Strengthening a Palliative Approach in Long Term Care (SPA-LTC)

CHPCA
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Need for a Palliative Approach in LTC

- As the population continues to age, more people will die in long term care (LTC) homes
- These people represent one of society’s most frail and marginalized populations who often struggle with managing multiple chronic conditions and social isolation
- Palliative care is complicated for residents who suffer with dementia due to the gradual loss of their cognitive abilities
  - decision-making related to care needs often rests with family members or health care professionals but decision making often occurs too late and in crisis mode
Need for a Palliative Approach in LTC

- Palliative and end-of-life care is poorly managed, especially in dementia
  - Poor symptom management
  - Lack of discussions about advance care planning or end of life issues
  - Inappropriate hospitalizations
  - Too many resident deaths in hospital
Trajectory of Care for LTC Residents
Palliative Approach in LTC

- Begins when residents are admitted into LTC; most have chronic, life-limiting conditions
- Based on symptom management and residents needs, not prognosis
- Interdisciplinary approach to care within a holistic perspective, resident-focused
- Focus on preparation and care planning
- Need for family education and support
Strengthening a Palliative Approach in Long Term Care (SPA-LTC) Projects

- **Improving Palliative Care in Long Term Care Homes Using Participatory Action Research**

- **Partnering Together to Improve Palliative Care in Long Term Care (CIHR PHSI)**
SPA-LTC Core Components

- **Develop PC Champion Team**
  - opinion leaders
  - meet monthly

- **Hold Comfort Care Rounds**
  - meet bimonthly
  - PC consultant to attend
  - education and reflection

- **Care Conferences**
  - occurs: 6 weeks post admission
  - goals of care discussed with family/resident and IP team

- **Implement PPS**
  - weekly if <30%
  - monthly if > 30%

- **Bereavement Follow-up**
  - occurs 1 month post-death
  - LTC staff calls family to provide support and referral if needed

- **EOL Family Care Conferences**
  - occurs if PPS<40%
  - family completes questionnaire before FCC
  - family meets with IP team

- **SPA-LTC Core Components**

  - Research Team
  - Advisory Board: Partners & Decision Makers
  - Community Palliative Care Consultants
Palliative Performance Scale (PPS)

- Staff indicate what percentage a resident is functioning at in areas such as activity level, self-care, intake and alertness
- Serves as a tool for communication between the interdisciplinary team, residents and families
- Can also be used as a guide to facilitate conversations about palliative care or transitioning into end-of-life care
- Can assist in care planning during a resident’s decline

http://www.palliativealliance.ca/assets/files/Alliance_Resources/Physical_Care/PPS._edited_Jan_242013.pdf
End of Life Care Conference

• Triggered by PPS score (<40%)

• A meeting held with staff, family and residents (if possible) to discuss end-of-life care

• Designed to help family and residents to:
  ◦ Clarify their goals and preferences for care
  ◦ Consider the site of care options (LTC, home, or hospital)
  ◦ Share information with staff and develop a partnership with staff
  ◦ Obtain informed consent about goals of care

https://www.youtube.com/watch?v=l-wvY9Mkqk8
Key Findings
Total (N=551)

Staff completed PPS on all residents

- PPS >50%
  - N=428 (78%)

- PPS 30-40%
  - N=110 (20%)

- PPS <30%
  - N=5 (1%)

Residents enrolled in study
N=40

Family Care Conferences held
N=24

Residents who died
N=11

- n=7

Time from FCC to death:
Range: 2 weeks – 6 months

n= 8 residents missing PPS scores

Time from FCC to death:
Range: 2 days – 2 weeks

n= 2 residents died before being recruited into the study

n=1

n=2

n=1

n=3

n=2
## Staff Participation in Family Care Conferences

<table>
<thead>
<tr>
<th>Discipline / Role</th>
<th>Family Care Conference (n=24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing (RN/RPN)</td>
<td>21 (88%)</td>
</tr>
<tr>
<td>Social Work</td>
<td>13 (54%)</td>
</tr>
<tr>
<td>Recreational Therapy</td>
<td>11 (46%)</td>
</tr>
<tr>
<td>Director/Assistant of Care</td>
<td>9 (38%)</td>
</tr>
<tr>
<td>Dietary</td>
<td>9 (38%)</td>
</tr>
<tr>
<td>Physician</td>
<td>8 (33%)</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>3 (13%)</td>
</tr>
<tr>
<td>Personal Support Workers</td>
<td>3 (13%)</td>
</tr>
</tbody>
</table>

- 4 disciplines attended on average
## Resident Deaths and Hospital Use

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pre N=551</th>
<th>Post N=551</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deaths</td>
<td>26%</td>
<td>21%</td>
</tr>
<tr>
<td>• In hospital</td>
<td>28%</td>
<td>27%</td>
</tr>
<tr>
<td>• At LTC home</td>
<td>72%</td>
<td>73%</td>
</tr>
<tr>
<td>ER Visits in the last year of life</td>
<td>65%</td>
<td>61%</td>
</tr>
<tr>
<td>• Last month of life</td>
<td>46%</td>
<td>40%</td>
</tr>
<tr>
<td>• Last week of life</td>
<td>27%</td>
<td>22%</td>
</tr>
<tr>
<td>• Average # of ER Visits/resident</td>
<td>1.2</td>
<td>1.1</td>
</tr>
<tr>
<td>→ Planned/Appropriate visits</td>
<td>83%</td>
<td>97%</td>
</tr>
<tr>
<td>→ Unplanned/Inappropriate visits</td>
<td>17%</td>
<td>3%</td>
</tr>
<tr>
<td>• Became hospital admissions</td>
<td>89%</td>
<td>89%</td>
</tr>
</tbody>
</table>

SPA-LTC PROJECT: TVN FUNDED 2014-2016
Develop PC Champion Team
- opinion leaders
- meet monthly

Hold Comfort Care Rounds
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- PC consultant to attend
- education and reflection

Care Conferences
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SPA-LTC Core Components

Research Team

Advisory Board: Partners & Decision Makers

Community Palliative Care Consultants
Advanced Frailty


Tips for Family and Friends

What is a Palliative Approach?

This pamphlet was made to help people with Advanced Frailty and their families know what to expect at the end of life so they can plan ahead. Talking about preferences early on is an important first step to a Palliative Approach to Care.

A Palliative Approach includes:
- Treatment of intractable conditions
- Pain and symptom management
- Social and spiritual support

For more information, please visit:
- www.virtualhospice.ca
- www.advancecareplanning.ca

Disease Progression

Physical Function

Acute event (e.g., hospitalization)

How does Frailty progress?

It is difficult to predict how long frail persons may live, so it is good to hope for the best and plan for the worst.

Frail residents may show a decline in:
- Muscle mass, and strength (weakness)
- Energy (fatigue)
- Walking speed or mobility
- Activity levels (lies in bed or sits in a chair most of the day)
- Ability to do daily activities (e.g., eating, toileting, bathing, walking)
- Appetite (weight loss)
- Cognitive function

The end stage of frailty is called “failure to thrive.” It may be related to one or more diseases.

Online Resources

1) John Hopkins Medicine: tips for staying healthy, helpful definitions
   http://www.hopkinsmedicine.org/health/healthy_age/healthy_body/try-six-ways-to-beat-the-frailty

2) City of Toronto: family LTC resources
   Go to http://www1.toronto.ca/
   Search “Long-term care family education”. Select the first link.
   Topics include: assistive devices, decision-making, continuity, etc.

3) Main Line Gastroenterology Associates (MLGAs):
   http://mainlinegastro.com/patient-
education/free-webinars/
   DOCH87DE.jpg

With a health care provider, explore and discuss options:
- To prevent or reduce injury from falling
- To prevent or reduce confusion (e.g., discontinue unnecessary medications)
- To manage symptoms from multiple chronic conditions
- For diet (e.g., supplements to deal with swallowing problems or weight loss)
- For dealing with fatigue (e.g., promote physical activity)

Your health is important too. If you are feeling overwhelmed, seek support from the Family Councils of Ontario.

www.fcoc.org
Phone: (416) 487-4355
Toll-Free: 1-888-283-8806

Living with Frailty

Frailty is a chronic progressive life-limiting illness. This means that symptoms worsen over time and may affect how long one lives. Frailty is:
- An age-related decline in health
- Linked to cognitive problems and having multiple chronic conditions (e.g., dementia, heart disease, cancer)

Final residents:
- Are at higher risk for falls, hospital admission, disability, and death
- Have problems with multiple body systems

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Toll-Free: 1-888-283-8806
Advanced Dementia

Tips for Family and Friends

Before a care decision is made:
- Consider your relative or friend’s end of life values and preferences
- Stay informed and ask questions
- Encourage your relative or friend to be as independent and participate in as many decisions as he or she is able

With a health care provider, explore and discuss options:
- To learn about how your relative or friend expresses feelings through his/her behaviors
- For communication (e.g., play music, show pictures, stories, and tell comforting stories)
- For eating if your relative or friend can no longer swallow food
- To maintain physical/social activities

Your health is important too. If you are feeling overwhelmed, seek support from the Family Councils of Ontario.

www.fco.og
Phone: (416) 497-4355
Toll Free: 1-888-283-8306

What Should I Ask About?

- What see are my or my relative or friend’s biggest fears about my/their health?
- How can I help maintain my or my relative or friend’s quality of life?
- How long can someone be in the later stages of dementia?
- When should I expect when I am or my relative or friend is dying?

Online Resources

1) Alzheimer Society of Canada:
2) Alzheimer Association (US):
interactive brain tour, common myths
http://www.alz.org/alzheimer_disease_publications.aspx
3) Comfort Care at the End of Life: how to support residents in LTC

The Palliative Approach for Advanced Dementia in Long Term Care

A Resource for Residents, Family and Friends

What is a Palliative Approach?

This pamphlet was made to help persons with Dementia and their families know what to expect at the end of life so they can plan ahead. Talking about preferences early on is an important first step to a Palliative Approach to Care.

A Palliative Approach:
- It is for residents in long term care (LTC) with conditions that have no cure
- Shifts focus from prolonging life to maintaining quality of life
- Is an active approach that can start at any stage of illness
- It is part of usual care
- Does not require a referral

What is Dementia?

Dementia is a chronic progressive life-limiting illness. This means that symptoms worsen over time and may affect how long one lives. Dementia:
- Affects a person’s thinking, mood, language, and behavior
- Is a group of illnesses (e.g., Alzheimer’s, Vascular, Frontotemporal, Lewy Bodies, and Parkinson’s dementia)

Residents with dementia:
- Will have bad days (more confusion) and good days (less confusion)
- Can live for years

How does Dementia progress?

It is difficult to predict how long someone with dementia may live, it is just as important to hope for the best and plan for the worst.

Late or Advanced Stage Signs:
- Severe memory loss (e.g., names, events)
- Loss of concept of time and space
- Difficulty with speech/language (aphasia)
- Loss of ability to use toilet, bathe, and walk without help
- Difficulty swallowing (pneumonia risk)
- Reduced interest in activities

End of Life Stage Signs:
- Change in circulation (e.g., cold hands/feet, skin breakdown)
- Gastrointestinal failure
- Pain, shortness of breath or agitation

Living with Dementia

The progression of dementia cannot be reversed and there is no cure. Being well-informed will help you to make care decisions.

version 4

Disease Progression
Advanced Heart Failure

Tips for Family and Friends

- Before a care decision is made
  - Consider your relative or friend’s end of life values and preferences
  - Stay informed and ask questions
  - Encourage your relative or friend to be as independent and participate in as many decisions as he or she is able

With a health care provider, explore and discuss options:

- For drugs to help with shortness of breath and fluid retention
- Before you give your relative or friend any over the counter drugs (e.g., Advil) or natural health products
- For diet (e.g., low salt intake or dealing with low appetite)
- For dealing with fatigue (e.g., promote physical activity)

Your health is important too. If you are feeling overwhelmed, seek support from the Family Councils of Ontario

www.fco.og.org
Phone: (416) 467-4355
Toll Free: 1-888-233-8006

What Should I Ask About?

- What are my or my relative or friend’s biggest fears about his/her health?
- How can I help maintain my or my relative or friend’s quality of life?
- What symptoms do I, my relative or my friend have that are related to HF?
- What are the options when I am or my relative or friend is no longer responding to the HF medications?
- What should I expect when I am or my relative or friend is dying?

Online Resources

1. Heart Failure Matters: interactive website that explains HF
   www.heartfailuermatters.org
2. BC Heart Failure Network: documents for HF self-care
   www.heartfailure.ca/for-patients-and-families/co-management-resources
3. American Heart Failure Society: 10 modules (medications, end of life)
   www.heartfailure.ca/for-patients-and-families/co-management-resources

The Palliative Approach for Advanced Heart Failure in Long Term Care

Version 3

A Resource for Residents, Family and Friends

What is a Palliative Approach?

This pamphlet was made to help persons with Heart Failure (HF) and their families know what to expect at the end of life so they can plan ahead. Talking about preferences early on is an important first step to a Palliative Approach to Care.

A Palliative Approach:

- Is for residents in long-term care (LTC) with conditions that have no cure
- Shifts focus from prolonging life to maintaining quality of life
- Is an active approach that can start at any stage of chronic illness
- Is part of usual care
- Does not require a referral

A Palliative Approach includes:

- Treatment of curable conditions
- Pain and symptom management
- Social and spiritual support

For more information, please visit:
www.usthuelogest.org
www.advancedcareplanning.ca

How does HF progress?

It is difficult to predict how long someone with HF may live, so it is good to hope for the best and plan for the worst.

Living with HF

The progression of HF cannot be reversed and there is no cure. Being well-informed will help you to make care decisions if you are able.

Talk to your or your relative or friend’s health care provider if you notice:

- More weakness or tiredness (fatigue)
- More shortness of breath with little activity or at rest
- Weight gain (fluid retention) or weight loss (losses or loss of appetite)
- More swelling in lower legs (edema) or in abdomen (ascites)
- Coughing (with or without spout) that may worsen when lying down
- Rapid or irregular heart rate at rest
- More problems with cognitive function
Advanced Kidney Disease

Tips for Family and Friends

Before a case decision is made:
- Consider your relative or friend’s end of life values and preferences
- Stay informed and ask questions
- Encourage your relative or friend to be as independent and participatory in as many decisions as he or she is able

With a health care provider, explore and discuss options:
- For drugs (e.g., allergy pills) or creams (e.g., calamine lotion or Unishield) to help with itchiness
- For clothing to help reduce itching (e.g., cotton)
- For diet (e.g., low protein and salt, ways to deal with low appetite/shaft)
- For dealing with fatigue (e.g., promote physical activity)

Your health is important too. If you are feeling overwhelmed, seek support from the Family Councils of Ontario
www.focus.ca
Phone: (416) 487-4355
Toll-Free: 1-888-283-8806

What Should I Ask About?
- What are my or my relative or friend’s biggest fears about his/her health?
- How can I help maintain my or my relative or friend’s quality of life?
- What symptoms do I, my relative or friend have that are related to AKD?
- What are the options when I am or my relative or friend’s kidney function is too low to respond to medications?
- What should I expect when I am or my relative or friend is dying?

The Palliative Approach for Advanced Kidney Disease in Long Term Care

Version 2

A Resource for Residents, Family and Friends

The Palliative Approach

A Palliative Approach includes:
- Treatment of curable conditions
- Pain and symptom management
- Social and spiritual support

What is a Palliative Approach?

This pamphlet was made to help persons with Advanced Kidney Disease (AKD) (also called CKD) and their families know what to expect at the end of life so they can plan ahead. Talking about preferences early on is an important first step to a Palliative Approach to Care.

What is AKD?

AKD is a chronic progressive life-limiting illness. This means that symptoms worsen over time and may affect how long one can live. AKD:
- Is also called end-stage renal failure
- Is mostly caused by hypertension (high blood pressure) or diabetes
- Occurs when the kidneys are no longer able to filter blood (kidney function is less than 15%)
- Causes wastes to build up in the body
- Residents with AKD can live without symptoms for months or years

How does AKD progress?

It is difficult to predict how long someone with AKD may live, so it is good to hope for the best and plan for the worst.

For more information, please visit:
www.virtualhospice.ca
www.advancecareplanning.ca

Disease Progression

The progression of AKD cannot be reversed and there is no cure. Being well-informed will help you to make care decisions if you are able.

Living with AKD

Talk to your or your relative or friend’s health care provider if you notice:
- Dry and itchy skin
- Confusion and sleep problems
- Lack of energy and tiredness (fatigue)
- Metallic taste in mouth
- Loss of appetite or weight loss
- Nausea and vomiting
- Shortness of breath
- Swelling of ankles (edema)
- Pale skin or cold feet (low iron)
Advanced Lung Disease

Tips for Family and Friends

- Consider your relative or friend’s end of life values and preferences
- Stay informed and ask questions
- Encourage your relative or friend to be as independent and participate in as many decisions as he or she is able

With a health care provider, explore and discuss options:

- To help with shortness of breath and coughing (e.g., opioids, oxygen therapy, breathing techniques)
- To prevent infections (e.g., hand washing, flu and pneumonia shots, avoid touching face)
- For diet (e.g., dealing with loss of appetite)
- For dealing with fatigue (e.g., promote physical activity)

Your health is important too. If you are feeling overworked, seek support from the Family Councils of Ontario.

www.lco.org
Phone: (416) 487-4355
Toll-Free: 1-888-283-8806

What Should I Ask About?

- What are my or my relative or friend’s biggest fears about his/her health?
- How can I help maintain my or my relative or friend’s quality of life?
- What symptoms do I, my relative or my friend have that are related to ALD?
- What are the options if I develop or my relative or friend develops heart failure as a result of ALD?
- What should I expect when I am or my relative or friend is dying?

Online Resources

1) Lung Association:
- Symptoms and signs of flare-ups
- Breathlessness and oxygen therapy
- Fatigue and exercise

2) COPD Foundation: symptoms, medications, oxygen, and webinars
www.copdfoundation.org

The Palliative Approach for Advanced Lung Disease in Long Term Care

Version 2

A Resource for Residents, Family and Friends

What is a Palliative Approach?

This pamphlet was made to help persons with Advanced Lung Disease (ALD) (also called COPD) and their families know what to expect at the end of life so they can plan ahead. Talking about preferences early on is an important first step to a Palliative Approach to Care.

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A Palliative Approach includes:

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- Pain and symptom management
- Social and spiritual support

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www.advancedcareplanning.ca

What is ALD?

ALD is a chronic progressive life-limiting illness. This means that symptoms worsen over time and may affect how long one lives. ALD:

- Occurs when damaged lungs are not releasing oxygen and carbon dioxide as well as they should
- Is a group of chronic lung illnesses (e.g. emphysema, chronic bronchitis, bronchiectasis, and asthma)

Residents with ALD:

- Will have bad days (more symptoms) and good days (less symptoms)
- Can live for months or years

How does ALD progress?

It is difficult to predict how long someone with ALD may live, so it is good to hope for the best and plan for the worst.

Living with ALD

The progression of ALD cannot be reversed and there is no cure. Being well-informed will help you to make care decisions if you are able.

- More shortness of breath with little activity or at rest
- More weakness or tiredness (fatigue)
- Cough and wheezes with more sporan
- Decreased activity level (stays in bed or chair)
- Low appetite and weight loss
- Swelling in feet and ankles (edema)
- More hospital visits or respiratory tract infections
- More problems with cognitive function
Advance Care Planning: Input from our Site Palliative Champion Teams

**Consistent experiences**
- Lack of knowledge about what ACP means
- Lack of knowledge/skills of LTC staff to have ACP discussions
- Need to start discussion prior or at least soon after admission to LTC

**Barriers**
- Time constraints of LTC staff
- LTC philosophy, e.g. medical treatment approach
- Readiness of family and residents to discuss ACP

**Facilitators**
- Administrator support, e.g. allocation of human resources & training
- ACP tools specific to LTC
Stakeholder Analysis

- **On-Line Stakeholder Survey**
  - 29/52 surveys with clinicians, decision makers, researchers
    - Response rate 55.7%
  - ACP activities scored high on the importance scale
  - Feasibility scores were lower

![Chart showing the importance and feasibility scores for an activity](chart.png)
Our Search for Tools

- Reviewed literature that reported the development or testing of an ACP tool

- 32 tools identified

- 4 final tools retained for review at meeting
  - Speak Up, Your Conversation Starter Kit, 5 wishes, Go Wish Card game
Meeting with Advisory Board

- To identify and build consensus on advance care planning tools that show promise for future implementation and testing in LTC

- To support the development of new inter-provincial, cross discipline networks and partnerships
Speak Up Workbook

Large, interdisciplinary initiative overseen by National Advance Care Planning Task Group

The workbook explains what advance care planning is and goes into some “key terms” families and residents should be aware of.

Helps guide a conversation about ones values surrounding end of life care through a series of questions
Your Conversation Starter Kit

This starter kit is meant to help initiate conversation with loved ones regarding end of life care.

The kit includes 4 steps: get ready, get set, go, and keep going.

The booklet provides facts, quizzes and questions, and is meant to gather many thoughts together.

Conversation Starter Translations in French, Hebrew, Korean, Mandarin, Russian, Spanish and Vietnamese.
Alzheimer’s and Dementia Version

Additional resource targeted specifically for families and loved ones of people with Alzheimer’s disease or another form of dementia who want guidance about how to facilitate conversation.

Helps facilitate conversations in the early stages of decline of ones disease.

Also shares ideas of how to use when the illness is so advanced that one cannot express his or her own thoughts.
New ACP Project

*Improving Advance Care Planning for Frail Elderly Canadians*

Team Leader: You, J.

Thank you!

kaasal@mcmaster.ca

Questions, Comments