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 cllsociety.org.
This program was made possible by grant support from Genentech, a member of the Roche Group, and Pharmacyclics, an AbbVie Company.
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
Learning Objectives

• 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?

• 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

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%

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)
Palliative Care – WHO Definition

• 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
Palliative Care affirms life and regards dying as a normal process

_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*
Palliative Care integrates the psychological and spiritual aspects of patient care

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

*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.

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.

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
Palliative Care will enhance quality of life, and may also positively influence the course of illness.
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 you own palliative care team
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 cllsociety.org/living-well-with-cll/planning-ahead
Advance Care Planning in CLL

• 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
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
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
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
Thank You for Attending!

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