

Common Advance Care Planning Language

Advance Care Planning is when you talk with your trusted family and friends about your wishes for future health care. You do this while you're still able to make decisions for yourself. As part of this process, you identify one person to be your substitute decision-maker. They'll make decisions for you when you are unable to do so, based on your previously stated wishes for future health care.

Advance Care Plan is a documented summary of your wishes about the kind of health care you think you would want. If you aren't able to speak for yourself, a health care provider asks your substitute decision-maker to make health treatment decisions for you. An advance care plan can help them do that. It is different from making plans for your finances, property, estate, will, or funeral arrangements.

Advance Directives or Living Wills: An "advance care directive" or "living will" used to be a way of documenting your advance care plan. It is not a legally binding document in Ontario.

Allow natural death means providing you with care that is comfort-focused and based on symptom management only, without prolonging or speeding along the dying process.

Capable (legal definition): To be 'capable' means that you are able to make health care choices for yourself, by yourself. This means that you are able to understand and appreciate the information you need to make informed decisions about your health care. You can understand what could happen as a result of those decisions (e.g., risks/benefits of agreeing or not agreeing to have different treatments).

Cardiopulmonary resuscitation (CPR) is an emergency medical procedure performed on someone whose heart has stopped (cardiac arrest) CPR attempts to restart the heart and blood circulation. It involves chest compressions (pressing up and down hard and fast on a person's chest) and artificial ventilation (where a tube is placed in the airway and then attached to a machine). It may also include the use of a machine called a defibrillator, which delivers an electric shock to the heart in an attempt to restore a normal rhythm.

Code status is a term commonly used among health care providers. It describes whether or not you want attempts made at CPR (cardiopulmonary resuscitation). A "DNR" (Do Not Resuscitate) and "No Code" are terms used if a person doesn't want to receive CPR. "Full Code" means the person would like to have CPR attempted.

Expressed wishes are your instructions about the medical interventions you would want your substitute decision maker and your health care providers to follow.

Goals of Care Discussions are conversations you and/or your Substitute Decision Maker (SDM) have with a physician or other health professional that take into account your current health, as well as your values and priorities to help make treatment decisions. This means that you speak with your loved ones and your health care providers about your health and what is important to you when thinking about treatment(s) that are being proposed or that you and/or your SDM may need to decide on.

Health care provider is a person licensed, certified, registered, or trained to provide health care. Examples include physicians, nurses, physiotherapists, registered dietitians, etc.

Informed consent is the permission you give to health care providers to receive treatments, allow medical tests or procedures to be done. Before you give verbal or written consent, health care providers must fully explain and make sure you understand the tests or procedures. You also need to understand any possible benefits and risks of those tests or procedures, and what other options there are.

Intubation is a life-sustaining measure, where a breathing tube is put into your airway. The tube is then connected to a ventilator (machine) that will breathe for you.

Life sustaining measures are any interventions aimed at prolonging your life. Interventions may include medications, procedures, and devices. The life sustaining measures offered will depend on the severity of your illness. Whether you chose to give consent for these measures depends on your values and beliefs. (Examples of life-sustaining measures include things like dialysis and ventilators.)

Medical interventions may include procedures or treatments that meet your medical needs and your goals of care.

Palliative Care is an approach to care that focuses on providing pain and symptom management and improving quality of life in those with a life-threatening or life-limiting illness. It is a holistic approach to care, where the 'unit of care' is the family/social support network of the patient AND the patient, rather than the patient alone. Care involves not only looking after the physical well-being of the patient but also their psychological, social, emotional, and spiritual well-being.

Palliative care can be provided by your health care team in any setting, including:

- Home (including retirement homes and long-term care facilities);
- Inpatient;
- Outpatient;
- Family medicine clinic; or
- Hospice or Palliative Care Unit

Palliative care includes but is not limited to end of life care. A palliative approach to care works best when started early in your illness journey, and works in alongside care providers focused on curative treatments.

Power of Attorney (POA) for Personal Care is a witnessed, signed legal document. In this document:

- You name a substitute decision maker;
- You give them the power to make decisions about all aspects of your personal care (when you are not capable), unless you specify otherwise;
- You outline their responsibilities to follow through with your wishes.

This includes decisions about your:

- Health care;
- Shelter;
- Clothing;
- Nutrition;
- Hygiene; and
- Personal safety.

This POA for personal care is only used if you become incapable (as defined above) of making a particular health care related decision. If you don't have POA for personal care, Ontario legislation (Health Care Consent Act) provides a list that will determine who your SDM will be.

The **provincial Do Not Resuscitate Confirmation Form (DNR-C)** is a form signed by your health care provider *at your explicit request* to indicate you do not wish to have resuscitation attempted; you do not wish to be a "Full Code." It is for use during transfer between home, hospital and healthcare facilities. <http://www.forms.ssb.gov.on.ca/mbs/ssb/forms/ssbforms.nsf/FormDetail?OpenForm&ENV=WWE&NO=014-4519-45>

Resuscitation status is used interchangeably with 'code status' and refers to whether or not you wish for CPR (cardiopulmonary resuscitation) to be provided.

Substitute Decision Maker (SDM) is someone who can legally make decisions for you when you aren't able to make them for yourself (i.e., not capable). This is a person you know well and trust, and importantly, someone who KNOWS what your wishes are regarding your health care. You can choose to appoint *anyone* who is willing and able to act on your behalf to be your substitute decision maker except:

- Someone who is paid to provide you with personal care;
- Your health care provider;
- Someone who is under the age of 16 years; or
- Someone who is mentally incapable. (This means they can't understand the information they need to make the decision or what may happen as a result of the decision).

Symptom Directed Management aims to identify your symptoms and pick treatments (actions or medications) aimed at symptom relief and for the best quality of life possible. Sometimes health professionals will describe this as symptom-focused care.

Ventilation – There are two main types of ventilation.

- a) Invasive mechanical ventilation is when a machine breathes for you. Intubation (a tube in the trachea/airway) is needed for this.
- b) Non-invasive ventilation may be used instead of invasive mechanical ventilation. It is the use of a device (such as a mask or piece of equipment that is placed in the mouth) to help your breathing, without intubation.

References

- Arthurs, E., Evans, J.M., Gradin, S., Khan, A.I., Kukreti, V., & MacKinnon, M. (2017). *Integrated Care Planning: An evidence-informed approach to designing and delivering coordinated, continuous and person-centred care for cancer patients*. Retrieved from <https://www.cancercareontario.ca/en/content/integrated-care-planning-%E2%80%93-evidence-informed-approach-designing-and-delivering-coordinated-continuous-person-centred-care-cancer-patients>.
- Canadian Hospice Palliative Care Association. (January 2012). *Advance Care Planning in Canada: National Framework*. Retrieved from <http://www.advancecareplanning.ca/wp-content/uploads/2016/08/ACP-Framework-2012-ENG.pdf>.
- Edmonds, K. P., Ajayi, T. A., Cain, J., Yeung, H. N., & Thornberry, K. (Oct 2014). *Establishing Goals of Care at any Stage of Illness: The PERSON Mnemonic*. *Journal of Palliative Medicine*, 17(10). Oct 2014. 1087-1087. Retrieved from https://www.researchgate.net/publication/266252300_Establishing_Goals_of_Care_at_Any_Stage_of_Illness_The_PERSON_Mnemonic <http://doi.org/10.1089/jpm.2014.0253>
- Goals of Care Discussion Tool*. Retrieved from <https://kghtoday.kgh.on.ca/cr/document/1695>
- Speak Up Ontario. Glossary of Terms. <http://www.speakupontario.ca/resource/advance-care-planning-terms/>
- Heyland, D., & Frank, C. (2015 or n.d.). *Cardio-Pulmonary Resuscitation (CPR): A Decision Aid for Patients and Their Families*. Retrieved from <http://www.thecarenet.ca/docs/ACPCPRTool.pdf>
- Health Care Consent Act, 1996, S.O. 1996, c. 2, Sched. A Retrieved from <https://www.ontario.ca/laws/statute/96h02>
- KGH Palliative Care, Social Work, Spiritual Care, and Oncology Patient Education. (2013). *A Guide to Understanding Death and Dying: Information for Family and Caregivers*. Retrieved from <http://www.kgh.on.ca/cancer-care/guide-understanding-death-and-dying-information-family-and-caregivers>
- Kingston General Hospital. (2014). *Palliative Care: Information for Patients and Families Referred to Palliative Care*. Retrieved from <http://cancercaresoutheast.ca/palliative-care-information-patients-and-families-referred-palliative-care>
- Myers, J., Cosby, R., Gzik, D., Harle, I., Harrold, D., Incardona, N., & Walton, T. (September 27, 2016).

Provider Tools for Advance Care Planning and Goals of Care Discussions. Toronto (ON).
Retrieved from <https://www.cancercareontario.ca/en/content/provider-tools-advance-care-planning-and-goals-care-discussions>

Substitute Decisions Act, 1992, S.O. 1992, c. 30
Retrieved from <https://www.ontario.ca/laws/statute/92s30>