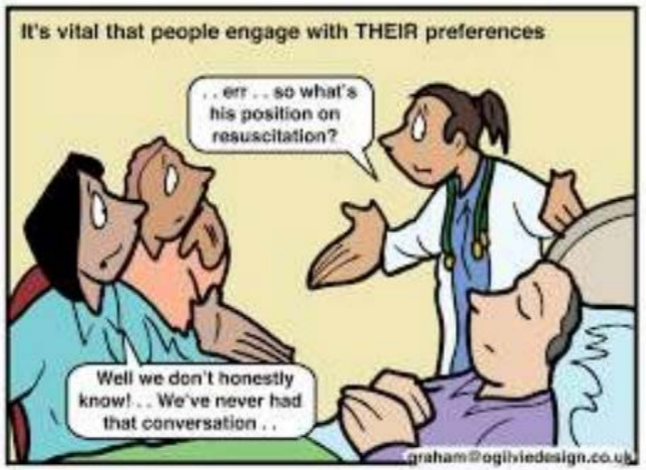
Conférence CREGÉS



Advanced Care Planning in Long-Term Care Settings

Donald Berman Maimonides Geriatric Centre

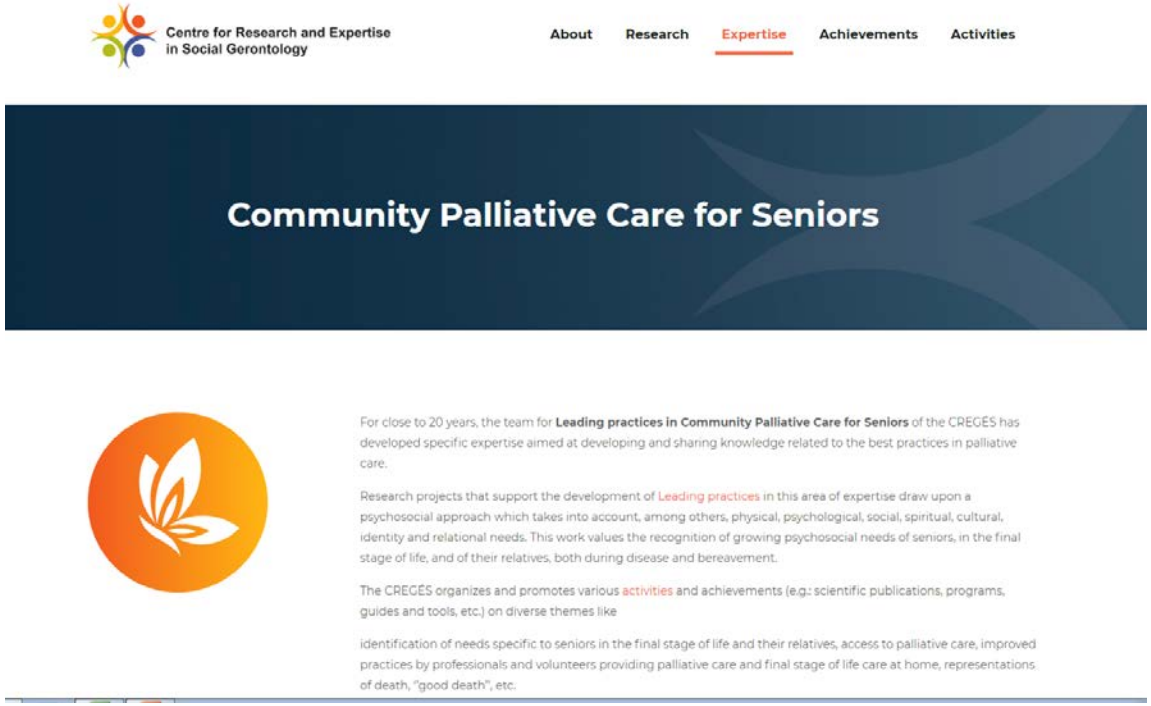
16 avril 2019

Centre de recherche et d'expertise en gérontologie sociale

Centre intégré universitaire de santé et de services sociaux du Centre-Ouest-de-l'Île-de-Montréal

Québec

https://www.creges.ca/palliative-care



https://www.facebook.com/Communaute-de-pratique-Soins-palliatifs-a-domicile

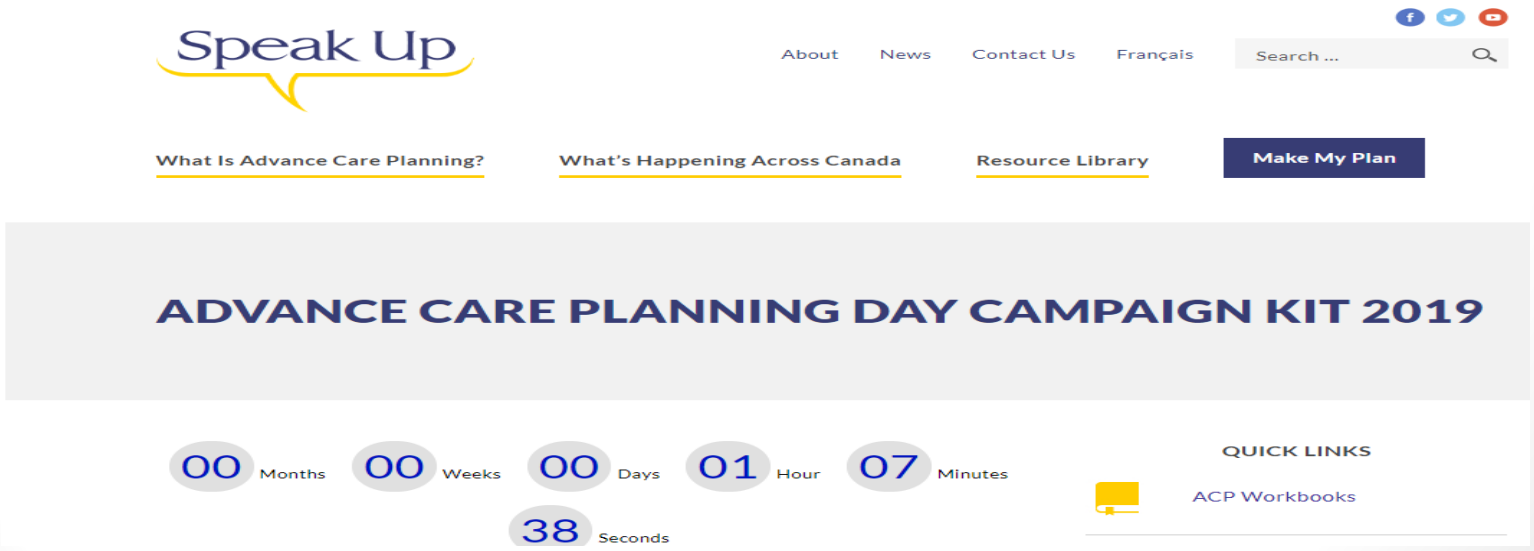
Why a presentation on April 16th?

- USA: National Healthcare Decisions Day

https://www.nhdd.org/#welcome

- Canada: Advance Care Planning Day

http://www.advancecareplanning.ca/resource/acp-day-campaign-kit-2019/



Speakers




- Patrick Durivage, M.Sc., S.W., Coordinator, Development of Leading Practices in Community Palliative Care, CREGÉS, CIUSSS West-Central Montreal
- Tamara Sussman, Ph.D., Associate Professor, School of Social Work, McGill University. Researcher at CREGÉS
- Kevin Hayes, M.Sc., Clinical Ethicist, Quality Directorate, CIUSSS West-Central Montreal
- Mark Karanofsky, MDCM, CCFP, FCFP, Assistant Professor, Department of Family Medicine, McGill University and Unit Director GMF-U Herzl

Overview of the Presentation

- Welcome and presentation of the speakers
- Patrick Durivage: advance medical directives (Act Respecting End-of-Life)
- Tamara Sussman: results from research project and of the tools used to initiate the conversation about end-of-life care
- Kevin Hayes: level of care or goals of care
- Dr. Karanosky: how palliative care approach is discussed with residents and caregivers in a long term care setting

- Question period

Objectives of Law 2 (Act Respecting End-of-Life)

- **The rights of the individuals**
- Highlight the importance of the **organization** and **management** of end-of-life care
- **Primacy of the wishes for care by the individual, particularly** in an advance medical directives regime.

Advance Medical Directives (AMD)

Advance medical directives are a way of expressing one's wishes in anticipation of **incapacity to consent to care** deriving from the Act Respecting end-of-life care.

A person can modify or revoke wishes expressed in his-her advance medical directives at any time.

Advance Medical Directives

- Recognition, in case of incapacity to consent to care, of the wishes expressed by Advance Medical Directives at the time the person was able to provide consent, without going through the intermediary of the mandatory. The parties are bounded by the wishes expressed by a person able to consent to care;

- Impossible to request medical aid in dying by an advance medical directives

- Made on a form prescribed by the Minister, in front of two witnesses or made with a notary. Form to order from the RAMQ;

- The Minister must establish and maintain a register the AMD;

- The Minister prescribes by regulation the terms of access to the registry.

Excerpt of the Advance Medical Directives in Case of Incapacity to Consent to Care form

- **For each item of care, check the box (one only) that corresponds to your wish, should the care become medically appropriate.**

End-of-life situation

- If I am suffering from a serious and incurable medical condition, and I am an end-of-life patient
- **Care A**
- □ I consent to **cardiopulmonary resuscitation**.
  □ I refuse cardiopulmonary resuscitation.
- **Care B**
- □ I consent to **ventilator-assisted breathing** or breathing assisted by another device.
  □ I refuse ventilator-assisted breathing or breathing assisted by another device.
- **Care C**
- □ I consent to **dialysis** treatment.
  □ I refuse dialysis treatment.
- **Care D**
- □ I consent to forced or **artificial feeding**.
  □ I refuse forced or artificial feeding.
- **Care E**
- □ I consent to forced or **artificial hydration**.
  □ I refuse forced or artificial hydration.

AMD: Application in Specific Clinical Situations

- **End-of-life situation**:
  - When a person is suffering from a serious, incurable medical condition and is at the end of life.
- **Situation of severe, irreversible loss of cognitive functions**:
  - When a person is in a comatose state that is judged irreversible, that they are permanently unconscious and confined to a bed, without any possibility of regaining consciousness.
  - When a person is in a permanent vegetative state, they are unconscious, but some reflexes are maintained, such as the capacity to open and close the eyes, or reaction to pain.
- **Another situation of severe, irreversible loss of cognitive functions:**
  - When a person is suffering from severe, irreversible cognitive impairment, without any possibility of improvement, for example Alzheimer's disease or another type of dementia at an advanced stage.

Source: http://publications.msss.gouv.qc.ca/msss/fichiers/2015/15-828-14A.pdf

How to obtain the Advance Medical Directives form

- Order it online or by telephone at 514-864-3411
- Fill out, date and sign the form.
- Have two witnesses age 18 or over sign the form.

➢ Submit your form in one of the following ways:

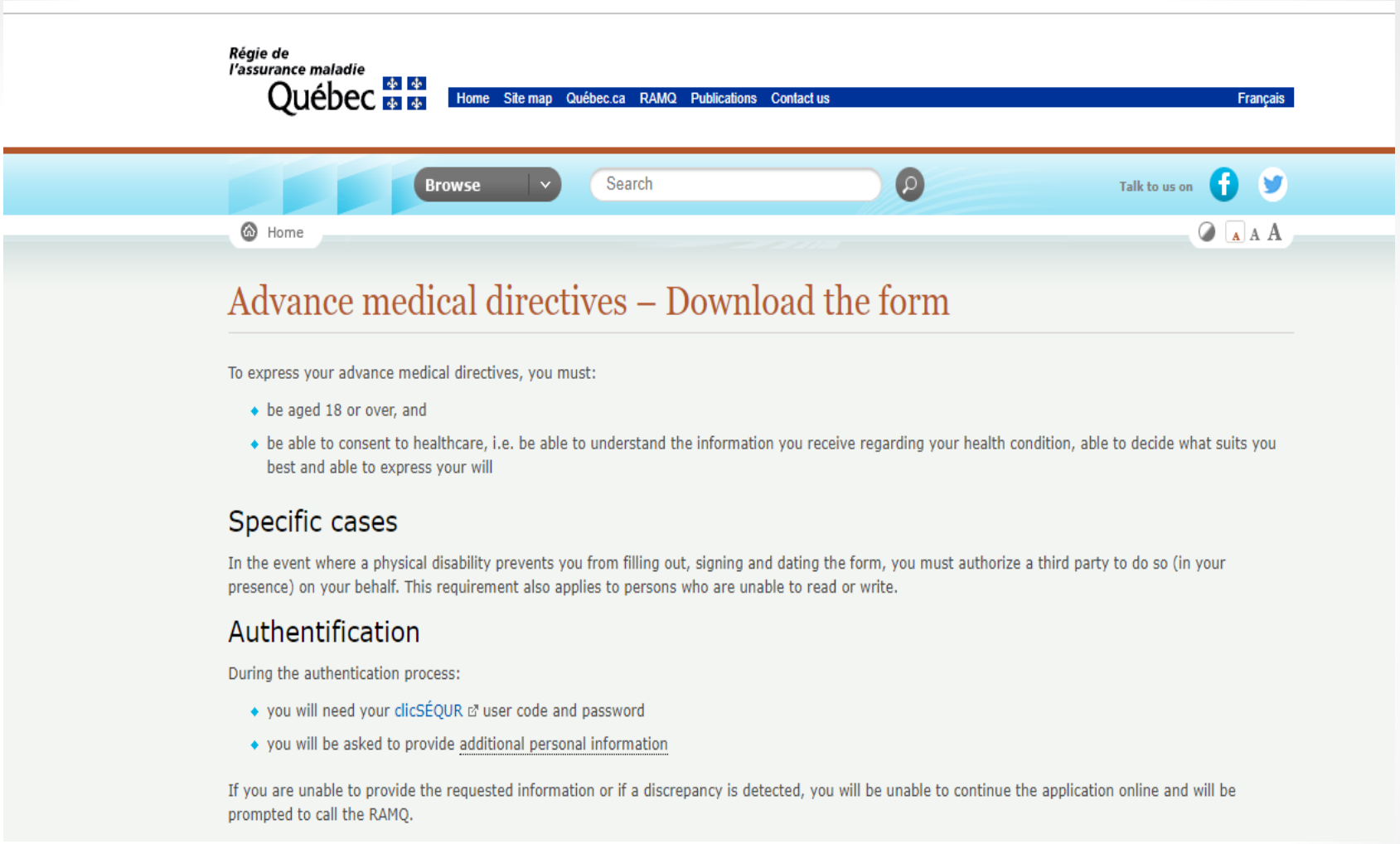
- mail it to the address below, so that it is deposited in the Registre des directives médicales anticipées:

Régie de l'assurance maladie du Québec

Case postale 16000

Québec (Québec) G1K 9A2

- Give a copy to your physician or to a healthcare professional, to file it in your medical record.



http://www.ramq.gouv.qc.ca/en/citizens/Pages/advance-medical-directives-download-the-form.aspx

Presentation by Tamara Sussman, Ph.D., Associate Professor, School of Social Work, McGill University. Researcher at CREGÉS

Using pamphlets in LTC to activate early conversations about end-of-life care

Tamara Sussman, MSW, PhD
Associate Professor, School of Social Work
McGill University

Canadian Frailty Network | Réseau canadien des soins aux personnes fragilisées

EXTENDICARE

McMaster University

Shalom Village

McGill

BACKGROUND

- Early **holistic** end-of-life conversations help prepare residents, families and staff for end of life decisions

- Despite the benefits such conversations are rarely offered in LTC. Barriers include:
  - **reinforcing stigma**
  - **Lack of available tools for illnesses of high prevalence in LTC**

- We developed five condition specific pamphlets to:
  - **educate residents and families about illness trajectories**
  - **activate conversations between families, residents and staff**

Illness Trajectory Pamphlets

- Lung disease, heart failure, kidney failure, dementia, frailty

Exterior Panels

Interior Panels

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 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.fco.ngo

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 should I expect when I am or my relative or friend is dying?

Online Resources

1) **John Hopkins Medicine:** tips for staying healthy, helpful definitions

http://www.hopkinsmedicine.org/health/healthy_aging/healthy_body/stay-strong-four-ways-to-beat-the-frailty-risk

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, continence, etc.

3) **Main Line Gastroenterology Associates (MLGA):**

http://mainlinegi.com/patient-education/hw-view.php?DOCHWID=abo3671

The Palliative Approach for Advanced Frailty in Long Term Care

Version 2

A Resource for Residents, Family and Friends

Technology Evaluation in the Elderly | Shalom Village | Extendicare | McGill | McMaster University

What is a Palliative Approach?

This pamphlet was made to help persons 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:**

- 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.virtualhospice.ca

www.advancecareplanning.ca

What is 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:

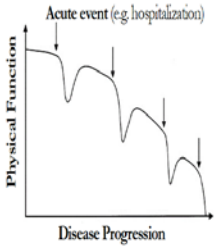
- An age related decline in health
- Linked to cognitive problems and having multiple chronic conditions (e.g. dementia, heart disease, cancer)

Frail residents:

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

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.**



Living with Frailty

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

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 for 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.

Objectives

- To evaluate the acceptability of the pamphlets from the perspective of residents, families & staff

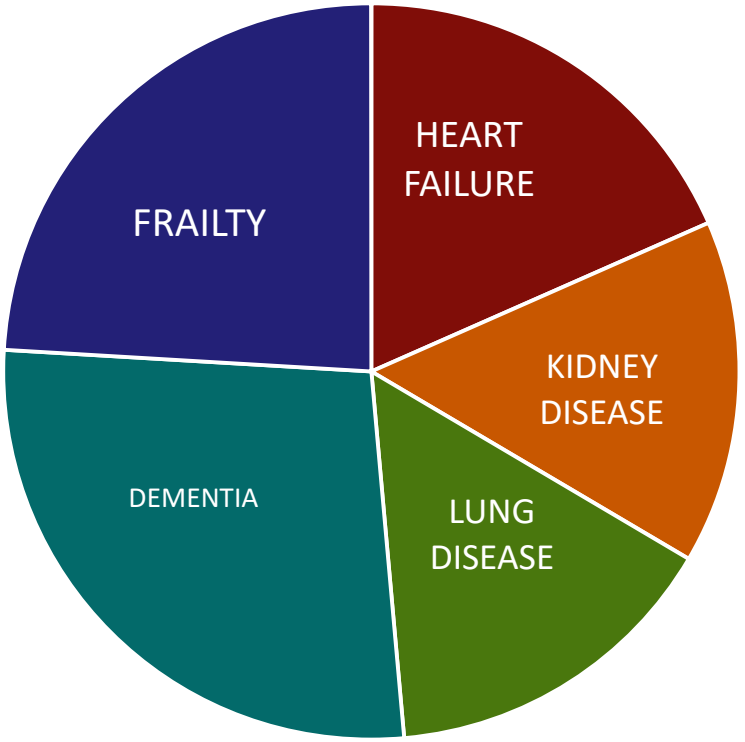
- To explore if an how pamphlets were used by residents, families & staff

METHODS

- Evaluation done within the context of a larger study (SPA-LTC)
  - 4 LTC homes in southern Ontario
- Pamphlet distribution open (wall displays, staff distribution)
- Surveys and focus groups
  - 57 residents/families surveys; 7 focus groups of 56 residents/families
  - 178 surveys

Results: Pamphlet Use

- A total of 348 pamphlets were used by residents and families from April to September 2016
- Pamphlets addressing frailty, dementia & heart failure most commonly used by residents and families
- Pamphlets addressing dementia and heart failure most commonly read by staff



Survey Results Residents & Families

Item Responses (n=57)	Number Who Agree (%)
Information clear & easy to understand	50 (88%)
Information relevant and meaningful	47 (82%)
Information distressing	11 (19%)
Encouraged to think about personal values More informed about what to ask	48 (84%) 40 (70%)
Increased comfort talking about EOL Had initiated conversations after reading pamphlets	36 (63%) 32 (65%) with families 21 (37%) with staff

Results Focus Group: Residents & Families

- Pamphlet (in) accessibility
  - "it tells you what you need to know without being too wordy" (resident)
  - Displays need to be on every floor for better resident accessibility
- Value of Illness Specific Information
  - "when I started reading I went oh my gosh this is exactly him right now.. All of a sudden you don't feel so helpless" (family)
- Protecting the other from an emotional topic
  - Residents and families alike all stated they appreciated information but worried about other's reaction

Staff RESULTS: Useful and Comfort

Item Responses (n=105)	Number Who Agree (%)
The information in these pamphlets is useful to residents/families	83 (79%)
I feel comfortable sharing these pamphlets in my workplace	82 (78%)
I plan to share the pamphlets in the future	76 (72%)
The information in these pamphlets could be harmful to residents and families	4 (2%)
I am the appropriate person to share these pamphlets	**53(50.5%)**

RESULTS: Mean Comparisons

Variable	Care Aides (n=33)	Registered Staff (n=42)	Support Staff (n=30)	Significance
Comfort with Distribution, Mean (SD)	**11.06 (2.68)**	**12.42 (2.92)**	**10.73 (3.02) (80.4)**	**p=0.02**
Perceived Usefulness	11.73 (1.94)	11.55 (2.31)	11.77 (2.08)	p=0.09

Staff RESULTS: Awareness and Use

Variable	Care Aides (n=61)	Registered Staff (n=58)	Support Staff (n=59)	Total (n=178)
Female, n (%)	50 (90.9)	49 (84.5)	45 (80.4)	144 (85.2)
College+, n (%)	43 (70.4)	54 (93.1)	42 (71.1)	139 (78.0)
Total Years in LTC, mean (SD)	10.79 (9.6)	9.96 (8.2)	9.83 (8.6)	10.21 (8.8)
Aware of Pamphlets	**37 (60.7)**	**52 (87.9)**	**37 (62.3)**	**125 (70.2)***
Read Pamphlet	**32 (52.5)**	**47 (81.0)**	**26 (44.1)**	**105 (59.0)***

RESULTS: Open Comments

Category	Examples	Frequency (n=54)
Pamphlets used for self education	**“helped me increase my own knowledge”**	**26 (48%)**
Pamphlets used to educate families/friends	“I wanted to educated families and residents and empower them to make their own decisions”	9 (17%)
General Comments about usefulness	“pamphlets are informative”	19 (35%)

CONCLUSIONS

- Pamphlets promising method of information sharing
- Activating discussions may require staff support
- Training and facility wide discussions required to improve staff comfort in end-of-life communication and discuss role of non- regulated staff
- Pamphlets available on Canadian Hospice Palliative Care Website- search SPA LTC

Publications

- Sussman, T., Kaasalainen, S., Bui, M., Aklhtar-Danesh, N., Mintzberg, S., & Strachan, P. (2017). “Now I don’t have to guess”: Using pamphlets to encourage residents and families/friends to engage in advance care planning in long-term care. *Gerontology & Geriatric Medicine.* 3, 1-11.

- Sussman, T., Kaasalainen, S., Eunyoung, L., Akhtar-Danesh, N., Strachan, P., Brazil, K., Bonifas, R., Bourgeois-Guerin, V., Durivage, P., Papaioannou, A., Young, L.(2019). Condition specific pamphlets to improve end-of-life communication in long-term care (LTC): Staff perceptions on usability and use. *Journal for Post-Acute and Long-Term Medicine (JAMDA),* 20(3), 262-267.

FUNDING ACKNOWLEDGEMENTS

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Canadian Frailty Network | Réseau canadien des soins aux personnes fragilisées

Kevin Hayes, M.Sc., Clinical Ethicist, Quality Directorate, CIUSSS West-Central Montreal

Goals of Care
(Previously known as Levels of Intervention)

Kevin Hayes
Clinical Ethicist
CIUSSS West-Central Montreal

What is the policy?

* A policy has existed for many years at the JGH regarding the process in place
* The policy is now in a revision stage following the INESSS implementation of its new guide for all healthcare establishments
* It is a Québec wide initiative

Guiding principles

* Adherence to our Mission-Vision –Values
* A vital partnership with patients, residents, clients, substitute decision-makers and families
* The organization respects human dignity by providing care that is clinically and ethically appropriate and through Goals of care conversations seeks to understand patient values regarding care choices.

Goals of Care Conversations

* These conversations take place early in the course of care
* They explore patients wishes and goals for care framed within the therapeutic options that the treating physician has determined appropriate for ones condition
* An advance directive (if completed and made available) may inform conversations regarding Goals of Care

Goals of Care Conversations

* They are done with the patient or resident
* If the patient lacks capacity to make the specific decision, then it can be done with the patients representative (ie substitute decision-maker)

Goals of Care Conversations

What's included in that conversation?

* Patients status, prognosis and anticipated outcomes
* Patients values, hopes, wishes
* Role of life support interventions/ risks and benefits
* Comfort measures
* Medical recommendations
* An offer to involve other resources to assist

Goal of Care Tool

A tool exists to facilitate communication between care providers, patients, residents and caregivers on Goals of Care

Goal A: Prolong life with all necessary care

Goal B: Prolong life with some limitations to care

Goal C: Ensure comfort as a priority over prolonging life

Goal D: Ensure comfort without prolonging life

Capacity to consent

* Ability to understand and appreciate one's condition, the purpose of a treatment and other options as well as the consequences of one choice over another
* A substitute decision-maker is someone who has the authority to consent to care on behalf of someone lacking capacity to make those decision.
* These decisions could include Goals of Care

The importance of the Advance Directive

* So each individual makes his own decision when and if the time comes

Mark Karanofsky, MDCM, CCFP, FCFP, Assistant Professor, Department of Family Medicine, McGill University and Unit Director GMF-U Herzl

Questions?

Speak Up

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What Is Advance Care Planning? What's Happening Across Canada Resource Library Make My Plan

QUÉBEC

- Curateur Public Québec □ My Mandate in Case of Incapacity
- Éducaloi – Incapacity
- Éducaloi – Mandates for Incapacity: Naming Someone to Act for You

QUICK LINKS

ACP Workbooks

http://www.advancecareplanning.ca/resource/quebec/

educaloi.qc.ca

YOUR STARTING POINT FOR LEGAL INFORMATION

HOME | THE LAW BY TOPIC | WEB GUIDES | ÉDUCALOI.TV | SERVICES & RESOURCES | DONATE TO EDUCALOI

Health

All | Quebec's Health System | Sexuality and Reproductive Health | Health Care | Loss of Autonomy and Protection of Vulnerable People | Doctors and Other Professionals | Workplace Safety

HOME ▸ HEALTH ▸ LOSS OF AUTONOMY AND PROTECTION OF VULNERABLE PEOPLE

Advance Medical Directives

OUTSIDE LINKS

Quebec health department: Advance medical directives

Chambre des notaires du Québec – Find a notary

https://www.educaloi.qc.ca/en/capsules/advance-medical-directives

Conclusion

References

- http://legisquebec.gouv.qc.ca/en/ShowDoc/cs/S-32.0001
- https://www.educaloi.qc.ca/en/capsules/advance-medical-directives
- http://www.advancecareplanning.ca/resource/quebec/
- http://www.ramq.gouv.qc.ca/en/citizens/Pages/advance-medical-directives-download-the-form.aspx
- http://irpp.org/wp-content/uploads/2019/03/Improving-Advance-Medical-Directives.pdf