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Person-Centred End-of-Life Planning for Direct Support Professionals

By Lesley Ahee

This topic can be deeply personal and sensitive to some. When reading this article, it is important to be gentle with oneself, as well as understand that it may bring up difficult memories of the loss of family, friends, and individuals once supported.

Have you ever thought about what you might need or want when you become aware that your end of life is nearing? Have you ever considered what dying well looks like? How would you want to support those you love, as they face this journey?

Now consider this as a direct support professional (DSP) working with an individual with an intellectual or developmental disability (IDD) who has been diagnosed with a life-limiting illness. Should your support look any different?

Person-centred death planning is a right that many supported individuals do not get to experience. It is a relatively new concept that is gaining more attention as the Death Positive Movement is becoming more widely recognized.

What is the Death Positive Movement and Person-Centred Planning?

The Death Positive Movement is a social and philosophical movement that encourages people to speak openly about death and dying. The movement seeks to eliminate the silence around death-related topics, decrease anxiety surrounding death, and encourages more diversity in end-of-life care options. This is where a professionally trained support person, often referred to as a death or end-of-life doula, might collaborate with individuals, their families, and their staff teams to help with facilitating the wishes of the dying individual. It is important to note that end-of-life care and planning does not need to be facilitated by professional doulas, but rather anyone in the individual's circle of support who has a respectful and trusted relationship.

We, as DSPs, are often so focused on person-centred planning while living, that we forget the importance of being able to make decisions around preparing for a good death. Person-centred planning is a collaborative approach to end-of-life care that prioritizes the individual needs and values of individuals, their support teams, and their families in decision-making, planning, and resultant health, and social care. It is built around the needs of the

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individual, with the individual always at the heart of every decision and given the right to choose how the journey is envisioned.

We are there to bring empathy, compassion, and be a caring presence. Ultimately, we are there to support all relationships with the dying person at the centre of them. We will companion the dying, and in turn, provide hospitality for the person you support. In this, we are giving them hope to live each day as well as possible and creating space for them to move toward their illness. This would include envisioning and helping build a safe and understanding environment to support an individual, as their condition deteriorates where their wishes and needs are respected.

Person-Centred Palliative Care Model - 6S

Person-Centred Palliative Care advocates for individuals to approach the remainder of their lives in the best way possible. For many years, a research group in Sweden, consisting of researchers together with nurses working in palliative care, developed a model for person-centred palliative care, known as the 6S-model (Osterlind and Henoeh, 2020). The model's key concept is Self-image, where the starting point is the individual with their own experiences. The other concepts: Self-determination, Symptom relief, Social relationships, Synthesis, and Strategies are all related to the patient's self-image, and often to each other.

Self-image refers to how an individual views themselves, and ultimately that the person should have the opportunity to have as positive self-perception as possible, despite their illness and dying. In order to live the best life possible, Symptom relief is key to control or decrease pain levels and distress. Social relationships reflect the person's needs for friendships and the feeling of belonging. Synthesis and Strategies refer to the individual's spiritual needs, and the importance for the individual to talk about their lives and their purpose, as well as how they foresee what their impending end of life might look like.

Self-determination speaks to the individual's need to be an active participant in their life and to face the end of life according to their own beliefs, values, and wishes. The individual's Self-determination needs to be acknowledged and respected by all those involved with their care, from DSPs to medical professionals.

Four Domains of End-of-Life Care

The 6-S Model leads perfectly into what is known as the Four Domains of End-of-Life Care, according to the Home Hospice Association. They are an integral pathway for DSPs to follow to ensure that the individual is in as much control of their dying wishes as they desire. The domains are 1. Advanced Planning, 2. Legacy Work, 3. Vigil, and 4. Grief and Bereavement.

1. Advanced Planning

Advance care plans (ACP) are not documents but are discussions; they can continually change and evolve throughout the continuum of care. A Substitute Decision Maker (SDM) may be part of the ACP. The SDM is a person verbally designated by the individual, stating that they have permission to make decisions on their behalf. It is important to note that requirements may vary between provinces and states, and the hierarchy can be different.

There are different aspects to ACP, with a Do Not Resuscitate Order (DNR) being one of them. This form is explained and completed by a doctor, and when agreed upon by the individual, the doctor signs it. If the individual wants to die at home, it is suggested that it is posted in an area that staff or family can access in case 911 is called. If the DNR is not produced to the paramedics, by law, they MUST try to resuscitate.

A DNR or AND (allow natural death) can be revoked by family if the individual is not alert. It is essential to continue to support the family as someone progresses in their journey and reassure them of the normal processes. It is also paramount to discuss the goals of care and resuscitation status frequently with the individual and family together to reinforce the individual's goals are being enacted as they transition. The individual can also change their mind ANYTIME regarding resuscitation status.

Another important discussion point with an individual who is on their end-of-life journey is fluid and nutrition replacement. Always do a check-in with the individual; if the person wishes to eat then they can be fed, just be conscious of the amount, as well as their abilities and limitations. However, if the person does not wish to eat, the rule is to go by the dying person's wishes; they guide our care, not the other way around. It is imperative to help educate the family about what happens when bodies can no longer process food. As people progress during their dying journey, their bodies no longer require the sustenance it once did. If you think of your body as a machine, food is the fuel; as the body breaks down, it no longer has the same energy demands, as if it was functioning at full physical capacity.

2. Legacy Work

People facing death often find themselves looking back at their lives and doing a "life review." Many feel the need to make meaning of the life they have lived and review what they have accomplished in their time here on earth. There are many types of Legacy Projects, and different projects will have different meanings for different people. One of the most important things to be mindful of is the length or size of the project. This is a decision that could be made based on prognosis and/or if the dying person wants to do it themselves, with their staff, or with their family. As DSPs, we can help create an awareness around that, and/or facilitate the family in participating and getting the project finished. Some types of Legacy Projects are:

- memory books
- memory boxes
- videos
- audio recordings
- writing letters
- photographs
- collages
- paintings
- music
- planting trees in honour
- benches

Creating a personal legacy is a way to shift perspective from a life lost, to a life lived through personal successes, meaningful experiences, and relationships, as well as to maintain hope through the end-of-life journey by finding meaning in the life they have lived.

Legacy projects give the dying person a sense of control over something when they feel they have lost control of most things, something positive and beautiful to focus on, and gives a way of bringing people together through meaningful conversations, expressions of forgiveness, storytelling, and shared laughter.

3. Vigil

The vigil refers to creating a death plan. Just as people who are pregnant create a birth plan, people who are dying may create a death plan. It can be very therapeutic and a legacy piece in

itself. Creating a death plan is a way for the dying person to have a say in how they envision dying, and we as DSPs and/or doulas help facilitate it. Within this plan, we determine:

Where?

- Where does the person want to die? At home, in hospital, hospice – it can be anywhere really, though it is important for them to understand that it may be helpful to have an alternate option as well if they are not well enough, or the time of year is a barrier.

Who?

- Who is there?
- Family members, staff, housemates, work friends? Is there a “guest list” and/or a “not welcome” list?

What?

- What is happening? Are people doing anything, or just visiting? Are they telling stories, eating, looking at old photos?
- What do they want to look at: Scenery? Window? Dim lighting? Candles?
- What do they want to hear? Is music being played?
- What can they smell? Food, essential oils being diffused? Window open?
- What are they feeling? Favourite pajamas or outfit, blanket, massage?

Why?

- Why do they want these things and people? Letting others know why this is meaningful to them can be important to make it all happen.

How?

As DSPs, we fill in the gaps during the vigil and help the individual prepare their dying space. Having a good rapport with the individual and their family will help give a clear vision of what they want their dying to look like.

4. Grief and Bereavement

Grief is a natural response to any type of loss, though we most commonly associate it with what we experience when someone we care about dies. Grief is the process that allows us to say goodbye to what was, and to prepare for that which is yet to come. We can experience grief on all levels; emotional, physical, mental, and spiritual. Grief is as unique and individual as a fingerprint; there is no right or wrong way to grieve. It is important for people to give themselves permission to grieve in their own way, to rely on their own intuitive grief process. The only expert on their grief is the person who is going through it. As DSPs, we provide care for individuals in a very personal manner and form strong bonds with them. It is only natural that we experience grief when we lose them, and even more so when other individuals replace them in residential care.

In his 2005 novel, *Companioning the Bereaved*, Alan Wolfelt writes the ‘11 Tenets of Caring for the Bereaved.’ These tenets are excellent reminders for those who support individuals who may be grieving the loss of someone important, or for anyone who is suffering a loss.

11 Tenets for Companionship the Bereaved

- Companionship is about being present to another person's pain; it is not about taking away the pain.
- Companionship is about going to the wilderness of the soul with another human being; it is not about thinking you are responsible for finding the way out.
- Companionship is about honoring the spirit; it is not about focusing on the intellect.
- Companionship is about listening with the heart; it is not about analyzing with the head.
- Companionship is about bearing witness to the struggles of others; it is not about judging or directing these struggles.
- Companionship is about walking alongside; it is not about leading or being led.
- Companionship is about discovering the gifts of sacred silence; it is not about filling up every moment with words.
- Companionship is about being still; it is not about frantic movement forward.
- Companionship is about respecting disorder and confusion; it is not about imposing order and logic.
- Companionship is about learning from others; it is not about teaching them.
- Companionship is about compassionate curiosity; it is not about expertise.

Conclusion

Many think that death is a dark and grim thing, but the truth is, death is the ONE thing that all of us have in common. We are all going to die someday – it is guaranteed. Death is natural. Death is not the opposite of life; death is a part of life. Just as there is much beauty in birth, there can be much beauty in death. However, because of the fear and stigma surrounding death, we miss many opportunities to learn.

This is why person-centred planning for individuals who are on their end-of-life journeys is so important. DSPs have the opportunity to help facilitate what is known as a good death for the individuals we support.

Being with the dying is a gift, as they offer a perspective that few others have. We all think we 'have time.' The dying may understand and feel that their time is limited, and so they are often much more alive in many ways than the rest of us.

There is much to learn from the dying; they are our greatest teachers. Journeying with each of them is an honour and a privilege that we should not take lightly.

About the Author

Lesley Ahee (she/her) graduated from Algonquin College in 1992 with a Developmental Services Worker diploma. In April 2023, Lesley graduated with a certificate as a Death Doula from Home Hospice Association. She has since been supporting individuals and support teams with end-of-life care and planning at Ottawa Carleton Association for Persons with Developmental Disabilities (OCAPDD). Lesley has been employed at OCAPDD for 32 years and is currently a Residential Supervisor. Her passion is to promote person-centred thinking not only during life, but also helping supported individuals who are dying.

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