Dying Happens

An Overview of Navigating the Medical System in Northumberland at End of Life

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Northumberland PACE Talks
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Virtual PACE Talk

Supporters:

Northumberland Hills Hospital
IMCare Internal Medicine Specialists
Northumberland Hills Hospital Foundation
Community Health Centres of Northumberland
Northumberland Family Health Team

www.PACETalks.com
PACE: Personalized Assessment and Change Education
I think there is a lot of misunderstanding what palliative care truly means vs end of life care. (Death isn’t always imminent once someone has been deemed palliative, types of intervention at this stage, etc...)
What IS palliative care?

• Specialized medical care for people living with a serious illness
At what point is the decision taken away from me?

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Capacity for Health Decisions

• Ability to understand the information about a treatment, and the consequences of choosing to take it or not
Is there a way to register for this? I would like to know more about becoming power of attorney and being directly involved in plan of care.
Decision Making on your behalf

• If you aren’t capable and a decision about your health needs to be made – Substitute Decision Maker steps up
• Role: to make the decision *they think you would have made*
Decision Making on your behalf

- Automatic Substitute Decision Maker
  - Hierarchy to be used if you haven’t specified someone else
  - All people in the category are equal and joint
  - If the automatic SDM isn’t themselves capable, it moves to the next person in the hierarchy
Automatic Substitute Decision Maker

- Spouse or Partner
- Parents or Children
- Parent with right of access only
- Siblings
- Any other relatives

Automatic Family Member SDMs
Decision Making on your behalf

• Intentionally name your Substitute Decision Maker by completing a Power of Attorney for Personal Care

www.SpeakUpOntario.ca
The importance of having a conversation with family to guide and direct care.

Without the ability to develop advance directives for our own end-of-life care, we may be depending on our POA for care to act on our behalf so we need to be sure that that person and close family know and understand our wishes.
Advance Care Planning

• Not specific decisions
• Conversations around what’s important to you

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Person-Centred Health Decision-making

A person’s values, wishes, beliefs and goals for their care

Capable person
 Advance care planning

Capable patient OR SDM(s)
 Goals of care discussion
 Consent
 Treatment or Plan Initiated

Treatment or care decision is to be made

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DNR (Do Not Resuscitate)

• Applies at death – DOESN’T guide your care in any other way
• Only indicates whether or not you would want CPR
I found in both experiences when my parents were passing away in hospital, no one could tell me about what was going to happen, what to expect. The drs and nurses avoided the topic. (Not the palliative care depts). I feel knowing what to expect would’ve helped the family.
Prognosis

“How long do I have, doc?”
“I had this neighbour once – doctors gave him 6 months. Spent his whole savings. Well didn’t he live 2 years...”
Prognosis

• Medical condition (e.g. cancer, heart disease, lung disease)
• What treatment options are there and how successful have they been?
• Other medical conditions
• Baseline health
• Progression over time
When the end is near. How do you say good bye?
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What are death doulas and why are they a good idea.
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Process of Dying

• Decreased energy, ability to do housework
• Increased fatigue – spending more time in bed/on couch
• Decreased appetite and weight loss
• Sometimes breathing changes
Support

• Family doctor or palliative care doctor
• Palliative care community team
• Spiritual care
• Home care
The very end – where to die

• Home
• Hospital
• Hospice
The very end – where to die

NHH Palliative Care Unit
The very end – where to die

Ed’s House Northumberland Hospice Care Centre
End of Life Care
Thank You