

Paving the Way: Best Practices in End of Life Support

By Susan L. Weiss, MS

"There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need caregivers." - Rosalyn Carter

When someone we love is diagnosed with a terminal illness, it often is a time of confusion and fear. Making sense of the diagnosis is one thing, but making headway through treatment choices, and or end of life decisions along with a person with developmental or intellectual disability can be more challenging. Caregivers are faced with acting as an advocate as well as being a translator, lay nurse, cook, and a whole range of other duties. As a caregiver, losing the ones we love the most is one of the most gut-wrenching experiences of life. It can also be the most affirming. If one is lucky, it brings the family together, with the hopes of surrounding them with love and light. Often times though, there is one person being the primary care provider. It is important the team that is supporting the participant and their family be on the lookout for caregiver "burnout." Family caregivers are the ones who often have to explain that the illness or disease that their loved one has may eventually curtail their lives.

As those who are working on behalf of the people we serve, it is vital for the IDT team to be on the alert for signs of burnout. They are:

- The caregivers emotions fluctuates more than usual due to lack of sleep, and heightened anxiety.
- The caregiver's immune system becomes taxed, thus they get sick more frequently.
- The primary caregiver can take on way too much because they feel no-one else can give the care that they would. I call this the "Energizer Bunny Syndrome." We all know how that turns out. Knowing how to ask for help can be very difficult for the caregiver. Aside from becoming a whirling dervish, the house can always wait to be cleaned, the phone to be answered. The time is now, to slow down and be with that person. Make memories, try to continue doing the things you love as much as you can. It is easy to get caught up in the drama instead of just sitting with that person and simply holding their hand.

Social Isolation- As the patient's condition becomes more critical, it is common for friends and family to not come by as often. The caregiver might also be so busy with caring for their loved ones, that they don't have the time to socialize. Ironically, this is the time that a support system needs to be utilized the most.

- The caregiver's sleep patterns are altered. It can manifest itself by the individual either not being able to sleep at all, or they are spending more time sleeping. This can be a major sign of depression.

It is important for the team to have an understanding why family members may not have investigated other resources They are:

- **The need to protect:** Families may feel that they are the only ones that can provide the care that the participant needs, and don't want to subject the individual to getting used to being cared by someone new.
- **Guilt:** Sometimes guilt can enter the picture. Often times, caregivers are under the mistaken impressions that as family members, they are solely responsible for this person's care. The guilt can build, if they don't feel they are rising to the occasion.
- **"Stranger danger":** Families can be skeptical of hired caregivers, whether they are providing in-home, assisted living, skilled nursing or any other kind of care.
- **Financial concerns:** There are still many gaps in our healthcare system. Often times the out of pocket costs become prohibitive, so the majority of care falls back to the family.

The IDT Team plays a vital role in assisting the family in finding supportive resources in the community. It is important that the family and the patient has a clear understanding of what their healthcare covers in the way of home healthcare, palliative or hospice care. The IDT team can also assist the family in targeting what other members of their community can assist with care. Caregivers are so focused on the day to day aspects of care, and may lose sight of the actual support they have, such as members of their church, etc. We must remember to keep the patients rights in mind, and to also seek out their ideas for who they want in their circle of friends. It is important for the team to clarify to the family and the individual in care, what the patient's rights and responsibilities are.

"There are 4 main categories of healthcare decision makers and each must be an adult with "capacity" in order to be the rightful or legal decision maker. According to the New Mexico Uniform Healthcare Decisions Act- "**Capacity**": an individual's ability to understand and appreciate the nature and consequences of proposed health care, including its significant benefits, risks and alternatives to proposed health care and to make and communicate an informed health-care decision." Starting from the beginning of this journey, it is important to provide the best information to the patient that is available about upcoming personal decisions. It is essential to provide information in a clear common sense way for that person to understand. It is vitally important to avoid telling your loved one more information they can handle at one time. As is the same for anyone of us, informational overload is a real problem, but for someone with a traumatic brain injury or other cognitive issues, this can be overwhelming and needlessly frightening.

There are several areas that family members and or advocates should address with their loved ones as they come to terms with their illness and possible end of their lives. First, it is important that the individual picks a trusted advocate or advisor to set their end of live decisions in place. This may seem like an obvious thing, but the reality is that those closest to us can be unable to follow through on their loved one's desires. There are various reasons for this, including assuming that that person is unable to cognitively make those choices. Also, the emotional impact on the family cannot be overlooked. There can also be other motivations that may need to

be addressed. Those who are assisting the individual needs to be good listeners, and not try to direct that person, but facilitate the process. Respect and dignity for that person's choices are paramount.

It is important to assist that person in figuring out what they want for their care and after life decisions. Does this person want to receive care at home, or in hospice? Your loved one may also be given the information pertaining to an "advanced directive" which allows them to make decisions on what sort of medical treatments they want in their last days. Does this person want to continue treatment to fight the disease? Do they want to be revived if have a cardiac arrest? Do they want to be on life supports? These are really tough decisions for anyone to make, but being able decide for oneself can be an empowering experience, especially for those who have spent their adult lives fighting for self-determination. There are many organizations which provide advance directives. Do they want to be cremated, or buried? These issues can be complicated to explain, but if you have concerns regarding how much that person understands, it is a good time to discuss how other members of the family died, and what their wishes were.

This conversation gives an opportunity to share memories of a grandparent, parent or sibling, and to discuss where they are buried. While difficult, this conversation can also provide a safe time to grieve about how you both are feeling about this person's transition. This also may be the time to discuss whether this person wants a memorial service, and what sort of religious or spiritual service they would like. If they are presently involved with a house of worship, it might be comforting to invite a clergy member to assist this individual with planning their service, or to pray and provide pastoral care. Financial considerations may also impact on their decisions, so it is essential to have a good understanding of what monetary resources are available when the conversation is ensuing.

One area that can be especially important to you loved one is where they want their possessions to go. For some, estate planning or a will might be needed, but if they don't have assets or bills, they might want to write down who they wish to get their stuff. Always check and see if a will, living will or trust is needed. Also if they have a loving pet companion, they might be worried about where they will be going. It could go a long way to bringing them comfort to know where that pet is going. It is important that this information is provided to anyone providing care for your loved one such as medical providers, and service support staff to make sure these decisions are carried out.

An important part of providing support to the participant and caregiver is access to support groups or counseling on end of life issues. It might be difficult to find a therapist that focuses on individuals with developmental disabilities who are facing a terminal illness, but there are therapists in the Albuquerque area who specifically serve people with disabilities. A suggestion would be to contact the agencies this person is currently utilizing, and see if they can give you a referral.

There are several things to keep in mind during this process:*

- Healthcare and Quality of life go hand-in-hand.

- It is imperative that paid IDT members (e.g. Case Managers, therapists, etc.) are always guided by the fact that they do not ever make healthcare decision for the individuals they serve.
- Keeping the above in mind, the identified healthcare decision maker or surrogate should be a regular participant at meetings (in –person, sending a designee or via conference calls) and that it is essential that a synergistic connection is developed among the healthcare decision maker(s) and the IDT members (paid staff) for the welfare of the individual they serve.
- Regardless of who the healthcare decision maker is, when it comes to communication, s/he should have a reciprocal and professional rapport with the other IDT members (individual, Case Manager, House Lead, etc.) whereby information is effectively and securely shared at the appropriate time and with those who should be made aware of the information.
- Distinguish between when the Healthcare Decision Maker has the sole responsibility of making an informed healthcare decisions (captured on a Decision Consultation Form) vs. when the IDT, as a whole, can put their heads together to come up with a viable, non-healthcare- related decision as one unit (captured on a Team Justification Form)
- Each member has his/her role, so no one is left out, but call it the nature of the beast or the luck of the draw... the Case Manager is responsible for generating and completing certain documents (e.g. Decision Justification Form) or assuring that the documents exists (Plenary Guardianship Letters) and that a copy is at the residence, Day program, etc. in regards to Healthcare Decision Making.
- Forewarned is Forearmed- Have preliminary discussions with the participant when things are going well, especially when it comes to healthcare. Having the “we will cross that bridge when we come to it” approach is not often prudent-as you will come up on the bridge faster than anticipated. Of course, this does not mean that you have to have all the answers right then and there. What it does mean is that one can get peace of mind when the “what if “ forms and documents are in place. For example- what if a guardian were to get into an accident – who would make decisions in his/her stead? Having a designated person) can help. Provisions of the NM Uniform Healthcare Decisions Act would allow a surrogate to be chosen in this instance. However, through a Power of Attorney, a guardian could choose an adult to take over the guardianship role and duties for 6 months while the guardian is recovering (check Probate Code section 45-5-104). *

For those people who are facing end of care issues, the importance of a working team is essential. It can be overwhelming and frustrating for family members and the participant to be getting mixed messages, or inconsistent information. It is imperative for team members to have a clear idea of what their roles are and to serve as a bridge, not a barrier. Support staff is there to pave the way for a transition that is life affirming, and as peaceful as possible.

Resources

www.finalchoices.org

California Coalition for Compassionate Care is a statewide partnership of more than 60 organizations dedicated to the advancement of palliative medicine and end-of-life care. It provides helpful Information about end-of-life decision making, legislation and forms. Downloadable copy of the Thinking Ahead Workbook and facilitator guideline are available on this site.

www.caringinfo.org

Caring Connections is a program of the National Hospice and Palliative Care Organization, a national consumer and community organization committed to improving care at the end of life.

www.agingwithdignity.org/5wishes.html

The Five Wishes document helps people express how they want to be treated if they are seriously ill and unable to speak for themselves. It includes medical, personal, emotional and spiritual needs.

www.dds.ca.gov/ConsumerCorner/Publications.cfm

The California Department of Developmental Services, Consumer Advisory Committee has developed numerous pictorial publications and DVDs that encourage self-direction and personal choice. The Thinking Ahead Workbook is also available for download.

“Guidelines for Community Programs, Case managers & IDT Members Regarding Advance Directives and Healthcare Decisions” coc.unm.edu→ Advance Directives **“guidelines”**

“NM Uniform Healthcare Decisions Act” - UNM HSC Institute of Ethics (505) 272-4566
hsc-ethics@salud.unm.edu

Medical Consultations:

DDSD Regional Offices – Nursing, Case Management, Behavioral supports

TEASC (Transdisciplinary Evaluation and Support Clinic) – (505) 272-5158

COC (Continuum of Care) – coc.unm.edu (505) 925-2350

CDD (Center for Development and Disability) (505) 272-3000

HDR (Healthcare Decisions Resource) via CoC (505) 925-2350

DDSD BBS (Bureau of Behavioral Support) (505) 841-5500

DDSD/ CSB (Clinical Services Bureau) (505) 841-5500

Office of Guardianship (505) 841-5369

Additional Forms (Search internet)

Ethics/Values- Values History UNM HSC Institute of Ethics (505) 272-4566 hsc-ethics@salud.unm.edu

Guardianship & conservatorship for Adult in New Mexico- (505) 216-1133

Funeral Funds/Trusts

NM MOST (Medical Order for Scope of Treatment) www.nmmost.org

NM/ EMS/DNR EMS Bureau (505) 476-8200 www.nmems.org

Decisions Consultation Form- coc.unm.edu → Advance Directives→ Decision Consultation Information

Team Justification Form – coc.unm.edu →Advance Directives→ Decision Consultation Information