

CLL SOCIETY

Smart Patients Get Smart Care™

Planning Ahead: Being Prepared for End of Life

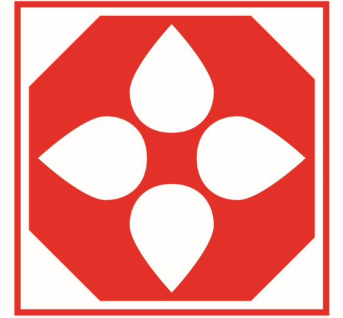
September 10, 2019

10:00 – 11:00 AM PDT / 1:00 – 2:00 PM EDT

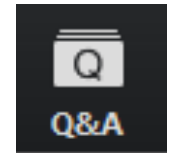
Housekeeping Notes

Welcome to the CLL Society Webinar!
The presentation will start momentarily

- Please direct your questions to CLL Society faculty or staff using the Q&A function (located at the bottom of your screen) at any time throughout the presentation
- You will receive a short email survey after the webinar. Your response will help CLL Society plan future webinars.
- The webinar is being recorded and all recorded webinars and the presentation slides will be available on our website via the Support Groups/Education page on cclsociety.org.



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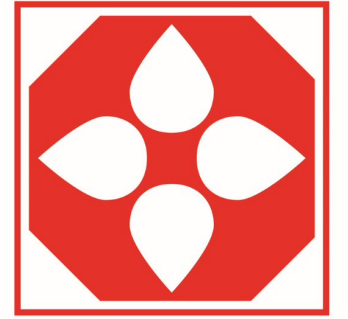
Question and Answer

Welcome
Feel free to ask the host and panelists questions

Type your question here

Send anonymously

This program was made possible by grant support from



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Speakers

Moderator: Brian Koffman, MDCM, DCFP,
FCFP, DABFP, MSEd

Executive Vice President and Chief Medical
Officer, CLL Society

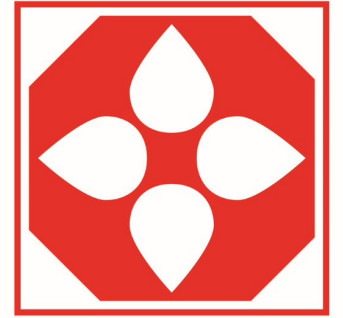


Speaker: Edward Ratner, MD

Associate Director, Education and Evaluation

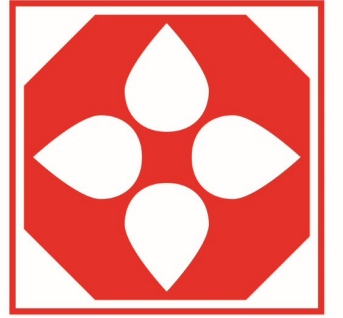
Minneapolis Geriatrics Research Education
Clinical Center (GRECC)

Minneapolis Veterans Administration
Medical Center



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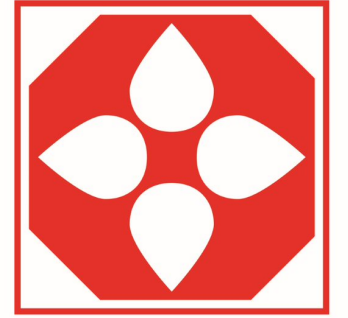
Learning Objectives



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- To be able to complete an advanced care planning process, with attention to issues related to CLL
- To be able to appropriately request a consultation from a palliative care specialist
- To know when and how to enroll in a hospice program

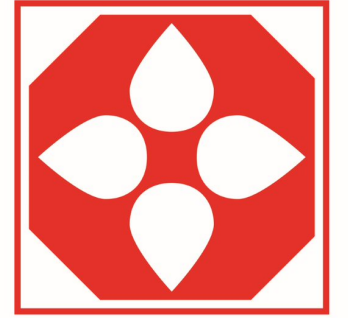
What is CLL?



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- Most common adult blood cancer
- Accumulation of a specific type of white (infection fighting) blood cell
- Related to genetic mutations one is born with, accumulate with aging, and/or are caused by environmental factors
- Life limiting problems include:
 - Diminished ability to fight infections
 - Inability to make other types of blood cells needed to prevent bleeding or maintain oxygen delivery

Statistics on CLL



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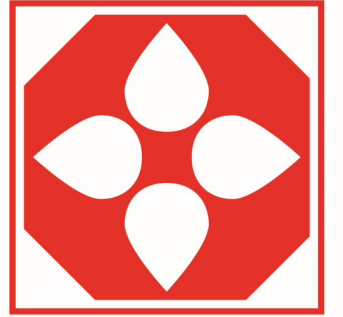
In 2019, in the US:

- About 20,720 new cases of CLL
- About 170,626 people with CLL
- About 3,930 deaths from CLL (~2% / year)
- Recently reported 5 year survival – 84%

www.Seer.cancer.gov/statfacts/html/clyl.html

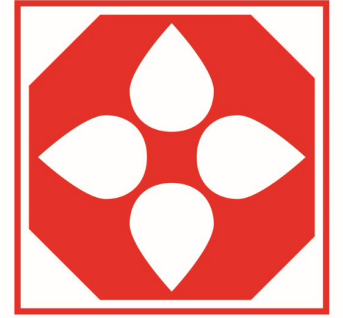
Goals of Health Care

- To live as long as possible (survival)
- To be able to do what I want to do (function)
- To be comfortable (physically, emotionally, spiritually)



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Palliative Care – WHO Definition



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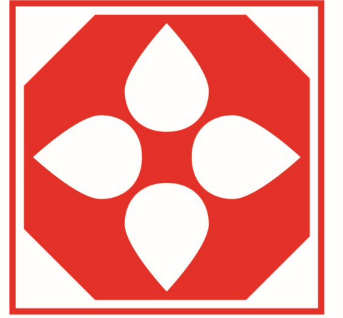
- Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

<https://www.who.int/cancer/palliative/definition/en/>

Palliative Care offers relief from pain and other distressing symptoms

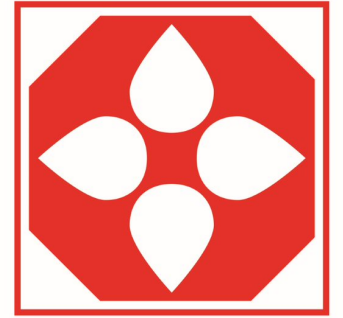
In CLL, this includes:

- *pain*
- *fatigue*
- *shortness of breath*
- *fevers*
- *night sweats*
- *insomnia*
- *medication side effects*



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Palliative Care affirms life and regards dying as a normal process



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In CLL, this includes:

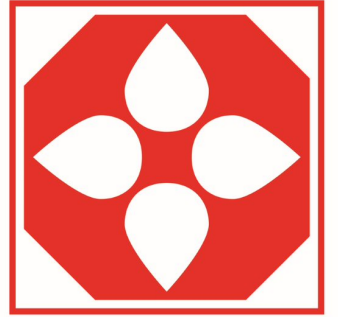
- *Honesty about prognosis*
- *Discussion of all treatment options, including the forgoing treatments*
- *Assistance with advance care planning*

For more information about Palliative Care visit cllsociety.org/living-well-with-cll/planning-ahead

Palliative Care intends neither to hasten or postpone death;

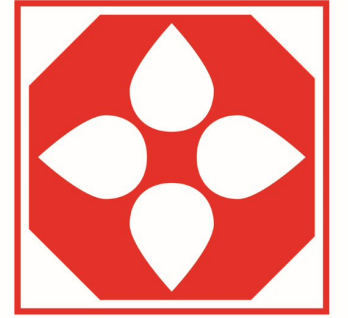
In CLL, this means:

- *Palliative care can be combined with CLL-specific medications and treatments*
- *Physician assisted suicide is to be avoided*



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Palliative Care integrates the psychological and spiritual aspects of patient care

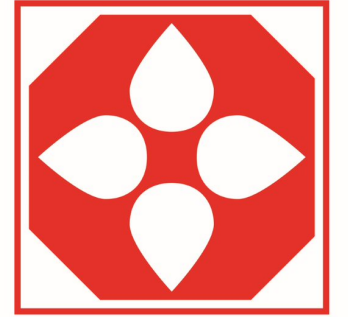


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In CLL this includes:

- *Empathy*
- *Mental health for anxiety and depression*
- *Support groups*
- *Encouragement of self-care*
- *Chaplaincy*
- *Encouragement of ritual or other religious/spiritual activities*

Palliative Care offers a support system to help patients live as actively as possible until death

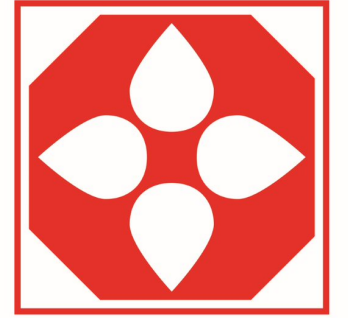


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In CLL, this includes:

- *Work and retirement planning*
- *Promotion of recreation and socialization*
- *Rehabilitation, when necessary*

Palliative Care offers a support system to help the family cope during the patients illness and in their own bereavement

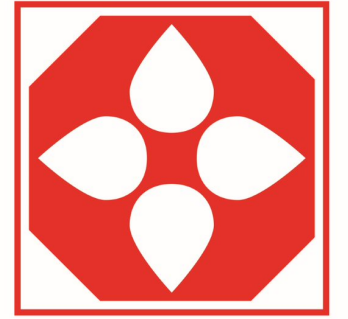


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In CLL, this includes:

- *Identification of key family members*
- *Inclusion of family members in clinic visits*
- *Promotion of CLL conferences, reading and support groups for family members*
- *Mental health services for family members*
- *Bereavement services*

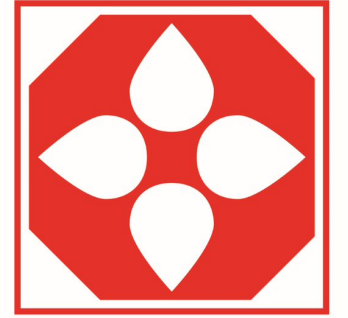
Palliative Care uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated



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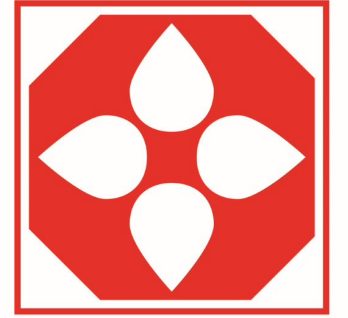
In CLL, this means:

- *Clinic care including clinicians besides the oncologist*
- *Coordination and collaboration between oncology and other types of palliative care clinicians and programs*



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Palliative Care will enhance
quality of life, and may also
positively influence the course
of illness

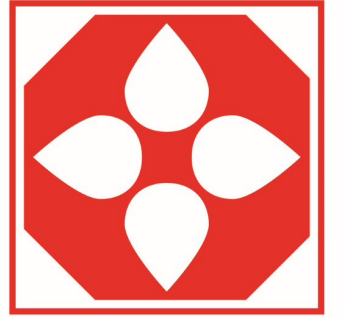


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Palliative Care is applicable early
in the course of illness, in
conjunction with other
therapies that are intended to
prolong life

What Can You Do To Address Palliative Care

- Bring family to appointments
- Ask for help with symptoms and feelings
- Ask for a referral to a palliative care team at your health care facility
- Ask for referrals to specific professionals
 - Mental health
 - Chaplaincy
 - Social Work
- Build your own palliative care team

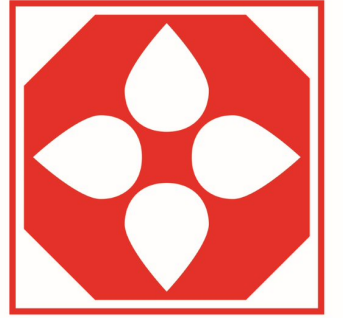


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Advance Care Planning

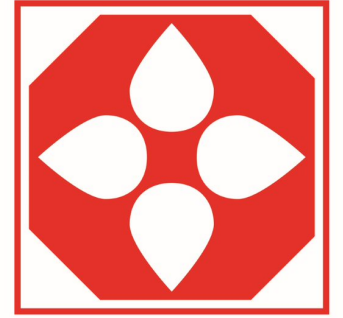
- Starts with discussion of goals and preferences
- May lead to:
 - Power of Attorney for Health Care
 - Health Care Directive
 - Provider Order for Life-Sustaining Treatment
- Can include funeral planning
- Is a gift to family members!

For more information about Advance Directives visit cillsociety.org/living-well-with-cll/planning-ahead



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Advance Care Planning in CLL

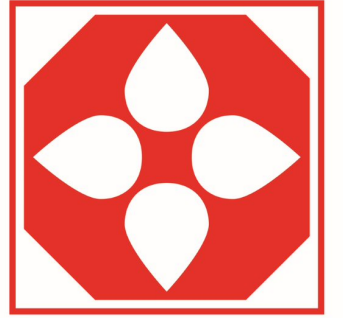


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- For times when a patient with CLL can't express preferences
- Allows family and providers to honor patient preferences without conflict
- Should address when treatments for CLL can be stopped or withheld, when
 - CLL refractory to standard treatments
 - CLL treatment causing suffering
 - Other illness is more life-threatening
 - Cognition or function is poor and unrecoverable

End of Life Care with CLL

- Now likely dying with CLL not directly related to CLL
- Life threatening CLL complications: anemia, infection
- Common EOL goals: remain at home, comfortable, not a burden
- EOL Choices: Hospital based, uncomfortable or experimental therapies vs. hospice care

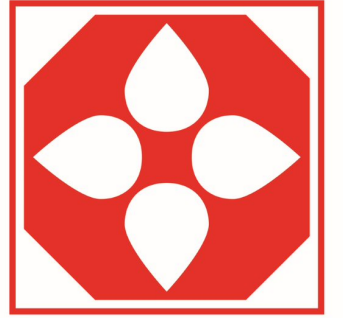


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Hospice

- Is a philosophy, program and insurance benefit
- Team approach to providing palliative care
- Offered in home, nursing facility, residential facilities and hospitals
- Fully covered by all insurers
- Supports both patients and families
- No obligation, no commitment enrollment

For more information about Hospice Care visit cllsociety.org/living-well-with-cll/planning-ahead



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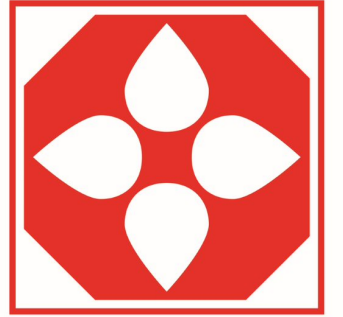
Choosing Hospice Care

Often not suggested by doctors in timely manner

Presumes life expectancy < 6 months – but unlimited time allowed

Should be offered/explained as option to ongoing CLL treatment when:

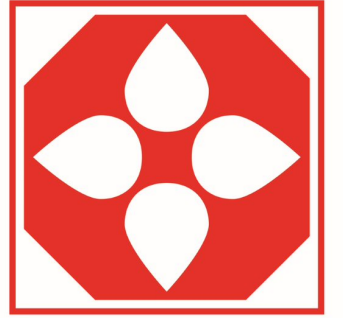
- Other (non-CLL) illness is terminal
 - Loss of ability to leave home easily
 - Intolerance of CLL treatments
 - Only experimental treatments for CLL remain
-
- Only Medicare service that allows self-referral



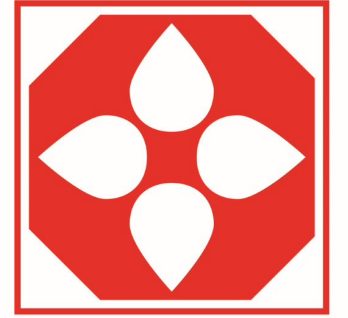
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Summary

- CLL may cause worry about end of life issues
- CLL requires palliative care from the time of diagnosis through bereavement
- Patients (and their families) may need to request or arrange palliative care services
- Advance care planning should be part of every CLL care plan
- Hospice is appropriate when comfort at home is the preferred option



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Thank You for Attending!

If you have any additional questions, please contact
support@cllsociety.org