informed verbally and in writing of your rights prior to the start of care in a language and manner that you can understand. We want you to be familiar with these Rights. You have the Right to:

1. To exercise one's rights as a patient of the Hospice.
2. Receive information about the services covered under the Medicare Hospice Benefit.
3. Receive information about the scope of services that the Hospice will provide and specific limitations on those services.
4. Be fully informed in advance about care/service to be provided, including the disciplines that furnish care and the frequency of visits, as well as any modifications to the plan of care.
5. To receive care and services that are adequate, appropriate, and in compliance with Federal and State Law & regulations.
6. Be informed, both orally and in writing, in advance of care being provided, of the charges, including payment for care/service expected from third parties and any charges for which the patient will be responsible.
7. Participate in the development and periodic revision of the plan of care.
8. Be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse or exploitation, including injuries of unknown source, and misappropriation of patient property.
9. Voice grievances/complaints regarding treatment or care that is (or fails to be) furnished and lack of respect of property by anyone who is furnishing care/service on behalf of the Hospice.
10. Have grievances/complaints regarding treatment or care that is (or fails to be) furnished or lack of respect of property investigated.
11. Confidentiality and privacy of all information contained in the patient record and Protected Health Information.
12. Be advised on **MVHPC's** policies and procedures regarding the disclosure of clinical records.
13. Refuse care or treatment after the consequences of refusing care or treatment are fully presented.
14. Be informed of patient rights under state law to formulate Advance Directives.
15. Receive effective pain management and symptom control for conditions related to the terminal illness.
16. Have one's property and person treated with respect, consideration, and recognition of patient dignity and full recognition of his or her individuality and right to privacy.
17. Be able to identify visiting personnel members through proper identification.
18. Recommend changes in policies and procedures, personnel or care/service.
19. Not be subject to discrimination or reprisal for the exercising of one's rights.
20. Choose a health care provider, including choosing an attending physician.
21. Receive appropriate care without discrimination in accordance with physician orders.

22. Be informed of any financial benefits when referred to **MVHPC**.
23. Be fully informed of one's responsibilities.
24. To receive a reasonable response to his or her requests of the agency.
25. To be notified within 10 days when the agency's license has been revoked, suspended, canceled, annulled, withdrawn, recalled, or amended.
26. Be informed of anticipated outcomes of care and of any barriers in outcome achievement.
27. Receive at least five days written and verbal notice prior to any reduction in services, discharge or referral from service, except when a medical emergency exists, when the patient's physician orders admission to an inpatient facility, or when discharge is determined necessary by the chief clinical officer to protect the health and welfare of the staff member providing services.
28. To call and ask questions or relay complaints about Hospice agencies: Including complaint concerning the implementation of Advance Directives.

In NC:

*The Division of Health Services Regulation for the **North Carolina** Department of Health and Human Services at (800) 624-3004. Calls are accepted 24-hours a day/7 days a week.*

In VA:

*The Office of Licensure and Certification for the **Virginia** Department of Health at (800) 955-1819 or (804) 367-2106. Calls are accepted 24-hours a day/7 days a week. The hours of operation are Monday – Friday, 8:00 a.m. – 4:30 p.m.*

Patients also possess basic responsibilities. These include:

1. The responsibility to remain under a physician's care while receiving services.
2. The responsibility to notify the agency first when any medical problems arise.
3. The responsibility to provide the agency with a complete and accurate medical history.
4. The responsibility to provide the agency with accurate insurance information and financial information.
5. The responsibility to sign required consents and releases for information.
6. The responsibility to participate in the care provided by asking questions and expressing concerns.
7. The responsibility to provide a safe home environment in which care can be provided.
8. The responsibility to cooperate with the physician, the agency, and other care providers.
9. The responsibility to accept or refuse treatment.
10. The responsibility to treat agency personnel with dignity and respect.
11. The responsibility to abide by agency policies that restrict duties the agency may perform.
12. The responsibility to advise the agency administration of any dissatisfaction or problems with your care.

NOTICE OF PRIVACY PRACTICES

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION.

PLEASE REVIEW IT CAREFULLY

OUR RESPONSIBILITIES

Mountain Valley Hospice & Palliative Care (MVHPC) is required by law to protect the privacy of your health information. We are required to provide you with this Notice of Privacy Practices to describe our legal duties and your rights with respect to your protected health information. We are also required to abide by the terms of this Notice which is currently in effect, and to notify you in the event of a breach of your unsecured health information.

HOW WE MAY USE AND DISCLOSURE YOUR HEALTH INFORMATION

The following describes the ways we may use and disclose your health information for treatment, payment and health care operations.

Treatment: MVHPC may use and disclose your health information to coordinate care within the Hospice and with others involved in your care, such as your attending physician, members of the Hospice's interdisciplinary team and other health care professionals who have agreed to assist us in coordinating your care. For example, we may disclose your health information to a physician involved in your care who needs information about your symptoms to prescribe appropriate medications.

Payment: MVHPC may use and disclose your health information so that we or others may bill and receive payment for the care you receive from us. For example, we may be required by your health insurer to provide information regarding your health care status, your need for care and the care that MVHPC intends to provide to you so that the insurer will reimburse you or the Hospice for services provided and received.

Health Care Operations: MVHPC may use and disclose health information for its own operations to facilitate the functioning of the Hospice and as necessary to provide quality care to all of our patients. Health care operations may include such activities as:

- Quality assessment and improvement activities.
- Activities designed to improve health or reduce health care costs.
- Protocol development, case management and care coordination.
- Contacting health care providers and patients with information about treatment alternatives and other related functions that do not include treatment.
- Professional review and performance evaluation.
- Training programs, including those in which students, trainees or practitioners in health care learn under supervision.
- Training of non-health care professionals.
- Accreditation, certification, licensing or credentialing activities.
- Review and auditing, including compliance reviews, medical reviews, legal services and compliance programs.
- Business planning and development, including cost management and planning related analyses and formulary development.
- Business management and general administrative activities of the Hospice.

For example MVHPC may use your health information to evaluate its performance, combine your health information with other patients in evaluating how to more effectively serve all Hospice patients, or disclose your health information to members of the Hospice's workforce for training purposes.

ADDITIONAL PERMITTED USES AND DISCLOSURES OF HEALTH INFORMATION

As Required by Law - We will disclose your health information when we are required to do so by any Federal, State or local law.

Public Health Risks - We may disclose your health information for public activities and purposes in order to:

- Prevent or control disease, injury or disability, report disease, injury, vital events such as birth or death and the conduct of public health surveillance, investigations and interventions.
- Report adverse events, product defects, to track products or enable product recalls, repairs and replacements and to conduct post-marketing surveillance and compliance with requirements of the Food and Drug Administration.
- Notify a person who has been exposed to a communicable disease or who may be at risk of contracting or spreading a disease.
- Notify an employer about an individual who is a member of the employer's workforce in certain limited situations, as authorized by law.

Abuse, Neglect Or Domestic Violence - We are allowed to notify government authorities if we believe a patient is the victim of abuse, neglect or domestic violence. We will make this disclosure only when specifically required or authorized by law or when the patient agrees to the disclosure.

Health Oversight Activities - We may disclose your health information to a health oversight agency for activities including audits, civil administrative or criminal investigations, inspections, licensure or disciplinary action. However, we may not disclose your health information if you are the subject of an investigation and your health information is not directly related to your receipt of health care or public benefits.

Judicial And Administrative Proceedings - We may disclose your health information in the course of any judicial or administrative proceeding in response to an order of a court or administrative tribunal as expressly authorized by such order or in response to a subpoena, discovery request or other lawful process, but only when we make reasonable efforts to either notify you about the request or to obtain an order protecting your health information.

Law Enforcement - As permitted or required by State law, we may disclose your health information to a law enforcement official for certain law enforcement purposes as follows:

- As required by law for reporting of certain types of wounds or other physical injuries pursuant to the court order, warrant, subpoena or summons or similar process.
- For the purpose of identifying or locating a suspect, fugitive, material witness or missing person.
- Under certain limited circumstances, when you are the victim of a crime.
- To a law enforcement official if we have a suspicion that your death was the result of criminal conduct, including criminal conduct at the Hospice.
- In an emergency in order to report a crime.

Coroners And Medical Examiners - We may disclose your health information to coroners and medical examiners for purposes of determining your cause of death or for other duties, as authorized by law.

Funeral Directors - We may disclose your health information to funeral directors consistent with applicable law and, if necessary, to carry out their duties with respect to your funeral arrangements. If necessary to carry out their duties, we may disclose your health information prior to and in reasonable anticipation of your death.

Organ, Eye Or Tissue Donation - We may use or disclose your health information to organ procurement organizations or other entities engaged in the procurement, banking or transplantation of organs, eyes or tissue for the purpose of facilitating the donation and transplantation.

Research Purposes - We may, under certain circumstances, use and disclose your health information for research purposes. Before we disclose any of your health information for research purposes, the project will be subject to an extensive approval process. This process includes evaluating a proposed research project and its use of health information and trying to balance the research needs with your need for privacy. Before we use or disclose health information for research, the project will have been approved through this research approval process. Additionally, when it is necessary for research purposes and so long as the health information does not leave our organization, it may disclose your health information to researchers preparing to conduct a research project, for example, to help the researchers look for individuals with specific health needs. Lastly, if certain criteria are met, we may disclose your health information to researchers after your death when it is necessary for research purposes.

Limited Data Set - We may use or disclose a limited data set of your health information, that is, a subset of your health information for which all identifying information has been removed, for purposes of research, public health, or health care operations. Prior to our release, any recipient of that limited data set must agree to appropriately safeguard your health information.

Serious Threat To Health Or Safety - We may, consistent with applicable law and ethical standards of conduct, disclose your health information if, in good faith, we believe that such disclosure is necessary to prevent or lessen a serious and imminent threat to your health or safety or to the health and safety of the public.

Specified Government Functions - In certain circumstances, the Federal regulations authorize us to use or disclose your health information to facilitate specified government functions relating to military and veterans, national security and intelligence activities, protective services for the President and others, medical suitability determinations and inmates and law enforcement custody.

Worker's Compensation - We may release your health information for worker's compensation or similar programs.

OTHER USES AND DISCLOSURES OF YOUR HEALTH INFORMATION TO WHICH YOU MAY AGREE OR OBJECT

Facility Directory: When you are in our Hospice facility, we may disclose certain information about you, including your name, your general health status, your religious affiliation and the patient suite you are in at the facility. We may disclose this information to people who ask for you by name. Please inform us if you want to restrict or prohibit some or all of the information that may be provided.

Persons Involved in Your Care: When appropriate, we may share your health information with a family member, other relative or any other person you identify if that person is involved in your care and the information is relevant to your care or the payment of your care. We also may notify your family about your location or general condition or disclose such information to an entity assisting in a disaster relief effort. You may ask us at any time not to disclose your health information to any person(s) involved in your care. We will agree to your request unless circumstances constitute an emergency or if the patient is a minor.

Fundraising Activities: MVHPC, our Hospice foundation, or our business associate may use information about you, including your name, address, telephone number and the dates you received care, in order to contact you for fundraising purposes. You have the right to opt-out of receiving these communications from us. If you do not want us to contact you for fundraising purposes, notify: *Brett Willis, Director of Development 1.888.789.2922* and indicate that you do not wish to receive fundraising communications.

AUTHORIZATIONS TO USE OR DISCLOSE HEALTH INFORMATION

Other than the permitted uses and disclosures described above, MVHPC will not use or disclose your health information without an authorization signed by you or your personal representative. If you or your representative sign a written authorization allowing us to use or disclose your health information, you may cancel the authorization (in writing) at any time. If you cancel your authorization, we will follow your instructions except to the extent that we have already relied upon your authorization and taken action.

The following uses and disclosures for your health information will only be made with your signed authorization:

1. Uses and disclosures for marketing purposes;
2. Uses and disclosures that constitute a sale of health information;
3. Most uses and disclosures of psychotherapy notes, if we maintain psychotherapy notes; and
4. Any other uses and disclosures not described in this Notice.

YOUR RIGHTS REGARDING YOUR HEALTH INFORMATION

You have the following rights regarding your health information:

- **Right to request restrictions** - You have the right to request restrictions on uses and disclosures of your health information for treatment, payment and health care operations. You have the right to request a limit on the disclosure of your health information to someone who is involved in your care or the payment of your care. We are not required to agree to your request, unless your request is for a restriction on a disclosure to a health plan for purposes of payment or health care operations (and is not for purposes of treatment) and the medical information you are requesting to be restricted from disclosure pertains solely to a health care item or service for which you have paid out-of-pocket in full. If you wish to make a request for restrictions, please contact the **Privacy Officer – Anita Smith Clinical Software Specialist**. 401 Technology Lane, Suite 200, Mount Airy, NC, 27030 or Toll Free at 1.888.789.2922
- **Right to receive confidential communications** - You have the right to request that we communicate with you in a certain way. For example, you may ask that the Hospice only conduct communications pertaining to your health information with you privately with no other family members present. If you wish to receive confidential communications, please contact the **Privacy Officer – Anita Smith Clinical Software Specialist**. 401 Technology Lane, Suite 200, Mount Airy, NC, 27030 or Toll Free at 1.888.789.2922. We will not request that you provide any reasons for your request and will attempt to honor any reasonable requests for confidential communications.
- **Right of access to inspect and copy your health information** - You have the right to inspect and copy your health information, including billing records. A request to inspect and copy records containing your health information may be made to the **Privacy Officer – Anita Smith Clinical Software Specialist**. 401 Technology Lane, Suite 200, Mount Airy, NC, 27030 or Toll Free at 1.888.789.2922. If you request a copy of your health information, we may charge a reasonable fee for copying and assembling costs associated with your request. You have the right to request that we provide you, an entity or a designated individual with an electronic copy of your electronic health record containing your health information, if we use or maintain electronic health records containing patient health information. We may require you to pay the labor costs incurred in responding to your request.
- **Right to amend health care information** - You or your representative have the right to request that we amend your records, if you believe that your health information is incorrect or incomplete. That request may be made as long as the information is maintained by us. A request for an amendment of records must be made in writing to **Privacy Officer – Anita Smith Clinical Software Specialist**. 401 Technology Lane, Suite 200, Mount Airy, NC, 27030. MVHPC may deny the request if it is not in writing or does not include a reason for the amendment. The request also may be denied if your health information records were not created by us, if the records you are requesting are not part of our records, if the health information you wish to amend is not part of the health information you or your representative are permitted to inspect and copy or if, in our opinion, the records containing your health information are accurate and complete.
- **Right to an accounting** - You or your representative have the right to receive an accounting of disclosures of your health information made by MVHPC for the previous six (6) years. The accounting will not include disclosures made for treatment, payment or health care operations unless we maintain your health information in an Electronic Health Record (EHR). The request for an accounting must be made in writing to the **Privacy Officer – Anita Smith Clinical Software Specialist**. 401 Technology Lane, Suite 200, Mount Airy, NC, 27030. The request should specify the time period for the accounting

starting on or after April 14, 2003. We would provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.

- **Right to opt-out of fundraising** - You or your representative have the right to opt-out of receiving fundraising communications. Instructions for how to opt-out are included in each fundraising solicitation you receive.
- **Right to receive notification of a breach** - You or your representative have the right to receive notification of a breach of your unsecured health information. If you have questions regarding what constitutes a breach or your rights with respect to breach notification, please contact the **Privacy Officer – Anita Smith Clinical Software Specialist**. 401 Technology Lane, Suite 200, Mount Airy, NC, 27030 or Toll free at: 1.888.789.2922
- **Right to a paper copy of this notice** - You or your representative have a right to a separate paper copy of this Notice at any time, even if you or your representative have received this Notice previously. To obtain a separate paper copy, please contact the **Privacy Officer – Anita Smith Clinical Software Specialist** 401 Technology Lane, Suite 200, Mount Airy, NC, 27030 or Toll free at: 1.888.789.2922

CHANGES TO THIS NOTICE

MVHPC reserves the right to change this Notice. We reserve the right to make the revised Notice effective for health information we already have about you, as well as any health information we receive in the future. We will post a copy of the current Notice in a clear and prominent location to which you have access. The Notice also is available to you upon request. The Notice contains, at the end of this document, the effective date. In addition, if we revise the Notice, we will offer you a copy of the current Notice in effect.

IF YOU HAVE ANY QUESTIONS REGARDING THIS NOTICE

MVHPC has designated the **Privacy Officer – Anita Smith Clinical Software Specialist** as its contact person for all issues regarding patient privacy and your rights under the Federal privacy standards. You may contact this person at: 401 Technology Lane, Suite 200, Mount Airy, NC, 27030 or Toll free at: 1.888.789.2922.

COMPLAINTS

You or your personal representative has the right to express complaints to the Hospice and to the Secretary of the U.S. Department of Health and Human Services if you or your representative believe that your privacy rights have been violated. Any complaints to the Hospice should be made in writing to the **Compliance Officer – Katrina McDowell Director of Quality and Compliance** at 401 Technology Lane, Suite 200, Mount Airy, NC, 27030. We encourage you to express any concerns you may have regarding the privacy of your information. You will not be penalized in any way for filing a complaint.

EFFECTIVE DATE

This Notice is effective **September 23, 2013**.

NOTICE OF NONDISCRIMINATION

Mountain Valley Hospice & Palliative Care complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex. Mountain Valley Hospice & Palliative Care does not exclude people or treat them differently because of race, color, national origin, age, disability, or sex.

Mountain Valley Hospice & Palliative Care:

Provides free aids and services to people with disabilities to communicate effectively with us, such as:

- Qualified sign language interpreters
- Written information in other formats (large print, audio, accessible electronic formats, other formats)

Provides free language services to people whose primary language is not English, such as:

- Qualified interpreters
- Information written in other languages

If you need these services, contact Mountain Valley Hospice & Palliative Care at 1.800.789.2922

If you believe that Mountain Valley Hospice & Palliative Care has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, or sex, you can file a grievance with:

Katrina McDowell, Compliance Officer
401 Technology Lane, Suite 200
Mount Airy, NC, 27030
1.800.789.2922
Fax: 1.336.789.1689
kmcdowell@mtnvalleyhospice.org

You can file a grievance in person by mail, fax, or email. If you need help filing a grievance, Katrina McDowell, Director of Quality is available to help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at <https://ocrportal.hhs.gov/ocr/portal/lobby.jsf>

Or by mail or phone at: U.S. Department of Health and Human Services 200 Independence Avenue, SW Room 509F, HHH Building Washington, D.C. 20201 800.368.1019, 800.537.7697 (TDD)

Complaint forms are available at <http://www.hhs.gov/ocr/office/file/index.html>

ATTENTION: If you do not speak English, Language Assistance Services, free of charge, are available to you. Call 1-800-789-2922. (TTY: 711).

Spanish - Español

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-800-789-2922 (TTY: 711).

Vietnamese - Tiếng Việt

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-800-789-2922 (TTY: 711).

Chinese - 繁體中文

注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電1-800-789-2922 (TTY : 711)

Korean - 한국어

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1-800-789-2922 (TTY: 711) 번으로 전화해 주십시오.

French - Français

ATTENTION : Si vous parlez français, des services d'aide linguistique-vous sont proposés gratuitement. Appelez le 1-800-789-2922 (ATS : 711).

Arabic - العربية

ملحوظة: إذا كنت تتحدث اذكر اللغة، فإن خدمات المساعدة اللغوية تتوافر لك بالمجان. اتصل برقم 1-800-789-2922 (رقم هاتف الصم والبكم: 711)

Gujarati - ગુજરાતી

સુચના: જો તમે ગુજરાતી બોલતા હો, તો નિ:શુલ્ક ભાષા સહાય સેવાઓ તમારા માટે ઉપલબ્ધ છે. ફોન કરો 1-800-789-2922 (TTY: 711).

Hmong - Hmoob

LUS CEEV: Yog tias koj hais lus Hmoob, cov kev pab txog lus, muaj kev pab dawb rau koj. Hu rau 1-800-789-2922 (TTY: 711).

Russian - Русский

ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-800-789-2922 (телетайп: 711).

German – Deutsch

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 1-800-789-2922 (TTY: 711).

Tagalog - Tagalog – Filipino

PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa 1-800-789-2922 (TTY: 711).

Mon-Khmer, Cambodian - ខ្មែរ

ប្រយ័ត្ន: បើសិនជាអ្នកនិយាយ ភាសាខ្មែរ, សេវាជំនួយផ្នែកភាសា ដោយមិនគិតល្អិត គឺអាចមានសំរាប់បំរើអ្នក។ ចូរ ទូរស័ព្ទ 1-800-789-2922 (TTY: 711)។

Karen - unD

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AusdmtCd<AerRM>Ausdmtw>rRpXRvXAwwXmbl.vXmphRAeDwrHRb.ohM. vDRIAud; 1-800-789-2922 (TTY: 711).

Japanese - 日本語

注意事項：日本語を話される場合、無料の言語支援をご利用いただけます。1-800-789-2922 (TTY: 711) まで、お電話にてご連絡ください。

Hindi - हिंदी

ध्यान दें: यदि आप हिंदी बोलते हैं तो आपके लिए मुफ्त में भाषा सहायता सेवाएं उपलब्ध हैं। 1-800-789-2922 (TTY: 711) पर कॉल करें।

Laotian - ພາສາລາວ

ໂປດຊາບ: ຖ້າວ່າ ທ່ານເວົ້າພາສາ ລາວ, ການບໍລິການຊ່ວຍເຫຼືອດ້ານພາສາ, ໂດຍບໍ່ເສັຽຄ່າ, ແມ່ນມີພ້ອມໃຫ້ທ່ານ. ໂທ 1-800-789-2922 (TTY: 711).

Persian (Farsi) - فارسی

بگيريد دت وجه: اگر ر به زبان فارسی گ فتگو می ک نید، ت سه یلات زبانی ب صورت رایگان ب رای شما . رف مها یم دشاب اب. 1-800-789-2922 (TTY: 711) ت ماس

Amharic - አማርኛ

ማስታወሻ: የሚናገሩት ቋንቋ አማርኛ ከሆነ የትርጉም እርዳታ ድርጅቶች፣ በነጻ ሊያግዝዎት ተዘጋጅተዋል። ወደ ሚከተለው ቁጥር ይደውሉ 1-800-789-2922 (መስማት ለተሳናቸው: 711).

Urdu - اُردُو

1-800-789-2922 (TTY: 711) کی خدمات مفت میں دست یاب ہیں۔ کال خ بردار: اگر آپ اردو بولتے ہیں، تو آپ کو زبان کی مدد ک (TTY: 711)۔

Bengali – বাংলা

লক্ষ্য করনঃ যিদ আপনি বাংলা, কথা বলেত পােরন, তাহেল িনঃখরচায় ভাষা সহায়তা পিরেষবা উপল আছ। েফান করন 1-800-789-2922 (TTY: 1-711)

Kru (Bassa) – Bàsòò-wùdù-po-nyò

Dè dè nià ke dyédé gbo: ǀ jǔ ké m̄ [Bàsó ò -wùdù-po-nyò] jǔ ní, níí, à wuḍu kà kò dò po-poò bé ìn m̄ gbo kpáa. Đá 1-800-789-2922 (TTY: 711)

Ibo – Igbo asusu

Ntị: Ọ bụrụ na asụ Ibo, asụsụ aka ọasụ n'efu, defu, aka. Call 1-800-789-2922 (TTY: 711).

Yoruba - èdè Yorùbá

AKIYESI: Bi o ba nsọ èdè Yorùbú ọfé ni iranlọwọ lori èdè wa fun yin o. Ẹ pe ẹrọ-ibanisọrọ yi 1-800-789-2922 (TTY: 711).

Compliance

Kids Path believes that achieving the highest ethical standards is essential to its mission. This dedication is important not only because we serve the community but also because a significant portion of our services are reimbursed through governmental programs which require complete integrity. If you become aware of any apparent violation of Kids Path policies we would like for you to report it to our Compliance Officer. You may contact the agency's Compliance Officer:

Katrina McDowell, Director of Quality & Education
401Technology Lane, Suite 200
Mt Airy, NC 27030
(336) 789-2922 ext. 1113 or Toll Free: 888-789-2922
kmcowell@mtnvalleyHospice.org

All persons making such reports are assured that the reports will be treated as confidential. In order to promote anonymous reporting of perceived violations of compliance policies, a hotline has also been established. Only the Compliance Officer will have access to this information.

Compliance Hotline: 1-866-273-5213

Hospice strives to deliver the highest quality service to the patients and families we are privileged to serve. We appreciate your use of our services, and we thank you for notifying us of your concerns.

Complaint and Appeals Process-North Carolina

You have the right to register any complaint or dissatisfaction with the Hospice services we offer and provide. You may do so without fear of reprisal or termination of services. To register a complaint, please contact the following person:

Tracey Dobson, Chief Clinical Operations Officer
401Technology Lane, Suite 200
Mt Airy, NC 27030
(336) 789-2922 ext. 1002 or Toll Free: 888-789-2922
tdobson@mtnvalleyhospice.org

You may present your complaint orally or in writing. We promise that you will receive prompt attention. If you are not satisfied with our response, we encourage you to contact the following offices, which regulate Hospice services in the areas we serve:

North Carolina Department of Health
& Human Services
Division of Facility Services
PO Box 29530
Raleigh, NC 27603
1-800-624-3004

Accreditation Commission for Healthcare
4700 Falls of Neuse Road, Suite 280
Raleigh, NC 27609
Phone: (919) 785-1214 Fax: (919) 785-3011
Hours of Operation: 8:00 AM – 5:00 PM
customerservice@achc.org

Complaint and Appeals Process-Virginia

Mountain Valley Hospice & Palliative Care strives to provide exceptional care to individuals with a limited life expectancy and their families. Each employee has been trained and not only meets standards within their profession, but standards that our organization feels important for our employees to have.

However, there are always circumstances which are unforeseen and maybe you feel that an incident needs reporting. **Mountain Valley Hospice & Palliative Care** has written policies and procedures for addressing complaints. You have the right to lodge complaints without fear of

discrimination, reprisal or interruption of care, treatment and services. All complaints are held in strict confidence.

At any time, an individual wishes to express a complaint; they may do so by phone or in writing. Once the complaint is received, it is reported to a supervisor and a complaint log, and complaint record will be completed. The Complaint will be reviewed with the appropriate supervisor and an investigation will begin. Contact may be initiated to the complainant for details related to the complaint lodged. We will make at least 3 attempts to reach you by phone to gather information and resolve the complaint. Then a proposed written resolution will be sent to the complainant within 30 days of receipt of the complaint.

All actions taken and follow-up will be documented and recorded. If at any time you are dissatisfied with the resolution, please utilize the agency appeal process. The appeals process is to contact by phone:

First

1. Chief Clinical Officer
Tracey Dobson, BSN, RN
Direct # 336-789-2922
Toll Free # 888-789-2922

Next

2. Executive Director
Denise Watson, RN, MSN/MBA/HC
Direct # 336-789-2922
Toll Free # 888-789-2922

Next, in writing:

- | | |
|--|---|
| 3. The Board of Members or
1477 Carrollton Pike
Hillsville, VA 24343 | 4. The Board of Members
18981 Jeb Stuart Hwy
Stuart, VA 24171 |
|--|---|

In the event the appeals process did not meet your satisfaction, please know you may also contact the Office of Licensure and Certification. This is the state agency which helps regulate Hospices within the Commonwealth of Virginia. They accept complaints in writing, by telephone, fax, email, in person, or anonymously. You may visit them on the web at:

<http://www.vdh.virginia.gov/OLC/contacts.htm>

Their contact information is:

Complaint Intake	1-804-367-2102 or 2103 – Main Phone Numbers
Office of Licensure and Certification	Fax # 1-804-527-4502
Virginia Department of Health	Complaint Hotline # 1-800-955-1819
9960 Mayland Drive, Suite 401	
Richmond, VA 23233-1463	

The contact information for our state ombudsman is:

Office of the State Long-Term Care Ombudsman
Virginia Association of Area Agencies on Aging (V4A)
24 East Cary Street, Suite 100
Richmond, VA 23219
Phone: 1-804-565-1600 Fax: 1-804-644-5640
Toll free: 1-800-522-3402
State Ombudsman: Joani Latimer jlatimer@thev4a.org
Assistant State Ombudsman: Gail Thompson gthompson@thev4a.org

Or:

Accreditation Commission for Healthcare
4700 Falls of Neuse Road Suite 280
Raleigh, NC 27609
Phone: (919) 785-1214
Fax: (919) 785-3011
Hours of Operation: 8:00 a.m.-5:00 p.m.
customerservice@achc.org

The Office of Licensure and Certification investigates complaints lodged against medical facilities in the Commonwealth of Virginia that are either licensed by the state or are Medicare/Medicaid certified. This includes, but is not limited to, nursing homes, hospitals, home health agencies, end-stage renal dialysis facilities, outpatient surgical hospitals, Hospices and clinical laboratories.

The use of the complaint form will assist the Center in determining if your complaint is within the Center's regulatory jurisdiction. If it is, the Center will conduct an investigation of your complaint and notify you of the results of our findings. If the complaint allegations do not fall within the Office of Licensure and Certification's jurisdiction, your complaint will be referred to the appropriate agency so that it might assist you and we will notify you of that action.

There are some issues, fees for example; that our agency does not regulate. We do regulate the quality of patient care, as governed by state and federal regulations, for licensed medical facilities and federal Medicare/Medicaid facilities.

Please be as thorough as possible when completing the complaint form. The Center reviews evidence that may exist in regard to an individual's allegations, therefore, the earlier you report an incident, the better the opportunity for our office to address your concerns with the appropriate facility staff and review information pertinent to your complaint.

Whenever possible, we encourage patients to directly address their concerns with the facility's administrator. Most medical facilities want to be informed if patients are dissatisfied with the care they have received. Do not hesitate, however, to immediately contact our office, using the toll free number, for complaints that may seriously jeopardize patient health and safety.

At the conclusion of the investigation, we will notify you if the complaint allegations were substantiated and if the facility was directed to take corrective actions.

Medical facilities are governed by federal and/or state regulations: some facilities participate in private, non-governmental accreditation organizations. There may be times that we find your allegations may be proven, however, no federal or state regulatory violation has occurred. In this instance, you have the option of informing the accreditation agency of your concerns or pursuit of other avenues available to health care consumers.

If you have any questions regarding your complaint or this process, please feel free to contact our offices. A copy of the complaint form has been provided for you in your Hospice folder.

Financial Responsibility

The Medicare/Medicaid Hospice Benefit

Medicare covers services provided by qualified Hospices which have been certified by Medicare. These same services are also covered under Medicaid. The Medicare/Medicaid benefit will cover the following services when authorized by Hospice:

- Nursing Services
- Personal care by a Hospice aide
- Medical equipment and supplies (such as a hospital bed, bedside commode, oxygen, standard wheelchair, shower chair, etc.)
- Medications are covered if they are reasonable and necessary for the palliation and management of the beneficiaries' terminal illness and related conditions as determined by the Hospice Attending Physician. Prior authorization is required for all medications.
- Psychosocial, spiritual, and bereavement counseling services (patient and family)
- Inpatient care for pain control and symptom management
- Short-term respite care in a facility under contract with Hospice
- Allied Health Professionals:
 - Physical Therapists Speech Therapists
 - Occupational Therapists Dietitians
- Lab and diagnostic tests that have been authorized and are necessary related to the terminal illness
- Ambulance service for the purpose of a change in level of care-transportation to the hospital for acute inpatient, respite care. Ambulance services may also be covered for transfer to a nursing home or physician appointments. All ambulance services must receive prior authorization.

Benefit Guidelines

Hospice is required to follow the guidelines established by Medicare/Medicaid for patients using the Medicare/Medicaid Hospice benefit. Please call us before using any of the following services:

Emergency room visits	Ambulance services	Procedures
Hospitalizations	Physician visits	New treatments

Hospice has contractual agreements with some area long-term care facilities. Services may continue without interruption if an admission to one of these facilities becomes necessary. Contact your assigned social worker for more information.

Revocation of Benefit

Should you desire coverage for services not offered under Hospice Plan of care, you may choose to self-pay or revoke the Hospice benefit and resume regular Medicare/Medicaid coverage. You can revoke at any time and will continue to be eligible for the Hospice benefit in the future.

Reimbursement and Cost of Hospice Services

As a licensed and certified provider of Hospice services, Hospice is able to bill Medicare, Medicaid, and some commercial insurance carriers. For patients without insurance, Hospice will provide services regardless of ability to pay. However, patients and families are required to:

- Report all household income
- Report personal assets
- Complete Sliding Fee Scale Application
- Pursue Medicare/Medicaid eligibility to demonstrate need.

Eligibility

To receive Hospice care under the Medicare/Medicaid Hospice benefit, an individual must be entitled to Medicare Part A/Medicaid and be certified by the attending physician and the Hospice medical director as having a life-limiting illness with six months or less to live, if the disease runs its normal course. An attending physician is the physician identified as having the most significant role in the determination and delivery of care. A physician visit is required to determine continued eligibility after 180 days of service. This visit may also be required if you have had Hospice services in the past.

The Medicare/Medicaid Hospice Benefit continues, as long as there is physician certification of the terminal illness. Patients can withdraw (revoke) the Hospice benefit at any time and resume all regular Medicare/Medicaid benefits.

Patients who no longer meet eligibility requirements will be discharged from Hospice and referred to appropriate services.

Medicare Advantage Plans

A Medicare Advantage Plan is a type of Medicare health plan offered by a private company that contracts with Medicare to provide you with all your Medicare Part A and Part B benefits. If your plan covers extra services like dental and vision benefits, it will continue to cover these services.

Information about Medicare Supplement Insurance Policies

If you have traditional Medicare, you might have a Medicare Supplemental policy (Medigap). This policy covers health care costs for problems that are not related to your terminal illness.

Medicaid

Hospice participation may limit Medicaid services. The Hospice benefit covers all care pertaining to or resulting from the terminal illness as discussed above. Hospice services may be provided to Medicaid beneficiaries who reside in a nursing facility if MVHPC has an agreement with that facility and how services are to be provided. The agreement specifies financial arrangements. The arrangement with nursing facilities includes the rate of reimbursement for the facility and collection of any patient monthly liability (PML). Services are also provided in assisted living facilities.

Any beneficiary who is dually eligible for Medicare and Medicaid elects both programs simultaneously. Medicare is the primary payer and Medicaid reimburses MVHPC for facility room and board charges.

Other Insurance Coverage for Hospice Services

For patients who are not Medicare/Medicaid eligible, Hospice will bill your insurance company for services which are covered. Many insurance companies include coverage for Hospice services.

The Hospice staff will provide the insurance company with the necessary paperwork for reimbursement. You are responsible for co-payments and deductible amounts.

Billing of Co-Payments and Deductibles

Hospice is required by your insurance company to bill for co-payments and deductibles for Hospice services. You will receive a bill from our office at the end of the month. It is our policy to provide services to our patients regardless of ability to pay.

If you have any questions regarding our billing policy, please call our office and speak with a Billing representative at (888)789-2922 or talk with your assigned social worker.

Self-Pay

Patients whose insurance will not cover Hospice services or who do not have insurance will be placed on a “per diem” status upon admission. Bills are issued from our office at the end of each month based on a daily rate.

Schedule of Fees and Charges for Hospice Services

If the patient has Medicare Part A or Medicaid, and elects the Hospice benefit, all fees and charges for services related to the Hospice terminal diagnosis and related conditions are covered if stated in the Hospice plan of care.

If the patient does not have Medicare Part A or Medicaid, but has private insurance that covers Hospice care, the insurance company will be billed. Patients are responsible for co-pays, deductibles, and any other charges as stated in their individual policy.

If the patient does not have insurance that provides for Hospice care, the patient will be billed at a daily rate. Should durable medical equipment be needed it will be billed by the company providing the service.

Fee Schedule for Hospice Services:

Routine Care:	\$148.00 per Day
Respite Care:	\$153.00 per Day
General In-Patient Care:	\$650.00 per Day
Continuous Care:	\$860.00 per Day
Hospice Home Residential Room & Board:	\$180.00 per Day

Correction of Billing Errors and Refund Policy

The Billing Department is responsible for researching and correcting billing errors. Billing errors charged to a patient will be corrected as soon as the error is discovered. Hospice will initiate a refund of money due because of an error within five (5) working days of discovering the error.

Questions about this information should be directed to a billing representative at (888) 789-2922.

Sliding Fee Scale

MVHPC has established billing and reimbursement procedures. Patients and/or their families will be financially responsible for Hospice services. A patient with no health insurance or limited health insurance will apply for a sliding fee. A sliding fee is the reduction of our normal charge to a lower charge based on the patient's income and household size. While **no patient will be denied care based on their inability to pay**, it is the patient's responsibility to prove their inability to pay by completing the Sliding Fee Application and pursuing Medicare/Medicaid eligibility.

During the initial admission/assessment process, billing policy and potential charges for Hospice services will be explained by the social worker or the admitting staff member. MVHPC staff will also ascertain whether the patient and/or family should apply for a sliding fee based on Hospice charges and the financial situation of the patient and/or their families. If appropriate, staff will provide the Sliding Fee Application and answer questions on how to complete the application. Staff can also assist with obtaining applications for Medicaid and State or County Special Assistance programs.

The Sliding Fee Application requires the information listed below. The application must be completed and received by MVHPC Billing Department within 14 days of the admission date. Full fees will be charged until an assessment qualifying the applicant for the sliding fee is completed. MVHPC Billing Department will notify the case social worker to notify the patient when the assessment is complete.

- Name/Address/Phone Number/Social Security Number
- **Income Verification** – Must provide a copy of page 1 of most recent federal income tax return (Form 1040 or 1040A) and a copy of recent wage statements, unemployment, or pay stubs. A statement from employer showing year to date earnings can be substituted for pay stubs. This must be done for each person in the household. Total income includes income from all sources such as employment, unemployment, self-employment, social security, child support, public assistance, housing allowance, military family allotments, disability, pension funds, savings/trusts, VA benefits, spousal support, food stamps, scholarships/grants and any other source of income.
- **Household Size Verification** – This is the number of persons in your family who live in the same household and who share income, food, and/or rent. The number includes you, your spouse, or any dependents. Your most recent income tax return is required.

You may also be asked to provide documentation of personal assets. This information is required for Medicaid eligibility. Assets that are usually counted for eligibility include:

- Checking and savings accounts
- Insurance policies
- Stocks and bonds
- Certificates of deposit
- Real property other than your primary residence
- Additional motor vehicles if you have more than one
- Vacation home or additional residence other than primary residence
- Full value of any asset that you own jointly with someone else.

Inpatient Care

Kids Path has a contract with the following in-patient providers. However, you are free to choose hospitals other than those under contract. If the patient has commercial insurance, then prior authorization may be needed and Kids Path needs to be notified. If the patient is a Medicaid recipient, then federal concurrent care laws allow the patient to receive care regardless of whether Kids Path has a contract with a certain facility.

Alleghany Memorial Hospital

233 Doctors Street
Sparta, NC 28675

Ashe Memorial Hospital

200 Hospital Avenue
Jefferson, NC 28640

Carilion Franklin Memorial Hospital

180 Floyd Avenue
Rocky Mount, VA 24151

Carilion New River Valley Medical Center

2900 Lamb Circle
Christiansburg, VA 24073

Davie County Hospital

223 Hospital Street
Mocksville, NC 27028

Davis Regional Medical Center

218 Old Mocksville Road
Statesville, NC 28625

Forsyth Medical Center

3333 Silas Creek Parkway
Winston-Salem, NC 27103

Hugh Chatham Memorial Hospital

180 Parkwood Drive
Elkin, NC 28621

Iredell Memorial Hospital

557 Brookdale Drive
Statesville, NC 28677

Memorial Hospital of Martinsville

320 Hospital Drive
Martinsville, VA 24112

Morehead Memorial Hospital

117 East Kings Highway
Eden, NC 27288

Northern Hospital of Surry County

830 Rockford Street
Mount Airy, NC 27030

Pioneer Community Hospital of Stokes

1570 North Carolina 8 & 89 Hwy North
Danbury, NC 27016

Pioneer Health Services of Patrick County

18688 Jeb Stuart Highway
Stuart, VA 24171

Pulaski Community Hospital

2400 Lee Highway
Pulaski, VA 24301

Twin County Regional

200 Hospital Drive
Galax, VA 24333

Wake Forest Baptist Medical Center

Medical Center Boulevard
Winston-Salem, NC 27157

Wilkes Regional Hospital

1370 West D Street
North Wilkesboro, NC 28569

Joan & Howard Woltz Hospice Home

945 Zephyr Road
Dobson, NC 27017

You are free to choose hospitals other than those under contract with Mountain Valley Hospice & Palliative Care. However, you will be responsible for all costs associated with that period of inpatient care. Traditional Medicare/Medicaid would not cover that hospitalization while you are still participating in the Hospice Benefit. You may consider revocation of the Hospice benefit at any time.

Making Important Health Care Decisions

Questions about health care are often complicated and painful. This conversation can be even more difficult between a parent and child. While parents are the primary decision maker for the children under the age of 18, having a discussion with the child may help the parent and physician allows the child's voice to be heard. Advanced Directives are typically legal documents that adults use. These documents can appoint a healthcare agent to make medical decisions for the adult patient (Healthcare Power of Attorney) and/or guide the adult patient's healthcare decisions, in the event the adult patient cannot make those decisions (Living Will). Children do not need these legal documents, but there are tools available to help guide important healthcare decisions.

My Wishes

My Wishes is a booklet written in everyday language that helps children express how they want to be cared for in case they become seriously ill. *My Wishes* also helps begin conversations among children, parents, and caregivers. *My Wishes* is not a legal document.

The booklet contains the following:

- How I Want People to Treat Me
- How Comfortable I Want to Be
- What I Want My Loved Ones to Know
- What I Want My Doctors and Nurses to Know

Voicing My Choices

Voicing My Choices: A Planning Guide for Adolescents & Young Adults helps young people living with a serious illness to communicate their preferences to friends, family and caregivers. It is designed for teens and young adults.

Voicing My Choices gives the teen/young adult a way to express something very important – their thoughts about how they want to be comforted, supported, treated, and remembered. *Voicing My Choices* was developed using feedback from young people living with a serious illness.

The booklet contains the following:

- How I Want to be Comforted
- How I Would Like to be Supported
- Who I Want to Make My Medical Care Decisions
- The Types of Life Support Treatment I Want, or Do Not Want
- What I Would Like My Family and Friend to Know about Me
- My Spiritual Thoughts and Wishes
- How I Wish to be Remembered

Physician Orders Concerning End-of-Life

Another part of Advanced Care Planning is physician orders for end-of-life wishes. These orders are written after important conversations and decisions have been made concerning life sustaining treatments.

Do Not Resuscitate Orders (DNRs)

Medicine and technology have given us the ability to restore and support breathing and heart functioning by mechanical means. In many cases, these are appropriate options. However, when an illness is terminal, these may not be beneficial. If you do not want resuscitation attempted for your child, talk with your nurse or social worker about an order which the physician signs. Kids Path will have the primary care physician sign the order and incorporate your wishes into your child's plan of care. The nurse or social worker will also obtain a form from your child's primary care physician that can be kept in your home to communicate your wishes to Emergency Medical Services personnel (rescue squad, ambulance personnel) that you do not want CPR (Cardio-Pulmonary Resuscitation) for your child. If you have questions about DNR orders, please do not hesitate to ask a Kids Path Team member for more detailed information.

Medical Order for Scope of Treatment (MOST)

MOST is a physician order that outlines a plan of care respecting your wishes for your child at end-of-life. It specifically addresses wishes related to nutrition, hydration, treatments, antibiotics, and resuscitation status. It is reviewed and updated, at least yearly, but also every time your child's condition changes.

In-patient Units

Most Hospice patients and families hope to be able to remain at home in the last days of life. In cases where this is just not possible, our in-patient units provide an alternative. MVHPC has two locations that are designed to be as homelike as possible.

Our in-patient units have qualified and highly trained staff with years of experience in providing pain and symptom management. Facility staff includes nursing, social work, Hospice aide, chaplain and counseling services. A full time medical director who is certified in Hospice and palliative medicine, provides physician services to each patient.

Both In-patient units are state of the art and provide a warm and secure environment with a homelike setting and feel. The facility offers an atmosphere that encourages families to focus on what matters most; being together, reminiscing and making memories.

Joan & Howard Woltz Hospice Home

The Joan and Howard Woltz Hospice Home is located in Dobson, NC and has 20 Hospice patient and family suites. The home is centrally located in the midst of peaceful farmland with a lovely view of the Blue Ridge Mountains. The in-patient Hospice facility provides a safe and comfortable place for patients who require a higher level of care to manage distressing symptoms, or who require care and support through the dying process.

For more information, or to view a virtual tour of the facility, please visit our website at:

www.woltzhospicehome.org

SECU Hospice Home of Yadkin

The SECU Hospice Home of Yadkin will be opening in the spring of 2017. It is a smaller facility that will offer a private, homelike setting – close to home. It will have six patient suites with private baths and enclosed outdoor patios. Other amenities include a chapel, family living room, kitchen and dining area, a teen room, child playroom, a community meeting room with covered patio, a sunroom, and covered porches. The outside spaces will include a children's playground and a beautiful courtyard with a view of Pilot Mountain.

Hours of Service

Kids Path services are available 24-hours per day, seven days per week. Feel confident that our staff is available to provide the support you need to be comfortable, secure and have peace of mind.

What to do after regular business hours, on weekends, and holidays:

Services are provided by our staff from 5:00 p.m. to 8:00 a.m. Monday through Friday and 24 hours a day on Saturdays, Sundays, and holidays.

To reach a nurse, please call:

- Mount Airy 336-789-2922
- Pilot Mountain 336-368-1260
- Elkin 336-526-2650
- Yadkin 336-679-2466
- Stuart 276-694-4416
- Hillsville 276-728-1030
- Martinsville 276-403-4764
- **1-888-789-2922 if you need a toll-free number.**
- In the unlikely event there is no answer, please call the Woltz Hospice Home toll-free **1-877-356-0356.**

Your Kids Path Team

You and Your Family - *You, our patient, and your family are the most important members of the Kids Path Team.* You determine, with the rest of the Kids Path Team, your plan of care. The rest of the Kids Path Team relies on you to let them know of needs, concerns, and questions. The Kids Path Team, also called the Inter-Disciplinary Group [IDG], meets every two weeks to discuss your plan of care.

Your Physician - _____

Your physician follows you and works with our staff to implement the plan of care. Kids Path physicians are also a part of your team and participate in the Inter-Disciplinary Group.

Your Kids Path Nurse - _____

The nurse works closely with the physician to ensure that you are kept as physically comfortable as possible. Pain control and symptom management will be primary concerns. Your nurse makes scheduled visits. A nurse is available 24 hours a day, seven days a week for emergency situations.

Your Kids Path Aide - _____

Hospice aides assist with personal care, such as baths, shampoos, and nail care. The Kids Path aide may help with light household chores in the patient's immediate living area and simple meal preparation for the patient.

Your Kids Path Medical Social Worker - _____

The Medical Social Worker is a part of your Kids Path Team and has specialized training in helping patients and families adjust to the changes brought about by serious illness. Focusing on both the concerns of the patient and the stress affecting the caregiver and family, the social worker provides supportive counseling and case management. Social workers provide individual and family support and help you and your family members access the resources necessary for your care.

Your Kids Path Chaplain - _____

As part of our team approach, Kids Path provides spiritual support for patient and families.

Your Kids Path Volunteer - _____

A trained Kids Path Volunteer can offer assistance in a variety of ways. This includes sitting with the patient, providing companionship, or providing practical support such as running errands or assisting with chores.

Your Kids Path Bereavement Coordinator - _____

Another member of the Kids Path Team is the Bereavement Support Coordinator. Bereavement is the time period just before or after a loss. Bereavement services are offered to every family and those in the community, who have suffered a loss. Even when death is anticipated, and the person was ill, it is still *never* expected. Learning to adjust to life after a loss can be challenging. Our team of bereavement professionals will "walk" with you at this difficult time, teaching about grief, answering questions, and staying in touch.

The Role of the Nurse

Every patient is assigned a Registered Nurse as case manager. The nurse case manager works with the patient/family, patient's physician, and the Inter-Disciplinary Group (nurse case manager, physician, medical social worker, chaplain, aide, Volunteer, and bereavement support) to meet the physical needs of the patient. The nurse case manager provides leadership to the Kids Path Team to help develop an individualized plan of care, where the patient/family determine their needs for care.

The role of the Kids Path nurse is to

1. Make regular visits at least one time per week
2. Evaluate the patient's physical needs
3. Evaluate the patient's pain
4. Evaluate the control of symptoms such as shortness of breath or constipation
5. Coordinate with the patient's physician to provide relief of physical symptoms
6. Arrange for medical equipment
7. Arrange for other services as needed
8. Review patient's medications on every visit.
9. Train you on pain and symptom management and how to care for your loved one.

Arranging for other services:

Kids Path is responsible for ensuring that all services provided to patients are furnished in a safe and effective manner and is in accordance with you/your loved one's plan of care. This means that your nurse case manager must be aware of any services or procedures that are not provided by Kids Path. These services must be approved prior to receiving treatment, supplies, equipment, medical transportation, scheduling appointments or procedures, or other services related to the patient's terminal illness. Without prior approval, patients and families may be responsible for any charges that are incurred.

Does every patient always see the same nurse?

We know that patients and families become close to the people who visit from Kids Path. Each patient is assigned a "primary nurse case manager," who visits regularly and manages the patient's care. Most every visit will be made by the patient's primary nurse case manager. However, there are exceptions, when the primary nurse case manager is not working due to vacation or illness. All of our Kids Path nurses are registered nurses or licensed practical nurses. Many of our nurses are also nationally certified in Hospice and Palliative Care.

The Role of the Medical Social Worker

The Medical Social Worker is a part of your Kids Path Team and has specialized training in helping patients and families adjust to the changes brought about by serious illness. Focusing on both the concerns of the patient and the stress affecting the caregiver and family, the social worker provides supportive counseling and case management.

The role of the Medical Social Worker is to:

1. Make regular visits every two weeks
2. Evaluate patient and family adjustment to illness
3. Identify patient and family needs related to social and emotional factors
4. Accesses community resources in order to meet patient and family needs
5. Educate families about grief, caregiver stresses, and pain management
6. Support effective coping skills and teach new coping skills
7. Identifying areas for reconciliation and closure
8. Evaluate financial resources or constraints

Does every patient receive Medical Social Work services?

Most patients/families benefit from Kids Path social work services. The Medical Social Worker provides active listening and allows patients/families the opportunity to express thoughts and feelings about both the impact of the illness and the quality of care being received.

Are Kids Path Social Workers part of the welfare system?

Kids Path social workers are considered Medical Social Workers in nature and are trained to help meet the unique needs of Kids Path patients. The Kids Path social worker role differs from social workers that are employed with local social services and mental health agencies, where protective services, foster care, and eligibility are located. Kids Path Social Work staff members are employed by Kids Path and they provide expertise in addressing the emotional, financial, and legal concerns that may challenge children and their families experiencing a life-limiting illness.

The Role of the Kids Path Aide

The Kids Path aide is a very important part of the Hospice Team. Each of the Kids Path aides are certified nursing assistants. The Kids Path aide comes into the home to provide personal care services to the patient as directed by the nurse case manager.

The role of the Kids Path Aide is to:

1. Provide bathing, hair care, mouth care, skin care, nail care.
2. Assistance with moving the patient from bed to chair
3. Assistance with repositioning patient if needed
4. Assistance with changing bed linens and bed making
5. Assistance with straightening the primary area where the patient stays

Kids Path Aide Documentation

Kids Path aides will be documenting the care they are providing by using your home telephone, if available. They will need to make a call when they arrive to verify duties for that visit and then just before they leave they will make a call to document the care they actually provided. They will be calling a toll free number therefore these calls will not result in any phone charges to your phone. Each call should be brief and not result in any inconvenience. Please feel free to discuss any concerns with your Kids Path Team.

Can the Kids Path Aide give medications?

The Kids Path aide may help the patient with self-administration of medication but may NOT prepare or administer any medications.

Will the Kids Path Aide clean house and do laundry?

The Kids Path aide can straighten the primary area where the patient stays. However, the Kids Path aide does not do general house cleaning. The Kids Path aide may wash a load of the patient's clothes or bed linens, but the family laundry is not done. The primary role of the Kids Path aide is to provide assistance with personal care, any cleaning or laundry will only occur if time allows.

Will the Kids Path Aide cook for the patient?

The Kids Path aide can heat a meal for a patient, if the food is already prepared. A sandwich can be prepared. However, the Kids Path aide does not cook or prepare meals.

Can the Kids Path Aide stay for several hours, while I run errands?

The Kids Path aide is in the home for personal care and stays for about 1-1 ½ hours. You do not need to be in the home during that time, but please be back to the home in that time frame. The Kids Path aide will need to leave to assist other patients. If you need more time away from the home, then one of our Volunteers may be able to help.

The Role of the Kids Path Chaplain/Spiritual Care Advisor

As part of our team approach, Kids Path provides spiritual support for patient and families. What is the purpose of spiritual care? Spiritual care arises from the belief that care of the body alone cannot be effective if the mind, heart, and soul are ignored. Most people, whether religious or not, have experiences that are spiritual in nature. Spiritual care for Kids Path relates to meaning and hope.

There are many benefits to spiritual care. It can create higher levels of spiritual well-being, which can lead to a higher quality of life. Religious beliefs can enhance the coping process and are comforting to those who are grieving.

The Kids Path Chaplain tries to gain a sense of what the spiritual picture is for each patient and family and may ask questions such as:

1. What is happening to you; body, mind and soul?
2. What gives you strength for this struggle?
3. What gives you hope today?

The role of the Kids Path Chaplain/Spiritual Care Advisor is to:

1. Make regular visits at 1-2 times per month
2. Actively listen so that patients and families can discuss their religious beliefs and questions without fear of condemnation
3. Provides opportunities for patients and families to explore the value and meaning of life, family connections, and grief
4. Provides opportunities for meditation, worship, blessings, and rituals
5. Listen to patient and family fears, hopes, pain, and dreams
6. Assist with funeral planning

What the Chaplain/Spiritual Advisor does NOT do

1. He/She does not replace the spiritual support of each family's minister, priest, or rabbi
2. He/She does not attempt to convert patients or families to a particular faith belief
3. He/She does not "preach" to patients or families

Does every patient receive spiritual care?

Chaplain services are optional. Every patient and family is offered spiritual support on admission. This service is offered to patient and families from any faith group or those with no particular faith group or belief system. You may request chaplain services on admission or at any time you are receiving Kids Path services.

The Role of the Bereavement Coordinator

Another member of the team is the Bereavement Coordinator. Bereavement services are offered to every family and those in the community. Even when death is anticipated, it is still *never* expected, especially for children. Learning to adjust to life after a loss can be challenging. Our team of bereavement professionals will “walk” with you at this difficult time, teaching about grief, answering questions, and staying in touch. Pre-bereavement services are also available as a support service that begins before the loss occurs.

The Kids Path Bereavement Program

Often overlooked in the events that surround death are children, who do not fully understand what has happened. Though a child’s grief may be different in duration or expression, it is no less real than the grief of adults. Kids Path offers bereavement services for children, who have suffered a loss, even if the family was not served by Kids Path or Mountain Valley Hospice & Palliative Care.

The Kids Path bereavement coordinator is highly trained in working with children and helping them through possible fears, anxiety, and questions about death and dying. Through the Kids Path program, we wish to assist children affected by illness and loss and understand that every child and situation is different. The Kids Path bereavement coordinator will work with children, who are seriously ill, siblings of a seriously ill child, or children, who have suffered the loss of a close adult (parent, grandparent, etc.)

Services offered to children:

1. One on one support and visits for the child/children before a loss occurs (pre-bereavement)
2. One on one support and visits for the child/children after a loss occurs
3. Phone calls to the child/children if needed
4. Provide active listening and set-up activities (art, play, etc.) to help the child/children with appropriate coping skills
5. Children’s support groups
6. Brighter Days Children’s Camp in the summer

Services offered to adults:

1. One on one support and/or visits before a loss occurs (pre-bereavement)
2. One on one support and/or visits after a loss occurs
3. An initial contact within two weeks of the loss for an initial visit
4. Quarterly contacts, which can be in the form of face-to-face visits, phone calls, and/or mailings lasting up to 13 months after the loss – more visits can be made if needed
5. Making contacts on significant dates
6. Educate clients on the grief process
7. Provide active listening and discuss appropriate coping skills

Bereavement Services to choose from:

1. Bereavement support visits (adults and children)
2. Quarterly contacts (face-to-face and/or by phone – for adults – children often need support over weeks and months)
3. Monthly newsletter (adults)
4. Support Groups (adults and children)
5. Grief classes (adults)
6. Remembrance Services (adults and children)
7. Camp (children)

Bereavement services are optional. Even if you decline bereavement services in the beginning, you may need the service later on. You can always contact Kids Path and a Bereavement Coordinator will contact you.

The Role of the Kids Path Volunteer

Kids Path is blessed with dedicated men and women from the community, who are committed to the caring and compassionate ministry of serving the families of our Kids Path. Our Volunteers are a vital part of the Inter-Disciplinary Group, which supports patients and families. All of the Volunteers complete a pediatric training program. While in training, Volunteers become familiar with the concept of patient care and examine their own attitudes and life experiences.

Volunteers will call before each visit. If you do not need their support on that day, that is okay. If you need to cancel a Volunteer visit, please call the Kids Path office and ask for the Volunteer Coordinator.

The role of the Kids Path Volunteer

1. Provide companionship to a child, while the caregiver runs errands, takes an undisturbed nap, showers, etc.
2. Read to children
3. Help make memory books/scrapbooking
4. Provide assistance with short errands
5. Provide meaningful and compassionate presence

How long can the Volunteer stay with a patient?

Kids Path Volunteers may be available 2-4 hours per week.

Will the patient always receive the same Volunteer?

Most often the same Volunteer will visit with a patient. There are times, when a different Volunteer may have to come. This is when the regular Volunteer is on vacation or ill.

Can I utilize Volunteer services for a one time need?

If you need a Volunteer to stay with a patient, while the caregiver goes to an appointment or attends a special occasion, please make the request as soon as you know the date and time. This will allow the Volunteer Coordinator sufficient time to help meet your needs.

How do I request a Volunteer?

You may ask anyone on your Kids Path Team: nurse case manager, medical social worker, chaplain, or Kids Path aide. They will contact the Volunteer Coordinator to help set-up Volunteer services for you.

The Role of the Caregiver

Taking Good Care of Yourself

Caregivers also need to receive care. Your emotional and physical well-being is very important and often difficult to maintain. Small things you do for yourself can make a *big difference*. It is important that those in the role of caregiver to care for themselves. This will allow the best care to be provided to your child.

Some suggestions are:

- **Accept help**

Friends, family, Volunteers, and hired assistants can be a great source of support. It is a good way to involve those people who offer to help, as well as a way to take a necessary break. In accepting help, it is best if you can be specific about your needs. Ask someone to run errands, do yard work, bring food, or sit with your child while you go for a walk or take a nap.

- **Take time for yourself**

A few quiet moments can be renewing. A walk with a friend can help you re-establish your perspective. A bath, while someone else cares for your child, can ease the aches of body and soul. It is important to make time for yourself and identify pleasurable activities as a part of the care-giving routine. Try to set a goal of at least one outing per week. This kind of personal time allows you to focus on other aspects of life.

- **Pay attention to your own physical needs**

You may be so busy being a caregiver that you forget about your own needs. Eating, sleeping, and exercising can make a big difference in your outlook. Healthy frozen dinners, meals prepared by a friend, a nap to offset missed sleep, and/or a short walk around the block can really help.

- **Practice relaxation techniques**

Pause for five minutes and breathe deeply. Count breaths or focus on pleasant images while sitting in a relaxed state in a quiet place. Try this especially when someone else is providing the child's care (like when a Kids Path Team member stops by). Don't forget that laughter and keeping your sense of humor are important too.

“The only courage that matters is the kind that gets you from one minute to the next.”

-Mignon McLaughlin

Tips from Someone Facing a Serious Illness

When someone we know is facing a terminal illness, we are often left feeling like we are helpless. However, we can help in seemingly small ways that can be very meaningful to one faced with such an illness. They might say:

- **Don't** avoid me. Be the friend, the loved one, you've always been.
- **Touch** me. A simple squeeze of my hand can tell me you still care.
- **Call** me to tell me you're bringing my favorite dish and what time to expect you.
- **Weep** with me when I weep. Laugh with me when I laugh.
- **Take** me out for a pleasure trip, but know my limitations.
- **Call** for my parent's shopping list and make a "special" delivery to my home.
- **Call** me before you visit, but don't be afraid to visit. I need you. I am lonely.
- **Help** me celebrate holidays (and life) by decorating my home.
- **Help** my family. I am sick, but they may be suffering.
- **Be** creative. Bring me a book of thoughts, taped music, a poster for my wall, or toys.
- **Let's** talk about it. Maybe I need to talk about my illness. Find out by asking me.
- **Don't** always feel we have to talk. We can sit silently together.
- **Help** me feel good about my looks. Tell me I look good, considering my illness.
- **Please** include me in decision making. I've been robbed of so many things.
- **Talk** to me about the future. Hope is so important to me.
- **Bring** me a positive attitude.
- **What's** in the news? Keep me from feeling the world is passing me by.
- **Just** send a card to say "I care."
- **Pray** for me and share your faith with me.
- **Tell** me what you'd like to do for me, and when I agree, please do it.
- **Tell** me about support groups so I may share with others.

Providing Care for Your Loved One

It is difficult to predict how each person will be affected by his/her illness; however, some of the most common symptoms are pain, nausea, vomiting, constipation, and insomnia. Each person reacts differently; therefore, each person must be treated individually. It is our experience that almost all symptoms can be controlled with the appropriate medication and with caring, supportive concern.

Providing for your physical comfort is our primary goal. Frequently, questions are raised about what to expect and what to do for comfort. The following are some general points to keep in mind. Your Kids Path nurse is always available for assistance with questions about physical comfort.

Pain Management

A primary concern of Kids Path care is to ensure that pain is controlled as much as possible for the child. Pain management is an important comfort measure. You may or may not have pain. It is important for the child and caregiver to learn how to assess pain so you can assist the physician and primary nurse in managing symptoms.

This simple scale given below will help rate the pain. Select the rating which best describes the pain.



Report this information to your nurse. The nurse will evaluate the pain further and contact the physician for medication orders if needed. Many times medications are the most appropriate way to control pain, but they must be taken properly. Each medication schedule will be different. The nurse will provide instructions regarding how, what, and when medications should be taken.

One of the primary concerns a new Kids Path patient may have is how pain is controlled. You may also have some concerns or misgivings about using the types of medications that are often prescribed to control pain.

It is difficult to predict how each child will be affected by his/her illness; however, some of the most common symptoms are pain, nausea, vomiting, constipation, and insomnia. Each child reacts differently; therefore, each child must be treated individually. It is our experience that almost all pain can be controlled with the appropriate medication and with caring, supportive concern.

Mild pain can be controlled by aspirin, acetaminophen, ibuprofen, or other non-steroidal, anti-inflammatory medications. Moderate to extremely severe pain is usually treated with narcotics.

Narcotics are used specifically to treat moderate to severe pain. Kids Path patients who have pain do not become addicted to narcotics. Only people who have no physical pain and take the drugs for the “high” become addicted. Medications are “titrated,” meaning adjusted, to fit the level of pain – small doses for moderate pain, larger doses for more severe pain. There is no average dose. Each child needs a specific dose determined by the degree of pain he/she is experiencing.

Some of our children do feel somewhat sleepy for the first two or three days after they are given the narcotic, but this is temporary and a more normal feeling returns.

Your doctor can know how much narcotic to give, only if you tell the nurse about the child's pain. Without your help, we have no way of knowing if the child is comfortable. Your nurse will contact your physician about the pain medication and make adjustments based on his/her orders. Every drug has a time span of effectiveness. Some drugs are given every three, four, six, or eight hours, and some have a time-release factor that allows them to be given every eight to twelve hours. Some medications are given by a patch placed on the skin and are changed every few days.

All medications should be taken as ordered. Some medications are given "as needed," but most pain medications are given on a regular schedule "around the clock." By taking the medication on a regular schedule, you prevent the pain from coming back. If you give the pain medication only when needed or only when the pain comes back, the child may need twice as much pain medication to get the pain under control, and it may take longer to achieve relief because the level of pain medication in the body has dropped. Untreated pain controls the child. By taking medication regularly, around the clock, you are in control of the pain. The effect of the narcotic does not wear off; if the pain gets worse, we simply adjust the dose until the pain is controlled again.

Points to Remember about Pain

1. It is important to give the medications as directed. Some medications need to be taken on a regular schedule so a level of medication is maintained in the blood to block the pain signals to the brain.
2. Pain is harder to control if it becomes severe.
3. Children with pain will not become addicted to pain medication. In this case, medications are taken to relieve the pain, not for a "psychological high".
4. Sleepiness occurring after beginning the medication is common. Intense pain prevents sleep. Relaxation occurs when pain is controlled, and this allows for much needed rest and sleep. Sleepiness usually wears off after a few days.
5. Adjustments in medication may be necessary depending on the illness and the child's pain tolerance. It is important to notify the nurse regarding significant increases or decreases in pain.

The Kids Path nurse will work closely with your attending physician. They will do everything possible to control pain. The medication can be given many ways:

- Most people will be able to take medications orally (by mouth).
- For those unable to swallow, medication can be given by placing it under the tongue, through an adhesive patch on the skin, directly rubbed into the skin, suppository, or through a needle placed under the skin or in a vein.

If you have questions and concerns that are not covered in this material, please do not hesitate; contact a Kids Path Team member who will help to answer your questions.

NPASS

The NPASS is the pain scale that is used to assess pain in **neonates**.

- A score <4 = mild pain (requires non-pharmacologic comfort measures).
- A score >5 = moderate to severe pain (most likely requires pharmacologic intervention in conjunction with comfort measures).

Assessment Criteria	Sedation		Normal	Pain/Agitation	
	-2	-1	0	1	2
Crying Irritability	No cry with painful stimuli	Moans or cries minimally with painful stimuli	Appropriate crying Not irritable	Irritable or crying at intervals Consolable	High-pitched or silent-continuous cry Inconsolable
Behavior State	No arousal to any stimuli No spontaneous movement	Arouses minimally to stimuli Little spontaneous movement	Appropriate for gestational age	Restless, squirming Awakens frequently	Arching, kicking Constantly awake or Arouses minimally/no movement (not sedated)
Facial Expression	Mouth is lax No expression	Minimal expression with stimuli	Relaxed Appropriate	Any pain expression intermittent	Any pain expression continual
Extremities Tone	No grasp reflex Flaccid tone	Weak grasp reflex ↓ muscle tone	Relaxed hands and feet Normal tone	Intermittent clenched toes, fists, or finger splay Body is not tense	Continual clenched toes, fists, or finger splay Body is tense
Vital Signs HR, RR, BP, SaO₂	No variability with stimuli Hypoventilation or apnea	< 10% variability from baseline with stimuli	Within baseline or normal gestational age	↑ 10-20% from baseline SaO ₂ 76-85% with stimulation- quick recovery ↑	↑ > 20% from baseline SaO ₂ ≤ 75% with stimulation- slow recovery ↑ Out of sync with vent

Categories	Scoring		
	0	1	2
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant frown, quivering chin, clenched jaw
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid, or jerking
Cry	No cry (awake or asleep)	Moans or whimpers; occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging, or being talked to; distractible	Difficult to console or comfort

Neonatal Infant Pain Scale			
NIPS	0 Point	1 Point	2 Points
Facial Expression	Relaxed	Contracted	-
Cry	Absent	Mumbling	Vigorous
Breathing	Relaxed	Different than basal	-
Arms	Relaxed	Flexed/stretched	-
Legs	Relaxed	Flexed/stretched	-
Alertness	Sleeping/calm	Uncomfortable	-

Maximal score of seven points, considering pain ≥ 4

Comfort Sedation Scale		
Characteristic	Evaluate	Points
Alertness	Deeply asleep	1
	Lightly asleep	2
	Drowsy	3
	Awake and alert	4
	Hyper alert	5
Agitation	Calm	1
	Slightly anxious	2
	Anxious	3
	Very anxious	4
	Panicky	5
Respiratory Response	No coughing	1
	Spontaneous respiration with little response to ventilation	2
	Occasional coughing with little resistance to the ventilator	3
	Active breathing against the ventilator	4
	Actively fighting the ventilator and coughing	5
Physical Movements	None	1
	Occasional, slight movements	2
	Frequent, slight movements	3
	Vigorous movements of extremities only	4
	Vigorous movements of extremities, torso, and head	5
Blood Pressure	Below baseline	1
	Normal	2
	Infrequent elevations of 15% or more	3
	Frequent elevations of 15% or more	4
	Sustained elevation greater than or equal to 15%	5
Heart Rate	Below baseline	1
	Normal	2
	Infrequent elevations of 15% or more	3
	Frequent elevations of 15% or more	4
	Sustained elevation greater than or equal to 15%	5
Muscle Tone	Relaxed/none	1
	Reduced muscle tone	2
	Normal muscle tone	3
	Increased tone/flexion-fingers/toes	4
	Extreme rigidity/flexion-fingers/toes	5
Facial Tension	Facial muscles relaxed	1
	Normal tone	2
	Some tension	3
	Full facial tension	4
	Facial grimacing	5

Excessive sedation: 8-16

Adequate sedation: 17-26

Insufficient sedation: 27-40

Shortness of Breath

Shortness of breath is different for each child. It may be described as not getting enough air, feeling that you cannot catch your breath, or a feeling of smothering. Shortness of breath can be very unsettling for both you and your child.

When shortness of breath occurs, perform the following steps and notify the Kids Path nurse:

1. Remain calm and reassure the child. Help them relax by encouraging them to take slow, deep breaths, breathing in through the nose and then breathe out through the mouth.
2. Prop the child in an upright position, using pillows for support if needed.
3. If oxygen is available, turn it on, adjust to the level of oxygen ordered, and place it on your child.
4. Turn on a fan to circulate air in the room
5. Keep the room cool.
6. If available, administer a breathing treatment or use inhaler.
7. You may administer medications that help with anxiety such as Ativan (Lorazepam) or Xanax (Alprazolam) as prescribed by the doctor.

Describing Breathlessness (Also known as Dyspnea)

As Hospice providers, we use scales to help us understand the level of difficulty you are having with any symptom. When you describe breathlessness, we would like for you to rate it on a scale of zero to four. We will refer to the following scale:

Scale	Description of Breathlessness
0	Breathless with strenuous exercise/activity.
1	Short of breath when hurrying on level ground or walking up a slight hill.
2	On level ground, walking slower or stopping to catch breath.
3	Unable to walk about 100 yards or after a few minutes on level ground.
4	Too breathless to leave the house or breathless with minimal or no activity.

Breathing Treatments

If your child is short of breath, your physician may order a breathing treatment which may be either an inhaler or a nebulizer treatment (aerosol treatments or med neb). Nebulizers change liquid medicine into a fine mist that your child will breathe into their airway. How often a nebulizer treatment is used will depend on:

- Physician order for the type of medicine and instructions for how often it can be administered
- How short of breath your child is
- The presence of wheezing

Oxygen Safety

We are always concerned about safety. On admission we will obtain an oxygen safety agreement. Your child may not be on oxygen at the time of admission; however, it is something that may be ordered for symptom management. It can help to reduce the work of breathing. We will review oxygen safety again at the time it is ordered. Our staff will not provide care in an unsafe environment. No smoking is allowed while staff is in the home.

Although oxygen is nonflammable it greatly accelerates the rate of combustion. Safe use of oxygen demands that all flammable materials and potential ignition sources be removed from the area. The following are some safety precautions to keep in mind:

- Do not smoke in a home where oxygen is used.
- Hang “No Smoking” signs on doors.
- No open flames such as candles, matches, lighters, etc.
- Keep oxygen source at least 10 feet from open flames, stoves, or any source of heat.
- No petroleum products on or near patient– Vaseline, lip balm, Chap stick, etc.
- Maintain a working fire extinguisher.
- Change batteries in your smoke detector every six months or as needed.
- Use oxygen in well ventilated spaces.
- Do not store oxygen in closets.
- Keep cylinders secured safely in an upright position – away from heat or sunlight.
- Turn oxygen off when not in use.
- Smokeless cigarettes can support an environment of combustion. Do not use.

Humidifier

A humidifier is a device that produces moisture. It is used to moisten the airway and provide relief from the dryness of oxygen use. It is important to always use distilled water in your humidifier as the mineral content of tap water may occlude the humidifier.

Cleaning and Care for your Oxygen Equipment

Do all cleaning and disinfecting in a clean environment. Avoid doing it after vacuuming, under an open window, or in dusty, dirty, smoky areas. You should:

- Wipe Oxygen equipment with a damp cloth to keep clean and dust free.
- Clean the mask or cannula with a damp cloth - daily.
- Replace the mask or nasal cannula – monthly or as needed.
- Replace the tubing – every three months.
- Clean the external filter every week by:
 - Removing the filter.
 - Rinse the filter thoroughly with warm water.
 - Squeeze water from the filter and pat dry with a clean towel.
 - Reattach the filter.

Refilling the Humidifier Bottle

If you are using a humidifier bottle with your oxygen concentrator, you will need to check the water level frequently. When the water is low or is not bubbling, you need to refill the jar. You may need to use a portable tank to ensure that your child has needed oxygen during the refilling process. You should:

- Wash your hands.
- Turn the oxygen off.
- Unscrew the jar from the humidifier bottle lid.
- Discard any water remaining in the jar.
- Rinse bottle under a strong stream of warm tap water. Shake off the excess water.
- Refill the jar with distilled water to the max fill line.
- Do not overfill the bottle. Too much water in the bottle will cause water to collect in your oxygen tubing.
- Screw the bottle back on the humidifier bottle lid until it is tight. Be certain the jar is screwed on straight. Cross-threading will cause oxygen to escape out the top of the jar.
- Turn the oxygen back on.

Your Hospice Team can also perform these tasks and help you put a plan in place to ensure they are done on a consistent basis. Please call us if you have any questions.

Nutrition

Many patients and families are concerned about nutritional needs. We will try to answer some of the most common questions asked about nutrition. We hope to help you understand nutritional needs. As a person nears the end of life, it is natural for their desire for food and water to decrease. As a terminal condition progresses, the body slows down and doesn't process food in the same way. Weight loss is expected and the patient may not feel hunger or thirst.

For many of us, preparing meals or feeding someone is a way of showing our love, concern, and how much we care. You may want to offer favorite foods but let the patient be the guide. They will let you know if food or fluids are needed or wanted. Respect their wishes by trying not to force food or drink. Sometimes the patient may appear thirsty but won't be able to drink water. You can be confident that small sips of fluid, ice chips, keeping the lips moist and mouth swabbing can provide comfort.

Preparing and serving a meal is one way we have learned to say "I love you" to someone. When your loved one is no longer able or wanting to eat, try showing your love in other ways: sit quietly and hold his/her hand, give a backrub, read, or listen to music together. You will find a variety of special ways to continue to show you care. These are some common questions we hear about nutrition:

Should the patient eat to keep up his strength?

Our bodies are much wiser than we give them credit for and will tell us what we need. Forcing food and water can cause serious complications such as choking, congestion, nausea or vomiting.

Food doesn't taste right. What am I doing wrong?

The disease process often distorts the taste buds, making food taste bland, sour, or salty. Meats and proteins frequently have an unpleasant metallic taste.

Is that why she won't eat what I fix for her?

Uncontrolled symptoms such as pain or nausea may also cause a loss of appetite. Working to control these symptoms can sometimes improve a patient's appetite.

She has just finished some radiation treatment. Would that take away her appetite?

Many treatments, including chemotherapy and some medications, have this effect.

What if our doctor recommends a special diet?

This should be followed if possible. Feel free to discuss diet problems with your nurse.

Helpful Hints and Suggestions

- Offer small, frequent (6-8) meals throughout the day instead of 2 or 3 large meals. Light foods (soups, fruits, gelatins, crackers, breads) usually are tolerated more easily.
- Serve small portions and use a small plate. A large plate filled with food can be overwhelming and give the patient a sense of failure if he can't finish it.
- Schedule meals for the child's pain-free and most energetic periods during the day.
- Don't force food. This may develop into a struggle where the person preparing the food feels rejected, and the child feels ungrateful or guilty for not eating.
- When the child is nauseated or in pain, liquid meals are often best – for example, soups, shakes, yogurt, cool drinks, etc. Popsicles sometimes taste good.
- Ice chips, flavored and unflavored, relieve the feelings of mouth dryness and discomfort.
- Protein supplements are often well tolerated.
- Instant breakfast mixes can easily serve as a full meal and are less expensive than supplements.
- Add dried milk or dried protein powder to liquid or soft foods to add calories.
- Buttermilk promotes easier digestion for some people.
- Drink fruit juices to provide additional calories.
- Give liquid in other forms, such as Jell-O, pudding, popsicles and ice cream.
- Avoid using straws, which may increase the swallowing of air, leading to burping or nausea.
- Children who can't speak will sometimes cough, clamp their teeth closed, bite the spoon, spit food or turn their heads to let you know they don't want to eat.

Anxiety and Sadness

Experiencing illness affects a person's mind, body and spirit. While you wouldn't want to assume what someone might feel, do be aware that people with a terminal condition may experience a variety of emotions. Fear, anxiety, anger, guilt, sadness and loneliness are just a few of the emotions they may feel, one at a time or simultaneously.

These feelings are a natural response to a terminal condition. Your role as a caring family member should be to listen to your loved one's thoughts and feelings without trying to change them. Don't try to take that necessary emotion away from them. You may be tempted to soothe or deny painful feelings, but a helpful response is to simply acknowledge them, listen, and understand. You will experience your own emotions. Always remember, your Hospice Team is here for you as well.

Emotions

This is an emotional time for the patient and family. It is often difficult to talk about feelings. This is normal and expected. Let's review some of the feelings you might experience.

Fear

Your fears are very real. Trying to figure out what you fear can help you face it and manage it. It will also help others support and care for you better. For example, if you're afraid of being alone, share this with your family so they can plan to have someone with you.

Sharing with loved ones and your Kids Path team gives them a chance to help you find ways to cope with and ease some of your fears. It gives them a chance to correct any wrong ideas you may have too. It can also give you a chance to look at and deal with some of your fears in new ways.

Anger

Anger is sometimes hard to identify, but ignoring it won't work. Very few people actually feel ready to die. It's perfectly normal to feel angry about your life being cut short – it's unfair and you have a right to be mad! Unfortunately, anger often gets directed at those closest to us, the ones we love the most. We feel safest with these people and know they will probably accept our anger and forgive us for it.

It may help to try to direct your anger at the disease and not your loved ones. You can try to channel your anger as a source of energy to help you take action where it is needed. You can use it as fuel to solve problems, to become assertive, or to get your needs met. You can sing at the top of your lungs, give a speech with vigor, or tell your family some things you really want them to know. Try to re-channel your anger to do meaningful, positive things.

Guilt and Regret

A person might regret or feel guilty about many things. Some feel guilt and regret about becoming a physical or financial burden. We may feel regret when we think that we should have done something differently. Or maybe there's something we wish we had not done at all. We may feel guilty when we don't meet our own or someone else's expectations.

It does not help to hold onto guilt or regret. Worrying endlessly about these things won't make you feel better about them. It won't improve your relationships with family members. It won't ease the burden they are carrying. It won't make you feel better. It won't make you live longer. It will only make you feel bad.

Sometimes the best thing to do is to decide to not feeling guilty about things that are out of your control. Simply let it go. You can't change the past, but there are things you might be able to do today. Apologize for the things you regret and ask for forgiveness. Be willing to forgive others and yourself. Fix what can be fixed and try to let go of the things that can't be changed.

This is a good time to talk with your children about the important things you want them to know. It's also good to talk to them about how to handle their feelings. You may want to write letters to the people you love, record messages for them, make videos they can watch – give them things they can keep to remember their time with you. Strengthen your relationships with loved ones. Live your life the best you can, and use your time for what's most important to you.

Grief

It is normal to feel intense grief during an advanced illness. You are grieving the loss of the life you have planned and expected. You can no longer look ahead to a seemingly “endless” future. And you may have lost many things already, such as the strength to walk or get around like you used to, or interest in eating the things you enjoy, or maybe the ability to get together with friends. You may feel distanced from friends who cannot handle their emotions. Many physical and emotional losses come before the loss of life itself.

The people you love are grieving too. How can you and those who love you find meaning in what's happening? Try to talk to your loved ones about the grief and loss of dreams you're all going through. Being able to rise above the grief and connect spiritually to something greater might help your loved ones heal.

Talking with someone about these feelings – a partner, a dear friend, a spiritual advisor, someone you trust – can help you process these feelings so that they no longer weigh you down. Once you have done this, you will feel a burden has been lifted and you can move on to the other physical and emotional tasks that make up the end of life. There are many important tasks at the end of life.

Anxiety and Depression

What does anxiety feel like? Anxiety has been described as having a nervous stomach, a shaky feeling all over, being short-tempered, a sense of dread or worry, or a fear of the unknown. It can be quite unpleasant.

Some anxiety is expected. If it is severe, it can be treated through counseling or with medicine. The goal is to make you more comfortable and help you better cope with the changes that are taking place. Anti-anxiety medicines or even anti-depressants can help. Counseling can be especially helpful in changing how you think about things so that you can focus on the present. Breaking problems into smaller, easier-to-manage pieces can be a good way to handle some kinds of anxiety.

Depression is more than just feeling sad. Depression includes feeling hopeless, helpless, useless, or sad for weeks at a time, and not having joy in any activity. These feelings are not normal, not even when life is ending. Depression can sometimes be helped with anti-depressants, counseling, or a combination of both. Managing anxiety and depression can make a big difference in how much joy or pleasure.

Feeling Alone

There can be a loneliness that is different from any other. It is a loneliness of the heart, even when you have people around you. There may be very few people who can really talk with you in a way that helps you feel less lonely. Some of them may be experts who are comfortable talking with people at the end of life, such as your Kids Path team. The ability for someone to be silent or listen when you need it will help with this feeling of loneliness. Finding those individuals that you can truly connect with is critical to easing this sense of intense loneliness.

Seek Meaning

Almost everyone wants to feel their life had purpose – a reason for their being on earth. Some people find meaning in their work. Others find that raising a family has brought them the greatest sense of joy and accomplishment.

It is helpful to go through a process of reviewing your life and figuring out for yourself what your purpose in life has been. What was your special contribution to the world? What have you done to make the world a better place? How would you like the world or your children, family, and friends to remember you? What were the things that you thought were really important and want your children to know about for their future? It doesn't have to be something huge or earth-shaking – look for those things that have been important to you and those around you.

Life is an experience is full of meaning. Reflect; share your thoughts, experiences, and wisdom. It is a gift that your friends and family can cherish for years to come. Understand that these feelings are a natural response to dying.

Family and Loved Ones

Your role as a caring family member should be to listen to your loved one's thoughts and feelings without trying to change them. Don't try to take that necessary emotion away from them. You may be tempted to soothe or deny painful feelings, but a helpful response is to simply acknowledge them. Listen and understand. You will experience your own emotions. Always remember, your Hospice Team is here for you as well.

Providing Care for Siblings and Sibling Involvement

Caring for a seriously ill child takes a tremendous toll on the whole family, and healthy siblings are no exception. As a parent, your exhaustion, stress, and uncertainty about how to respond to the needs of other kids may make you feeling guilty and even more tired than you already are. You might be tempted downplay or ignore the impact that your child's illness may have on his or her brothers and sisters.

By being aware of what healthy siblings are going through and taking a few steps to make things a little easier, you can address many issues before they unfold or become problematic.

A Sibling's Feelings

It is normal for family routines and dynamics naturally change when a child is ill. This can be very confusing and stressful as a parent, and these changes can also be confusing and stressful for healthy siblings. The stress can lead to anxiety and fear, and the siblings can possible have feelings of loss of their "normal life."

It's normal for healthy siblings to:

- worry that the sister/brother will die
- fear that they or other loved ones will catch the sibling's disease
- feel guilty because they're healthy and can enjoy activities that the sibling cannot
- be angry because parents are devoting most of their time and energy to the sick sibling
- feel neglected and worried that that no one in the family cares
- resent the sibling who never has to do chores
- resent that the family has less money to spend now because the sibling is sick
- wish things could be like they were before the illness
- feel guilty for being "mean" to the sibling in the past (prior to the illness)
- experience worry or anxiety about an uncertain future

The way siblings express their needs or try to get attention will vary. Each sibling is an individual and will behave differently - some may act out, some may try to be the perfect child. Behavioral and emotional changes and/or outbursts may be an indication of the feelings of loss the sibling is experiencing.

Signs of Stress and Loss

Pay attention to any changes in kids' behavior, and talk to them frequently about how they're doing and what they're feeling. The more room kids have to express their emotions, the less emotional turmoil and fewer behavioral problems they're likely to have.

Signs of stress in kids can include:

- changes in sleep patterns
- changes in appetite
- changes in mood or behavior
- changes in school functioning (poor grades, less socialization with friends)

Younger children often pick up on your stress and may start doing things they did when they were younger and had already outgrown (thumb sucking, wetting the bed).

You may not see any of these signs, but be aware that your child is feeling stress.

You Can Help

You may not be able to take away the pain and feelings of loss and stress, but you can make them feel secure, cared for, and supported.

The following are suggestions to help, however, you may want to consider using the help of the Kids Path Bereavement Coordinator or a professional counselor.

Focus Forward

You may feel guilty for not being a perfect parent to your healthy children, but try not to dwell on this. Instead, make a point of recognizing your kids' feelings and needs now, and go from there.

Open Communication

Encourage siblings to talk about their emotions: good, bad, guilt, loss. Attempt to identify behaviors and name them. This can be difficult when you're tired, stressed, or at the hospital or clinic for long periods of time. However, it only takes little time, attention and conversations for your healthy kids to know that their needs are important.

Try to Keep Your "Normal"

Try to treat your kids equally. It is easy to loosen the strings on your healthy children, but maintaining current rules and enforcing them minimizes jealousy and guilt. It shows your child that you still care and are paying attention to their actions. Be careful not to rely on healthy kids as caregivers before they are physically and emotionally ready. Accept help from other adult caregivers, so that you can maintain a routine and provide that little bit of attention to your healthy kids.

Say Yes to Help

Accepting help with transportation, meals, childcare, and other daily activities can take some pressure off of you so that you have the emotional reserves to be there for your family. You'll also be teaching your kids a valuable lesson about accepting generosity from others.

It's Okay to Have Fun

Enjoying yourself and having fun can go a long way in relieving stress and recharging energy. In addition to trying to maintain a normal schedule, whenever possible set aside family time for all of your kids that *does not* focus on the illness. Also, plan some one-on-one time with your healthy kids where the focus is on them and their activities and not on the illness.

Be Patient

Patience is essential when healthy siblings are trying to make sense of their emotions. At a time when your nerves are wearing thin, it can be hard to stay patient and attentive, but it is needed for siblings. However, it's not a good idea to let kid act inappropriately or get away with behavior that was not acceptable before the illness. Instead of making the child more relaxed, it could cause more anxiety. Once again, normalcy is important.

Include Siblings

Including healthy kids in some of the doctor visits and hospital sessions can help them understand the illness. They also can benefit from connecting to other sibling in the same situation. In addition, giving healthy kid "jobs" can help them feel like an important part of what is happening with the illness as well as an important part of family's changing situation. You can let them tell you how they'd like to be involved — maybe helping with light and, most likely neglected, house chores, making cards, books, or videos to keep their sibling with an illness occupied, etc.

Confidence as a Caregiver

As death approaches, the members of your Kids Path Team want you to know what to expect. Know that you can call Kids Path for assistance at any time. We will review signs of the dying process and focus on providing care that promotes physical and spiritual comfort. Not all signs and symptoms of the dying process occur with every child or in any particular order. Some things you may see:

- **Coolness** of hands, arms, and feet; discoloration/mottling of the extremities – blood flow is decreasing throughout the body.

What you can do:

Use a warm blanket or provide gentle massage of extremities.

- **Fever.** As the body becomes weaker, so does the temperature control mechanism in the brain.

What you can do:

If a fever develops, let your nurse know. You may apply a cool wash cloth to the forehead or use a fan in the room. Your nurse may suggest Tylenol if the fever is high.

- **Sleeping.** Your child may spend an increasing amount of time sleeping, and at times, be difficult to arouse.

What you can do:

Let your child sleep. Provide a quiet, calm environment with soft indirect lighting. Soft music may help them rest.

- **Decreased Socialization.** Withdrawing from family and friends is a normal part of the dying process. Your child may seem unresponsive and may be difficult to arouse.

What you can do:

You may wish to plan visits and activities for times of day when your child seems most alert. Speak to the child in your normal tone of voice. Identify yourself by name when speaking to your child.

- **Disorientation.** Your child may seem to be confused about time, place, and names of people.

What you can do:

Report these symptoms to your Kids Path nurse. Identify yourself when speaking to your child. Speak softly, clearly, and truthfully. Reassure your child by reminding them of your presence and support. Limiting visitors can sometimes decrease the level of disorientation or confusion.

- **Restlessness.** Your child may become restless and use repetitive motions – pulling at linens or trying to drink from a cup that is not there.

What you can do:

Let the Kids Path nurse know if your child is agitated or restless. It may be helpful to utilize other members of the Kids Path Team such as the social worker and/or chaplain for additional support. Remain calm and speak in quiet, natural tones to provide reassurance. Soft music, light touch or holding your child's hand may be comforting.

- **Visions.** Your child may talk to family members or friends who have passed on before or claim to have spoken with people who are not visible to you. These experiences are normal and common.

What you can do:

Just because you cannot see or hear them does not mean it is not real to your child. Affirm his or her experiences and do not try to contradict. These experiences can be a source of comfort and inspiration to your child.

- **Incontinence.** Urine output normally decreases and may become darker and odorous. Your child may lose control of urine and/or bowel function as the muscles in that area begin to relax.

What you can do:

Your Kids Path Team may suggest using disposable briefs and under pads. Check your child frequently to ensure that they are dry and comfortable. If your child is not able to void and they appear uncomfortable, contact your Kids Path nurse to determine whether there may be a need to insert a catheter.

- **Fluid and Food Decrease.** They may want little or no food or fluid. The body's need for nourishment is decreasing.

What you can do:

Follow your child's cues. Do not try to force food or drink. Provide mouth care to keep lips and mouth moist.

- **Congestion/Changes in Breathing Pattern.** Irregular breathing patterns which may include long pauses before the next breath, or congested sounds may occur. This does not indicate the onset of new or severe pain.

What you can do:

Contact your Kids Path nurse who may be able to make changes that will keep your child more comfortable. Elevating the head of the bed or turning your child to the side may help to drain secretions. Frequent mouth care helps ensure the lips and mouth remain moist.

During this time of transition, you may want to sit with your child. Provide personal care to keep them clean and dry. Never assume they cannot hear you. Talk to them and say the things you need or want to say. Give them your support and understanding as a gift of love. Take this opportunity to reminisce and share gratitude or forgiveness.

Remember that we are available to visit. We want to ensure that you have what you need to provide care.

When Death Occurs

No one can predict the moment of death. Some pass on while others are present. Some appear to wait until they are alone to pass. When your child has passed:

- breathing and heartbeat will cease.
- there will be no response to your voice or touch.
- his/her eyes may be partly open.
- the jaw will relax and the mouth will open.
- there may be a loss of bowel and bladder control.

There is no need to call 911 or contact the funeral home.

When your child passes, please contact Kids Path **1-888-789-2922** or **1-877-356-0356**.

We will visit and remain with your family to provide support as you grieve your loss and make final arrangements.

When the Kids Path nurse arrives, we will:

- listen to your child's heart and lungs to confirm death
- provide personal care for the child
- contact the funeral home

No matter how well prepared you may be, death can still feel like a shock. When an expected death occurs after a long illness, it can seem unbelievable. The whole situation may feel unreal, and difficult to grasp what has actually happened. Even if you think you have prepared yourself – at least intellectually – for the death, it is normal to feel intense emotions when someone close has died.

Disposal of Medications

We are required to educate patients and families about medication tracking and disposal policies. When your loved one is receiving services from MVHPC, we will monitor all medications for appropriate use. Our agency has provided you with a copy of our policy and Federal Guidelines for Disposal of Medications.

Although we monitor and track all medications, we are concerned about those medications that are labeled as a "Controlled Substances". These are drugs that are regulated by state and federal laws that aim to control the danger of addiction, abuse, physical and mental harm, the trafficking by illegal means, and the dangers from actions of those who have used the substances.

At the time of your loved one's death, a nurse will visit and review disposal of unused medications. Federal Guidelines require that all controlled substances are wasted. **Federal Law prohibits the transfer of prescription drugs to any person other than the patient for whom it was prescribed.** Never use medications that are prescribed for someone else. All medications are prescribed based on specific symptoms and medical history. Your loved one's medications may be dangerous for someone else.

Most drugs can be thrown in the household trash, but you should take certain precautions before tossing them out. A few drugs should be flushed down the toilet. Any MVHPC Nurse that visits at the time of death, can assist with disposal when there is written permission. MVHPC staff cannot remove any medications from the home.

Guidelines for Disposal of Unwanted Medications in the Home

- Follow any specific disposal instructions on the drug label. Do not flush prescription drugs down the toilet unless this information specifically instructs you to.
- If no instructions are given on the drug label and no take-back program is available in your area, throw the drugs in the household trash, but first:
 - Take them out of their original containers and mix them with an undesirable substance, such as used coffee grounds or kitty litter. The medication will be less appealing to children and pets, and unrecognizable to people who may intentionally go through your trash.
 - Put them in a sealable bag, empty can, or other container to prevent the medication from leaking or breaking out of a garbage bag. Mark through any identifying information on the prescription bottle before throwing away.

Other Resources for Disposal and Donation of Prescription Medication

Like you, we are conscious of preserving our resources and not wasting medication that could be used. We have included information about some of the places to donate or recycle medications.

There are limited resources for the disposal of controlled substances. Your local Police Department can also assist with collection and disposal of these medications. Take advantage of community drug take-back programs that allow the public to bring unused drugs to a central location for proper disposal. The Drug Enforcement Administration is sponsoring National Prescription Drug Take Back Days (www.deadiversion.usdoj.gov) throughout the United States. There are also free clinics throughout the state that can use prescription medications that are not expired. They cannot use controlled substances. You can visit the following websites to learn more about clinics that can use these medications:

www.ncfreeclinics.org or www.AWARE Rx.org or www.projectlazarus.org

Surry Medical Ministries: 336.789.5058 – open on Tuesday Evenings-local clinic

Medications That Can Be Flushed	
Medicine	Active Ingredient
Abstral , tablets (sublingual)	Fentanyl
Actiq , oral transmucosal lozenge *	Fentanyl Citrate
Avinza , capsules (extended release)	Morphine Sulfate
Buprenorphine Hydrochloride , tablets (sublingual)*	Buprenorphine Hydrochloride
Buprenorphine Hydrochloride; Naloxone Hydrochloride , tablets (sublingual) *	Buprenorphine Hydrochloride; Naloxone Hydrochloride
Butrans , transdermal patch system	Buprenorphine
Daytrana , transdermal patch system	Methylphenidate
Demerol , tablets *	Meperidine Hydrochloride
Demerol , oral solution *	Meperidine Hydrochloride
Diastat/Diastat AcuDial , rectal gel	Diazepam
Dilaudid , tablets *	Hydromorphone Hydrochloride
Dilaudid , oral liquid	Hydromorphone Hydrochloride
Dolophine Hydrochloride , tablets *	Methadone Hydrochloride
Duragesic , patch (extended-release) *	Fentanyl
Embeda , capsules (extended release)	Morphine Sulfate; Naltrexone Hydrochloride
Exalgo , tablets (extended release)	Hydromorphone Hydrochloride
Fentora , tablets (buccal)	Fentanyl Citrate
Kadian , capsules (extended release)	Morphine Sulfate
Methadone Hydrochloride , oral solution *	Methadone Hydrochloride
Methadose , tablets *	Methadone Hydrochloride
Morphine Sulfate , tablets (immediate release) *	Morphine Sulfate
Morphine Sulfate , oral solution *	Morphine Sulfate
MS Contin , tablets (extended release) *	Morphine Sulfate
Nucynta ER , tablets (extended release)	Tapentadol
Onsolis , soluble film (buccal)	Fentanyl Citrate
Opana , tablets (immediate release)	Oxymorphone Hydrochloride
Opana ER , tablets (extended release)	Oxymorphone Hydrochloride
Oxecta , tablets (immediate release)	Oxycodone Hydrochloride
Oxycodone Hydrochloride , capsules	Oxycodone Hydrochloride
Oxycodone Hydrochloride , oral solution	Oxycodone Hydrochloride
Oxycontin , tablets (extended release) *	Oxycodone Hydrochloride
Percocet , tablets *	Acetaminophen; Oxycodone Hydrochloride
Percodan , tablets *	Aspirin; Oxycodone Hydrochloride
Suboxone , film (sublingual)	Buprenorphine Hydrochloride; Naloxone Hydrochloride
Xyrem , oral solution	Sodium Oxybate
Zubsolv , tablets (sublingual)	Buprenorphine Hydrochloride; Naloxone Hydrochloride

FDA's Web page on Disposal of Unused Medicines is continuously revised:
(www.fda.gov/Drugs/ResourcesForYou/Consumers/BuyingUsingMedicineSafely/EnsuringSafeUseofMedicine/SafeDisposalofMedicines/ucm186187.htm) (Last accessed 2/2015)

MVHPC Policy

Policy Number:
PC.M70

MEDICATIONS – USE AND DISPOSAL OF CONTROLLED AND OTHER MEDICATIONS

Page 1 of 2

NHPCO Standard(s):	CES 4.5; CES 4.12; CES 20.1
Regulatory Citation(s):	42 CFR 418.106(e)(2)(i); 418.106(e)(2)(A); 418.106(e)(2)(B); 418.106(e)(2)(C)(i-ii); 21 CFR Parts 1300, 1301, and 1304; 12VAC5-391-460
L-Tag(s):	L694, L695, L696, L697, L698
ACHC:	HSP7-6B; HSP7-6C
POLICY:	MVHPC instructs patients/caregivers in the safe use and disposal of controlled substances and all other medications in accordance with State and Federal regulations.
DEFINITION:	<i>Controlled substances - drugs that are regulated by state and federal laws that aim to control the danger of addiction, abuse, physical and mental harm, the trafficking by illegal means, and the dangers from actions of those who have used the substances. Such drugs may be declared illegal for sale or use, but may be dispensed under a physician's prescription.</i>
PROCEDURES:	<ol style="list-style-type: none">1. Provide a copy of written policies and procedures on the management and disposal of controlled drugs and other medications to the patient or patient representative and family. Written information is contained in the Reference Guide.2. Discuss policy and procedure for managing the safe use of all medications with the patient or representative and the family. Information should be provided in a language and manner that they understand.3. Document in the patient's record that written policies and procedures were provided and discussed with patient and family. Reviewed at the time of admission and documented.4. The RN Case Manager or designee will monitor and track all medications.5. The RN Case Manager or designee identifies and documents any misuse or diversion of controlled substances and notifies the attending or hospice physician, the pharmacist, and the Clinical Director of further intervention. This may include reporting the diversion to appropriate authorities. An incident report is completed.

Disposal of Medications

1. Federal Law prohibits the transfer of prescription drugs to any person other than the patient for whom it was prescribed.
2. Medications that are no longer needed by the patient are disposed of in compliance with State and Federal regulations. Medications that are not a controlled substance may be donated when appropriate.
3. All disposal instructions and activities are documented. MVHPC staff may not dispose or remove any medications from the home.
4. A hospice nurse may instruct you on how to dispose of medications.
5. A hospice nurse will notify every pharmacy that has dispensed partial quantities of a Schedule II controlled substance within 48 hours of the patient's death.

Disposal of Medications – IPU

1. Medications are disposed of in accordance with state and federal requirement.
2. Accurate records are maintained on the receipt and disposition of all controlled drugs.
3. The N.C. DHSR Department of Controlled Substance inspector will make annual visit (or as needed) for purpose of reconciling and destroying controlled medications.
4. All controlled medications that require disposal are secured in a designated locked cabinet in the medication room and behind a locked door. Director of IPU is the only individual who has access to cabinet and maintains record.

Updated: 3/7/16

Donations and Memorials

Kids Path and Mountain Valley Hospice rely on donations and memorials from our friends and the community. We are a non-profit organization and all gifts are tax-deductible. Our mission is to provide services to our patients regardless of their ability to pay. Donations make it possible for us to extend a hand to everyone who comes to us for care. Through the generosity of our supporters we are able to continue services and programs, for example:

- ◆ Volunteer recruitment and education
- ◆ Patients and families unable to pay
- ◆ Brighter Days Children's Camp
- ◆ Bereavement support
- ◆ Community education
- ◆ Kid's Path
- ◆ Pet Peace of Mind
- ◆ We Honor Veterans
- ◆ Transitions

Memorial Gifts

Friends and families may want to honor a loved one by making a memorial gift to Kids Path. When arrangements are made with the funeral home and newspaper, the most often used wording is, "In lieu of flowers, the family asks that memorial gifts be made to the Kids Path Program." We send an acknowledgement to the donor and primary caregiver. This informs the family that a gift was made in honor or memory of their loved one.

Wills and Planned Giving

In addition to a will, there are many other forms of planned giving, such as Charitable Gift Annuities, Charitable Remainder Trusts, and Pooled Income Funds. If you have specific questions, please contact your attorney or financial planner.

Other Ways to Help

As time goes on, many families we have worked with want to help us educate the community about Kids Path care, or simply want to stay in contact. This can be done in a variety of ways. You may volunteer to serve on a committee or help in the office, attend special events, and make annual donations. Whether or not you continue to be involved with our program, we appreciate the honor of serving you.

Safety

Safety is a concern for all of us. To provide for your safety, we ask our staff and Volunteers to schedule their visits so you will be expecting them. They also have name tags which identify them as Kids Path personnel. For your safety, we ask your help as well. Please secure and stow away weapons in a locked area, confine animals which may become upset by visitors and turn on outside lights (if available) when expecting visitors after dark. Thank you for your cooperation.

Basic Home Safety

It is important that your home is safe to maintain an environment for optimal health. A safety checklist for health care ensures that basic safety measures are in place. These safety checks keep you safe and decrease the risk of accidents that can escalate into serious illnesses. Safety checks also give you and your family members' peace of mind.

- **Fire Safety:** Never smoke in bed! Smoking in bed is extremely dangerous and is one of the leading causes of fire in the home. Install smoke detectors on each floor of your home and in each room if possible. Test the smoke detectors occasionally and replace batteries twice a year to maintain proper working conditions. If you use a small space heater in winter, do not put it near curtains or a bedspread. These materials may be flammable and cause the fire to spread quickly. Never leave kerosene heaters, wood stoves, and fireplaces unattended. Develop a fire safety plan. Outline a safety route out of your home that is quick in case of a fire. Place the outline on a wall near your bed so that you can see it if needed. In the event of a fire in your home, immediately call **911** and tell the operator that you have a **FIRE EMERGENCY**.
- **Environmental Safety:** Secure loose rugs, runners, and mats to the floor. Repair or replace torn, worn, or frayed carpeting to prevent falls. Make sure hallways and stairs are well-lit and free of clutter. Have a key accessible near doors locked with deadbolts. Keep hazardous tools and firearms locked up. Cover unused outlets and do not overload extension cords. Store cleaning fluid, polishes, bleach, and all poisons separately and mark containers clearly.
- **Bathroom:** Equip bathrooms with grab bars near the toilet and above the bathtub. The bars need to be sturdy and a different color than the wall to avoid confusion. A stool in the bathtub will help the person to sit while bathing, instead of getting tired or dizzy while standing. A bath mat with good suction placed in the bathtub will minimize slipping and falling.
- **Kitchen:** When you are cooking, do not leave the kitchen. Supervise the food until it is finished and then turn the stove completely off. Do not lay towels or dish washing cloths on the stove. If it is near the burner, it could ignite and start a fire. Also, wipe up grease and oil spills immediately after cooking. Keeping the burners clean can eliminate future grease fires. Keep a workable fire extinguisher in the kitchen if an emergency occurs.
- **Bedroom:** A light switch or lamp that is easily accessible should be near the bed without getting up to reach it. Nightlights should also light the path from the bed to the bathroom to stop stumbles and falls. Place a phone beside the bed with numbers for emergencies, family, neighbors and friends.

- **Medications:** Keep all medications properly labeled in the container they were dispensed in and in a safe place that children cannot reach. Refill the prescription ahead of time so you will always have it available, your case manager will help with this. Discard all medications after the expiration date. If desired, pills may be placed in a medication dispenser with compartments marked with time of day to give each medication. Make sure compartment is clearly marked and you understand directions to prevent taking the wrong pill at the wrong time.
- **Standard Precautions:** We are committed to controlling the spread of disease and infection. Our staff follows *Standard Precaution* which is a method of handling all blood, body fluids and airborne secretions as being potentially infectious, regardless of the patient's diagnosis. You should expect good hand-washing and the use of proper protective equipment by any of our staff.

Disaster Planning

Kids Path, as a provider of pediatric palliative care services, feels a responsibility to our patients, staff, and community to be well prepared in the event of a disaster.

Although disaster situations are not common in our area, they do occur. We all remember the destruction of the tornadoes and hurricanes that did so much damage in our community in recent years.

We feel it is vitally important that we be prepared for disastrous situations before they occur. The following information and suggestions will help you to plan ahead. If a disaster does occur, you will be better prepared.

1. Keep an emergency kit in your home. Include the following items:
 - Candles or kerosene lamp
 - Cigarette lighter (matches are often unreliable)
 - Flashlight and batteries
 - Portable radio with batteries
 - Bottled water
 - First aid kit
2. If a storm is approaching the area, listen to weather updates frequently.
3. Do not let medications fall below a three day supply before refilling.
4. If a disaster situation occurs, our agency will attempt to contact you. If you have left your home and are at a different location, please call our agency and inform the staff of your location. If the agency is unable to contact you due to loss of telephone service, we will be attempting to make the local EMS aware of any of our patients who may need immediate attention. If telephone service is interrupted, you should try to tune in to a local radio station for possible information updates related to the disaster.
5. As long as telephone lines are intact, we ask that you contact our agency for any medical needs, so that we may assure that you receive the assistance you need. Attached you will find a listing of emergency telephone numbers.

Emergency Telephone Numbers for North Carolina

Agency/Service	Mount Airy	Elkin	Pilot Mountain	Yadkinville
MVHPC Hospice Offices	336-789-2922	336-526-2650	336-368-1260	336-679-2466
Aerocare	336-786-1410			336-527-4302
Mount Airy Drug	336-786-5506			
Duke Energy	1-800-769-3766			
Energy United	1-800-386-4833			
Surry Yadkin Electric	1-800-552-0077			
Red Cross	336-786-4183			336-724-0511
Emergency Management Services (EMS)	336-783-9000	336-835-6113	336-783-9000	336-679-4232
Fire/Police	911	911	911	911

Television & Radio Stations

WPAQ Radio 740 AM	336-786-6111
WSYD Radio 1300 AM	336-786-2147
WWWJ Radio 1360 AM	276-236-2921
WBRF Radio 98.1 FM	276-236-9273
WIFM Radio 100.9 FM	336-835-1233
WXII Television Channel 12	336-721-9944

Hospitals

Alleghany Memorial Hospital	336-372-5511
Ashe Memorial Hospital	336-846-7101
Davie County Hospital	336-751-8100
Davis Regional Medical Center	704-873-0281
Forsyth Medical Center	336-718-5000
Hugh Chatham Memorial	336-527-7000
Iredell Memorial Hospital	704-873-5661
Moses H. Cone Memorial	336-832-7000
Northern Hospital of Surry County	336-719-7000
Pioneer Community Hospital-Danbury	336-593-2831
Wake Forest Baptist Medical Center	336-716-2011
Wilkes Regional Medical Center	336-651-8100

Emergency Telephone Numbers for Virginia			
Agency/Service	Hillsville	Martinsville	Stuart
MVHPC Hospice Offices	276-728-1030	276-403-4764	276-694-4416
Horizon Healthcare Management	1-800-220-9292		
Lincare-Galax	276-238-8880		
Lincare-Martinsville		276-647-7536	
Medi-Home Care Martinsville		276-666-9800	
Appalachian Electricity & Power	1-800-956-4237		
Emergency Management Services	276-728-4141 or 276-730-1395		
Red Cross	276-236-2891		276-694-3505
Fire/Police	911	911	911

Television & Radio Stations	
WPAQ Radio 740 AM	336-786-6111
WSYD Radio 1300 AM	336-786-2147
WWWJ Radio 1360 AM	276-236-2921
WBRF Radio 98.1 FM	276-236-9273
WIFM Radio 100.9 FM	336-835-1233
WHEO Radio 1270 AM	276-694-3114
WLSL television Channel 10	540-981-9110
WDBJ Television Channel 7	540-344-7000
WXII Television Channel 12	336-721-9944

Hospitals	
Carilion Memorial Hospital-Franklin	540-483-5277
Carilion New River Valley Medical Center	540-731-2427
Carilion Roanoke Memorial Hospital	540-981-7000
Columbia Montgomery Regional-Floyd	540-745-9670
Forsyth Medical Center	336-718-5000
Lewis Gale Medical Center- Salem	540-776-4000
Memorial Hospital of Martinsville	276-666-7200
Montgomery Regional Hospital- Blacksburg	540-953-5122
Northern Hospital of Surry County	336-719-7000
Patrick Hospital, LLC	276-694-3151
Pioneer Health Services of Patrick County	276-694-8600
Pulaski Community Hospital	540--994-8100
Twin County Regional Hospital	276-236-8181
Veterans Administration Hospital- Salem	540-982-2463
Wake Forest Baptist Medical Center	36-716-2011
Wythe County Community Hospital	276-228-0200