Community Palliative Care Resources & Serious Illness Conversations

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Depending on where people live, community resources varies.

Common community resources include:

- Home care nursing
- Home support workers
- Physiotherapist/occupational therapist
- Case managers
For those living at home for several years with a chronic serious illness........

Community services likely involved include:

- Case Managers

- Physio or occupational therapist (short term only)
Many of the sick will have Home Support Workers (HSW)

- Helps with personal care
- Light cleaning around bathroom after showering/bath
- Some can do light laundry
- Light meal prep (but not cooking)
- Does not do heavy cleaning/housework
Community Health Nurses (CHN) can also visit.....

- Wound care when the sick person is not able to get out
- Medication management
- Pain or other symptoms related to illness
- Disease progression
- End of life care
- Any condition which requires a skilled nursing assessment and the person is having difficulty getting out of the house
Case managers, rehab staff, community health nurses can refer to the following resources:

**Dieticians**
- Usually 1 or 2 visits to guide family in terms of what foods are good for the sick person

**Speech language pathologists**
- Can go in to check problems with swallowing, make recommendations

**Respiratory therapists**
- Help those who are on ventilators or have special oxygen needs
Volunteers

- Visit for companionship (reading, playing cards)
- Shopping companion
- Volunteer drivers

Hospice Volunteers

- Visit while family takes a break
- Healing touch
- Companionship
- Vigils
When the sick are declining......

Signs:

- Homebound
- Require cane/walker/wheelchair to get around house
- May have more symptoms related to illness(es)
- Needing more help/support with bathing, meals
Options for Care...where can the sick go?

Home

- Community health nurses hopefully are involved
Most areas have a similar model of care

- The sick person is the center of care
- Community health team works with the client/family/caregivers and family doctor to come up with a plan of care
- Community health nurse (CHN) is the “quarterback” who organizes care and makes referrals to other team members
Most important resources: the
Family Doctor or Nurse Practitioner (NP)

- Usually have the longest relationship with the client
- Is the “go to” person for the community team
- Central person who receives reports from specialists/other health care professionals
- When no further treatment options, specialists turn person back to family doctor or NP
Palliative care services also vary by area

- Some areas have a consultation team (Vancouver, Richmond, Fraser health areas)
- Others have more of a primary care palliative team (Coastal)
- For areas with a consult team, role is to support the home care staff and family doctor in caring for the sick person at home
Encouraging the sick to think about quality of life

- Anyone living with a serious illness can benefit from a palliative approach to care
- Encourage the sick to talk to the family doctor/NP – ask about what is available
- If told, it’s too “early”, or “you don’t need palliative care”, encourage the sick to advocate

That chilling phrase...

- I'm sorry... take him home... ‘there’s nothing else we can do’
- No - there’s ALWAYS something we can do
Options for Care

Palliative Care Units

- Are for those with a serious illness who are having difficult symptoms such as pain, breathing problems, vomiting, which cannot be managed at home
- Community health nurses play a key role in getting a bed without having to go to emergency
Options for Care

Hospices

- For end of life care
- Usually the person’s last 3 months of life
- Focus is supporting a natural and peaceful death
Options for care

Long term care homes

- Meant for people who require nursing care on a 24 hr basis
- People who likely will live several months to a year(s)
- Waiting list for most facilities
What Matters Most to Me?

- Project started in Vancouver Coastal Health 3 years ago
- Known as IPACE – Integrating a Palliative Approach by Having Conversations Early
- Teaching all disciplines to have conversations with every patient about his/her wishes
- Shift the culture to find out about the patient’s wishes and supporting these
What happens if a person needs health care services?

- What does he/she need to know?
- What does he/she need to do?
- How is the best way to prepare as health condition changes?
Early conversation flyer

- Adapted from Ariadne Lab’s work
- Focuses on what is important to the person
- Helps start conversations with loved ones
- Share with all of your health care providers so that they are aware of wishes
It is hoped that the sick people whom you see have made their wishes known

- Helps health care providers plan for what to do when the person’s health condition changes
- Aligns the person’s values with care
- Helps direct family if the sick person is no longer able to make decisions
Two stories

DOROTHY

EDNA
Both are living at home..........

**DOROTHY**
- 85 years old, former teacher
- Early dementia and heart failure
- Lives with husband in a bungalow

**EDNA**
- 72 year old widow, housewife
- Breast cancer diagnosis in 2015 and had this treated
- Has 5 children and many adult grandchildren
Sharing wishes...

**DOROTHY**
- Filled out the Early conversations flyer
- Shared with daughter and family doctor
- Decided that with her dementia, she should fill out her rep agreement and enduring power of attorney

**EDNA**
- Felt that she has beaten her cancer decided that she did not want to think too much about the future
- Never spoken to her children about her wishes including her wish to never go to a Nursing Home or be a ‘vegetable’
- Has not talked to her family doctor about her wishes, no one in her family knew of Edna’s future wishes
3 months later, both Dorothy and Edna had a major stroke

**DOROTHY**
- Went to hospital and received treatment for her stroke
- Her daughter informed the team that her mother would not want a feeding tube, further IVs, and tests given the chance of reversing would be minimal as per the doctor
- Dorothy died peacefully a week later receiving supportive palliative care surrounded by family; family grateful

**EDNA**
- Went to hospital and received treatment for her stroke
- She was given tube feed, urine tube, IVs, and went through multiple test including ICU stay even though the chance of reversing would be minimal as per the doctor
- A week later, Edna is still in ICU and remains unconscious. None of her 5 children know what to do and there is rising conflict between siblings about what is best for mom
Cues to listen for when visiting the sick

- “I am getting so tired of this illness”
- “I really don’t want any more treatment”
- “I don’t want to go to hospital anymore”
- “I don’t want more blood tests”
- “I just want to die”
- “I have had enough”
Open up the conversation

- I’m wondering if you can tell me more about what you are feeling?
- I am wondering if you have shared this with your doctor/nurse/specialist? How about your family members?
- It might be a good time to share your feelings/wishes so that your health care team can help you make decisions that won’t leave you feeling this way.
It’s really about..........

- Letting people know that they have a choice in their treatment and health care decisions
- Validating how one is feeling
- Empowering the sick to talk about what is important to health care team and family members
- Listening........
What might I see when I visit sick people?

- Physical changes (weakness, weight loss, fatigue, pain, breathing problems, other symptoms)
Emotional changes

- Mood changes (depression, anger, withdrawn, agitation)
- Strained relationships with loved ones
Spiritual angst

- Questioning God
- Asking “why me”
- Talking about being “punished”
- Fear of the unknown