

# Living with Bone Marrow Failure:

*An approach to Symptom Management*



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AAMAC Education Day – October 16<sup>th</sup> 2010

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<http://go.to/funpic>



# Disclaimer

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- I am not a Haematologist.
- I Am a Palliative Care Physician.
- What is he?
- Why is he here?



# Palliative Care

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- *"Is an **approach** that improves the quality of life for patients and their families facing challenges associated with life threatening illnesses 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"*

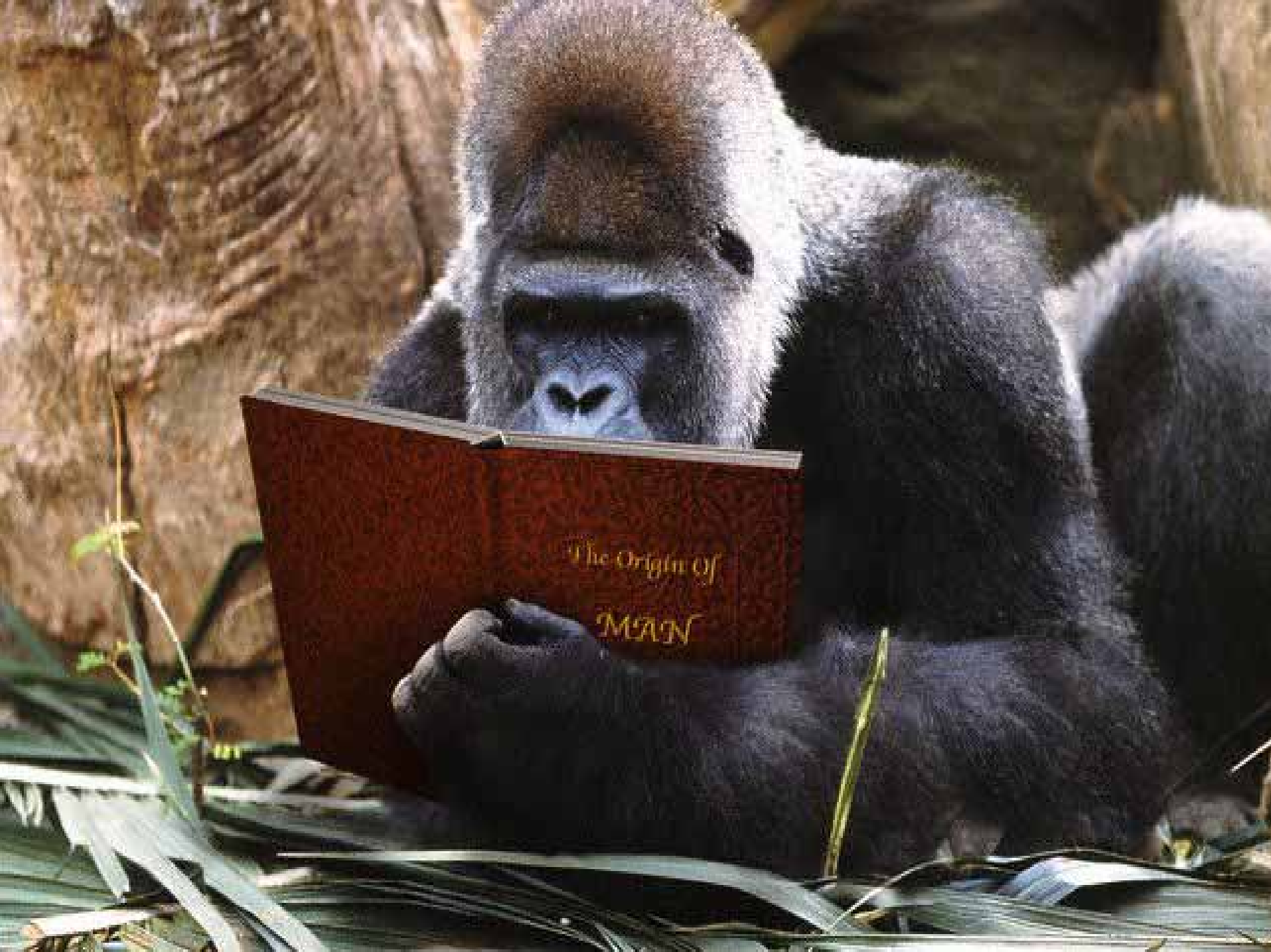
WHO Definition ( 1993)



# Outline

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- My understanding of MDS.
- Palliative care today.
- Symptom Management.
- A primer on fatigue.
- Supportive care throughout the disease.
- You are not alone.....



The Origin of  
MAN



# Myelodysplasia Is.....

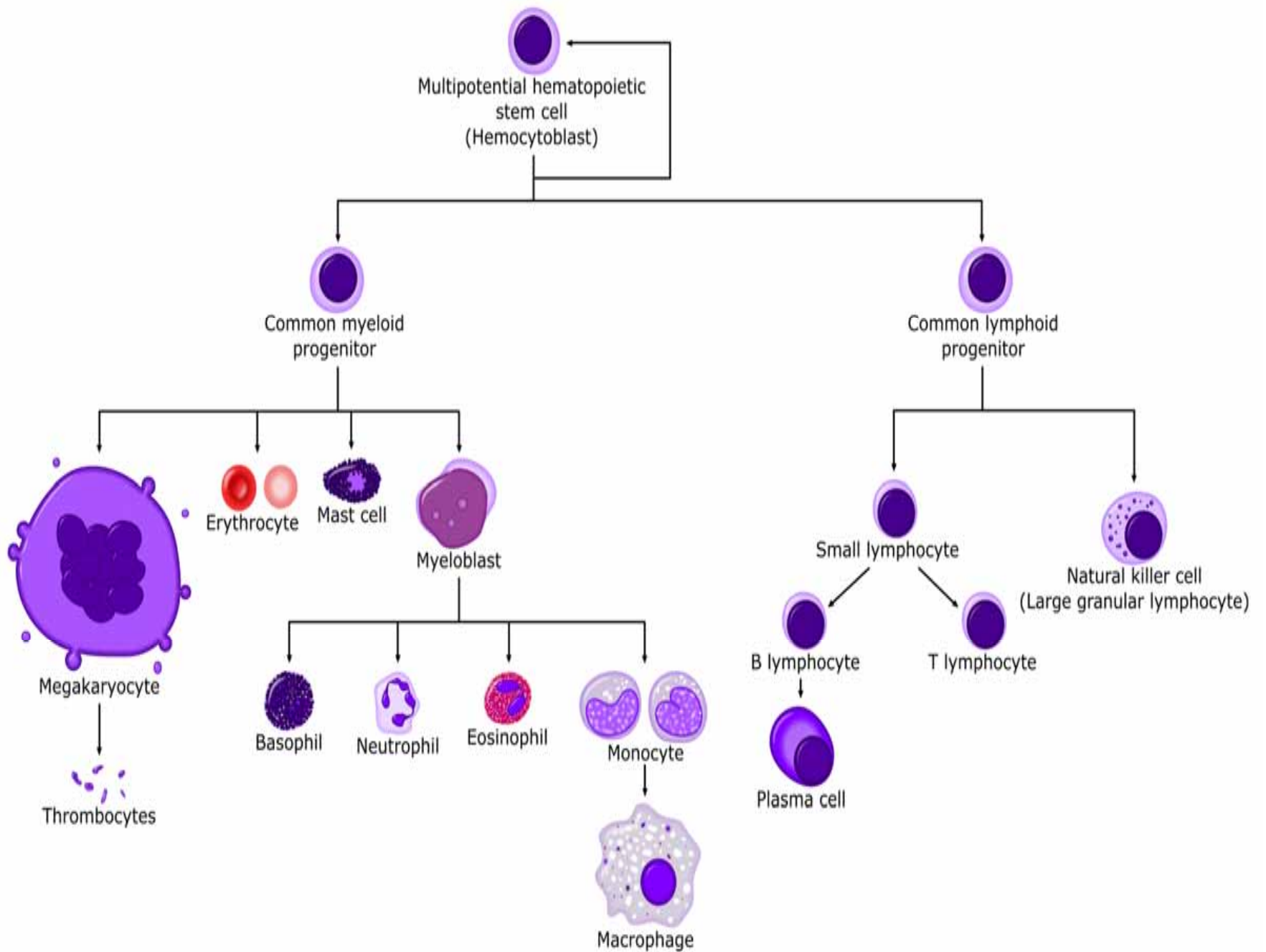
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- Clonal stem cell disorder characterized by: ineffective hematopoiesis with peripheral blood cytopenias due to dysplasia.
- Abnormalities in 1 or more cell lines
  - Erythroid = Anaemia
  - Granulocytes = Infection
  - Megakaryocytes = Bruising/ Bleeding disorders.

Miller KB. *Curr Treat Options Oncol.* 2000;1:63-69.

Kurzrock R. *Semin Hematol.* 2002;39 (suppl 2):18-25.

Yue G. *Leuk Res.* 2008;32:553-558.





# Individual and Environmental factors contribute to MDS risk

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- Idiopathic condition in >80% of cases
- Secondary MDS
  - Immuno suppressants
  - Ionizing radiation
  - Chemotherapy
  - Industrial and agricultural chemicals

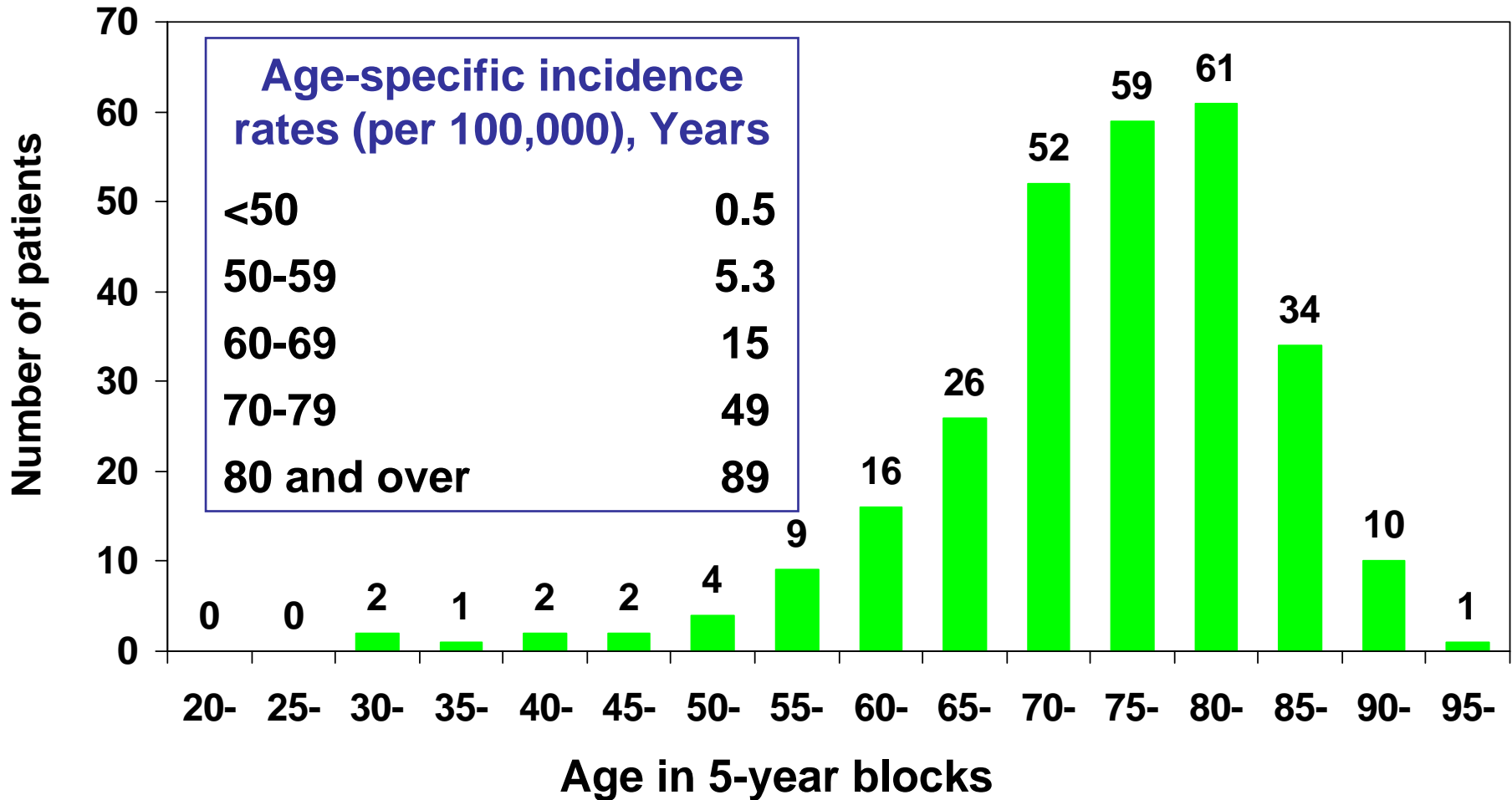


# MDS is a common hematologic disease with variable prognosis

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- Based on U.S. data, there may be 1500-2000 new adult cases per year in Canada.
  - Male gender (M:F $\geq$ 1.4)
  - Recent analysis shows 1.6 cases per 1000 patients over 65 years old per year.
  - Older age (median age at diagnosis 65-75), more likely to have comorbidities.

# Median age of MDS onset is >70 years



Incidence of MDS in a population served by one district hospital between 1981 and 1990 in Bournemouth, England



# Treatment Options in MDS

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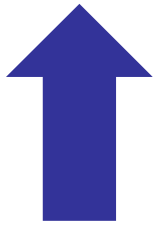
**CURE: Allogenic Stem Cell transplantation.**

*Many higher risk MDS patients are poor candidates for BMT due to advanced age and health status.*

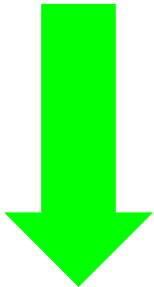
- **Supportive – Palliative Care includes:**
  - Transfusion ± chelation agents
  - Antimicrobials , vaccinations etc.
  - Growth factors
    - ESA +/- G-CSF
    - TPO agonist
  - Anti-fibrinolytics

# MDS Supportive Care

## Goals



Extend survival  
Improve quality of life



Decrease risk of AML transformation  
Decrease transfusion needs  
Minimize infectious complications

Supportive Care is Cornerstone of Rx

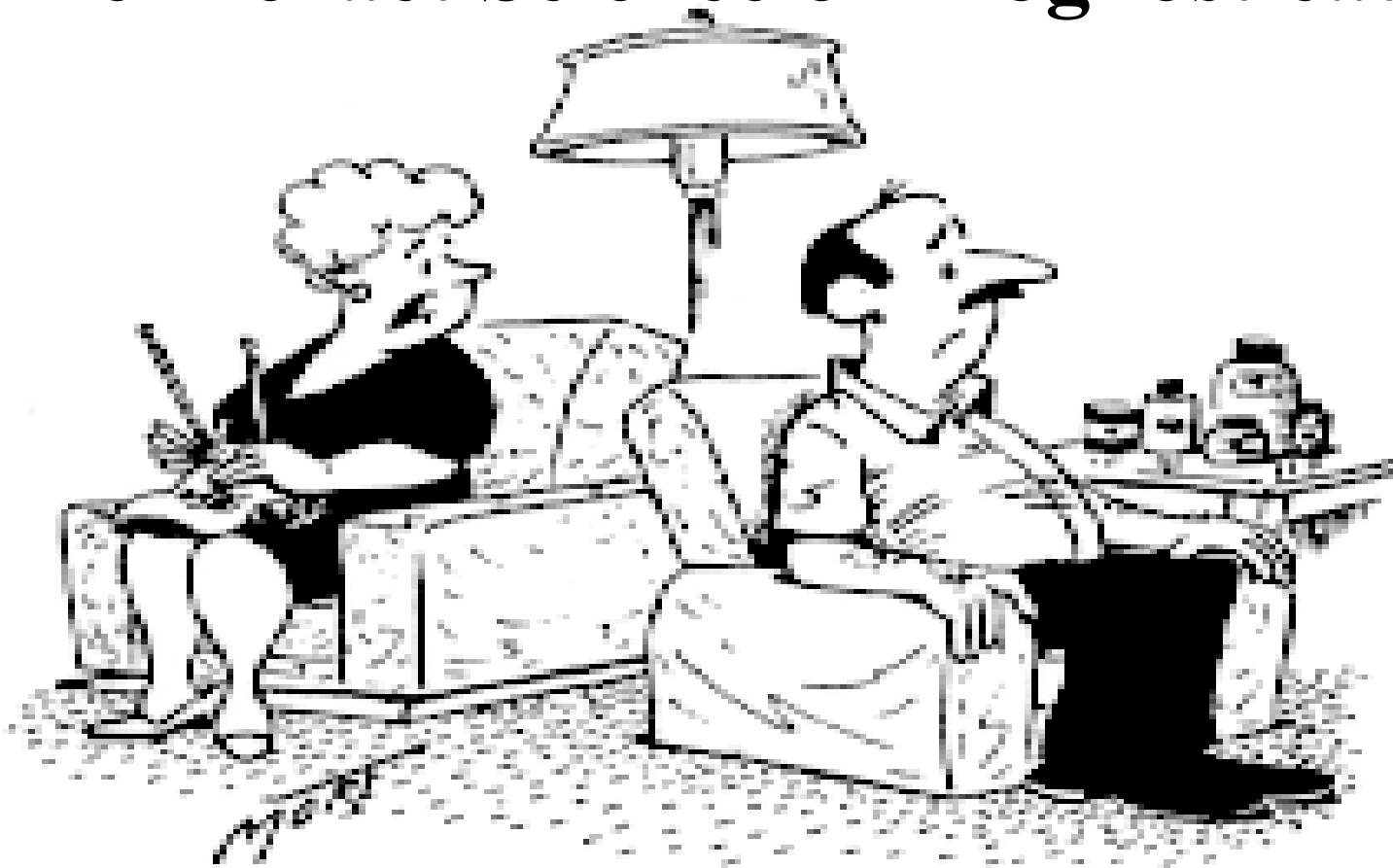
# MDS is a common Hematologic disease with variable prognosis (cont'd)



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- Median survival of 0.4 to 5.7 years, depending on MDS subtype.
- Bone marrow failure
  - 20%-40% of patients succumb to infection or bleeding before AML progression
- Approximately 40% of patients transform to AML

# The Inexact Science of Prognostication.



**"I think you should sue the doctor for malpractice! Two years ago he gave you only six months to live!"**



# Role in MDS

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- Supportive care is the mainstay of management of patients with good prognosis MDS and those with poor prognosis disease where clinical factors precludes intensive therapy.
- Focus of care is on palliation and improving quality of life.



# Palliative Care

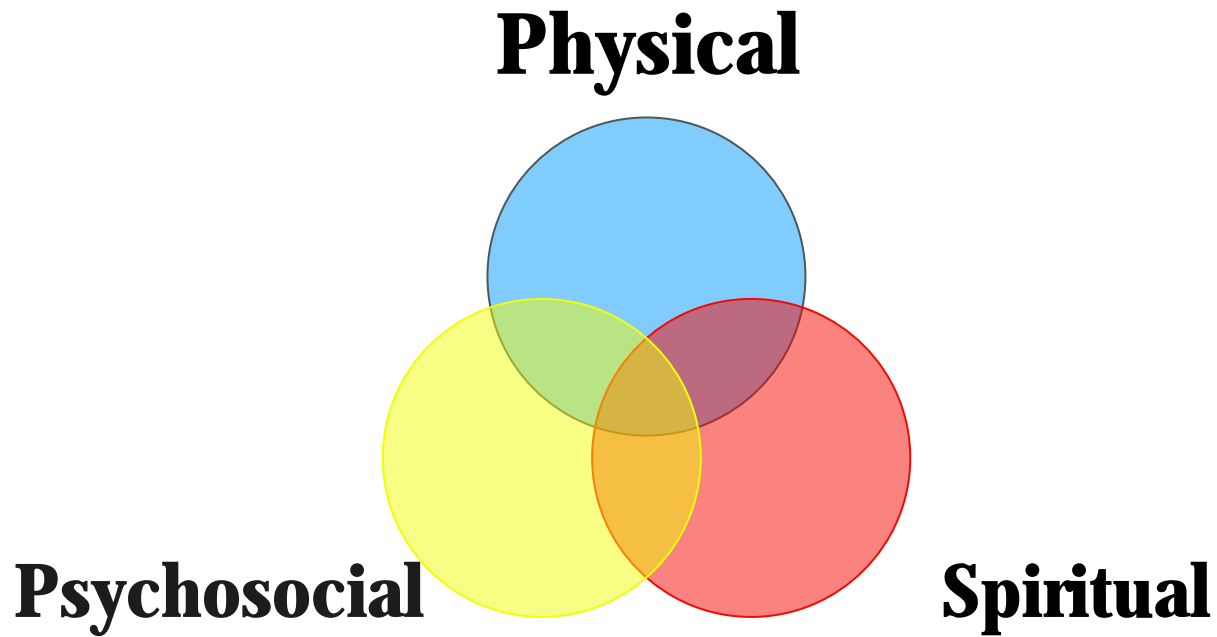
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- *"Is an **approach** that improves the quality of life for patients and their families facing challenges associated with life threatening illnesses through **the prevention** and **relief of suffering** by means of early identification and impeccable assessment and treatment of pain and other problems physical, psychosocial and spiritual"*

WHO Definition ( 1993)

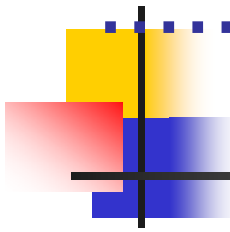
# Concept of Whole Person Care

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# Who does Palliative care ?..

## .....The Mutlidisciplinary Team.

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- Nurses,
  - Physicians,
  - Occupational Therapists,
  - Physiotherapists,
  - Social Workers,
  - Respiratory Therapists,
  - Psychologists,
  - Administrative support workers,
  - Pastoral care,
  - Volunteers,
  - Any service that may be useful for an individual case

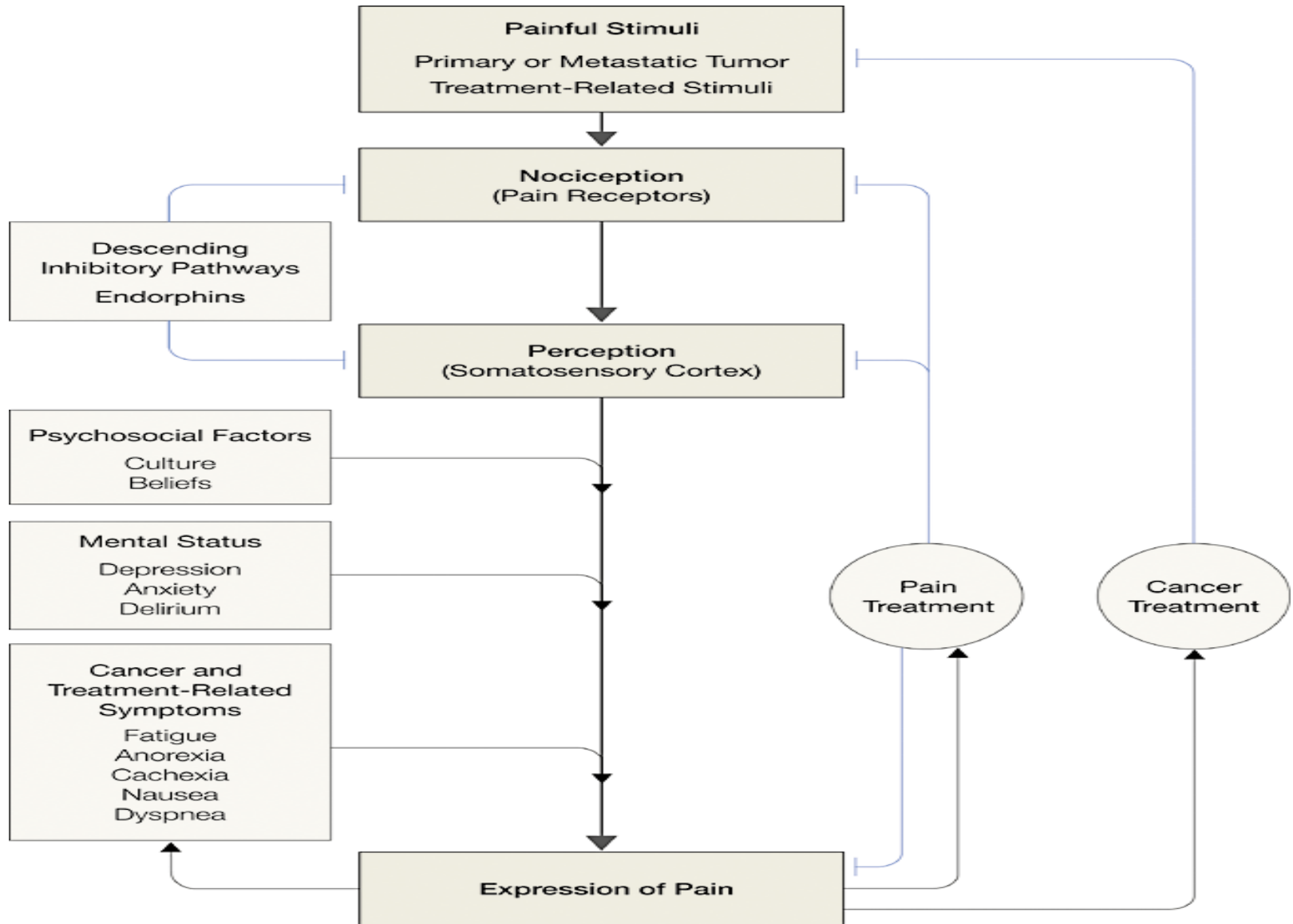


# Principles of PC-S Care

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- Expert Symptom assessment
- Good Communication: Listen
- Patient Centered care: Involvement in decisions.
- Whole Person care: Psychosocial factors
- Multidisciplinary team work
- Attention to detail
- Know the person and not just the disease.
  
- There is never “nothing more that can be done”, but goals and expectations will change with time.

# Steps Involved in the Expression of Pain

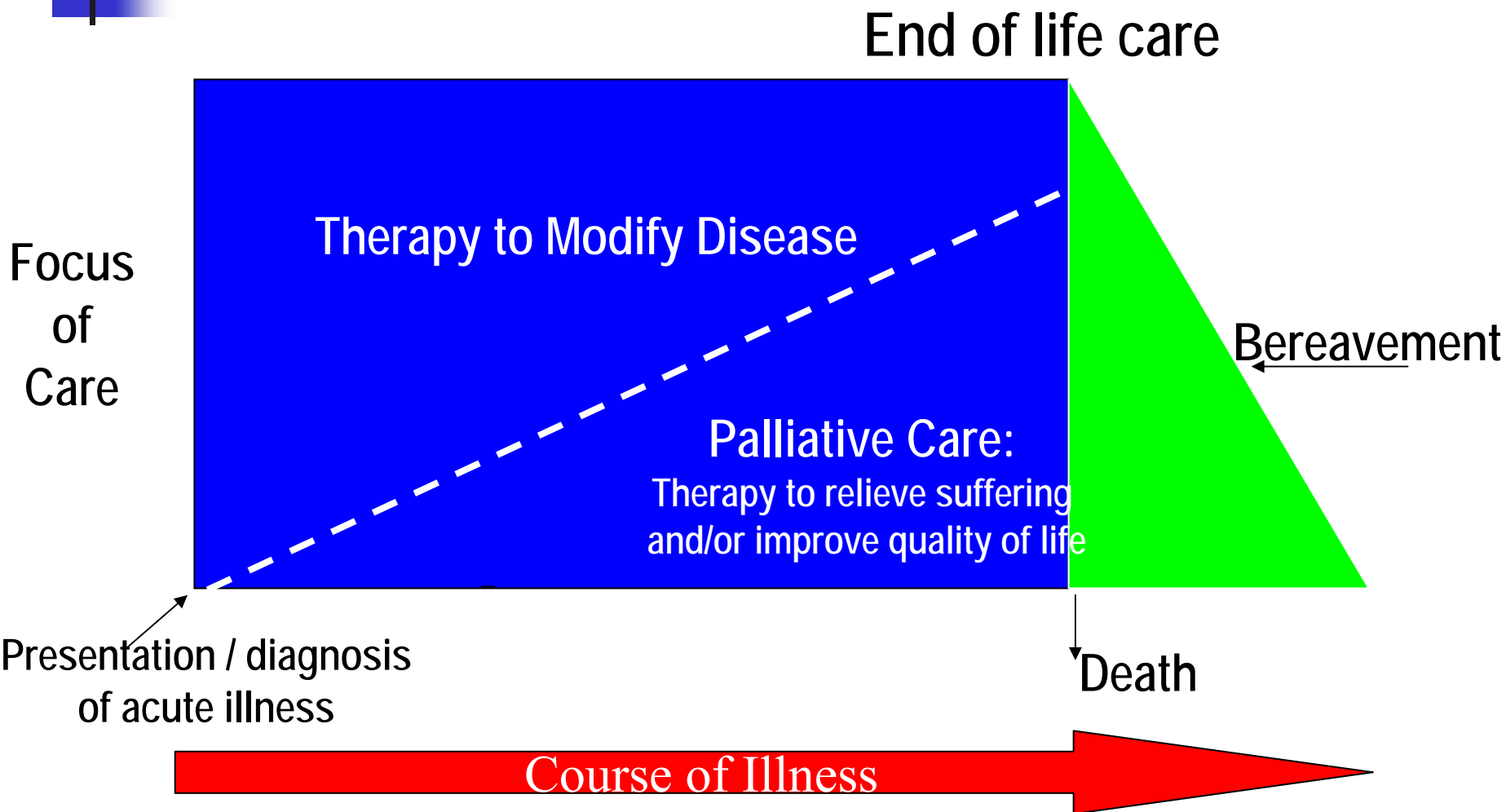


# Old Model of Palliative Care

by Dame Cicely Saunders



# Evolving Roles of Curative and Palliative-Supportive Care





# Palliative Care @TOH And Hem Onc

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- 145 Consults/yr ( Total 2600 /yr)
- Average patient age: 47 (18-84)
- Course of repeated crises.
- Often recover.....repeat consults.
- Issues: Pain: multifactorial
  - Fatigue
  - Mucositis
  - Anorexia
  - Dyspnoea
  - End of Life care issues.
- Symptom control + support = Improved QOL



# Symptom Management

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- Before you can manage a symptom you need to know it is there.
- Symptoms are subjective.
- Ask or you will not know.
- Screening tools help both patient and healthcare teams e.g. ESAS
- Regular monitoring essential.
- Tools can monitor effectiveness of care.

**Edmonton Symptom Assessment System:  
Numerical Scale  
Regional Palliative Care Program**

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	

Patient's Name \_\_\_\_\_

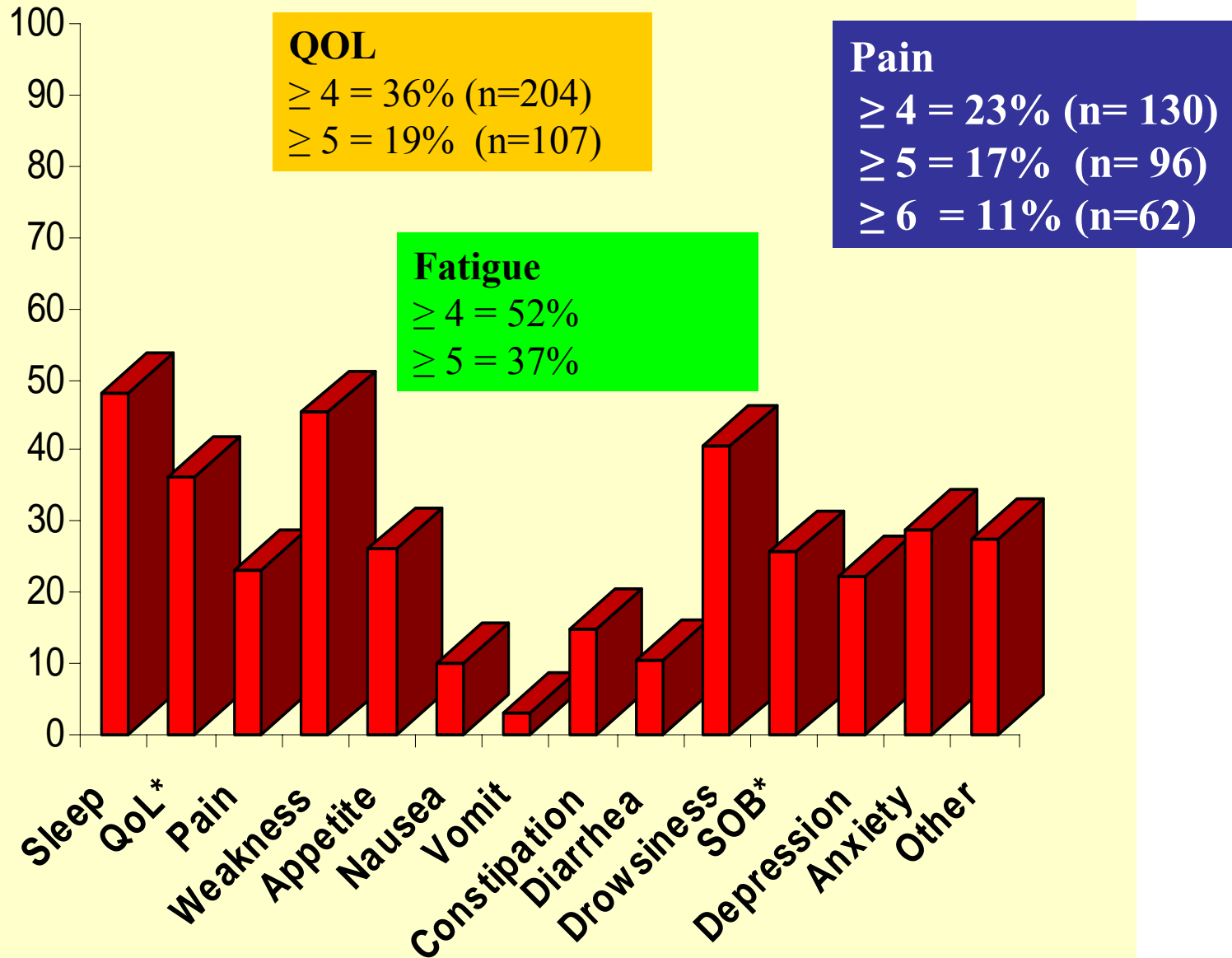
Date \_\_\_\_\_ Time \_\_\_\_\_

Complete by (check one)

- Patient
- Caregiver
- Caregiver assisted

**BODY DIAGRAM ON REVERSE SIDE**

# Prevalence of Moderate Symptom Distress (ESAS $\geq 4$ ) (N= 561)





# Principles of PC Symptom Control

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- Be proactive: Ask about symptoms...screen.
- Aim to find the cause...don't assume!
- Treat promptly.
- Constant symptom requires constant rx.
- Reassess Regularly.
- Whole person approach.
- A Multidisciplinary team approach.

# A Multidisciplinary Team Approach





# TOH Programs for you....

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- Hematology Oncology Program
- Psychosocial Oncology Program (PSOP)
- Palliative Care Program
- + + + + + + + +



# Fatigue...the commonest symptom

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- “ A distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness .....that is not proportional to recent activity and interferes with usual functioning.

*NCCN 2208*

- Commonest symptom (80-90%)
- May be isolated or as one element in a cluster of symptoms such as pain, depression, sleep disturbance etc.
- Best assessed by patient self report...screening tools BFI



# Fatigue is multifactorial

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- Contributing factors

Anaemia

Endocrine: Hypothyroidism, Adrenal insufficiency hypogonadism, diabetes.

Cardiac or Pulmonary insufficiency.

Fluid + electrolyte imbalance

Infection

Depression/ anxiety,

Medications

Etc.....etc



# Fatigue: Management...treat the underlying cause if possible.

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- Transfusions
- Epo
- Exercise
- Energy conservation+ activity management
- Education
- Optimize sleep quality
- Relaxation
- Massage
- Various meds.....of varying effectiveness



# Transfusion therapy in MDS

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- RBC transfusions often improve QOL
- No absolute Hb level can determine timing
- Platelet transfusions more variable and depend upon short and long-term goals, increments and clinical bleeding

# Transfusion therapy in MDS (cont'd)



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- Risks of RBC transfusion:
  - Febrile, non-hemolytic reaction
  - Allergic reaction
  - Volume overload
  - Iron overload → increased toxicity of BMT
  - Transmission of infectious agents.

As condition progresses, the timing of transfusions becomes linked more to subjective patient symptoms rather than actual lab values.



## Supportive Care ..other roles.

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- A crucial part of whole person care includes Advance Care Planning, that is best done when you are well.
- Ensure personal wishes for care are known to your family/ support.
- Identify Power of Attorney ( POAs)
- Living will
- Resuscitation preferences.

# Advanced Care Planning: Status Identified in ER

2008 audit at TOH ER of Cancer Patients who attended the ER within 2 weeks of death.

Type	Yes	NO Unknown
DNR status known / documented.	19.8%	80.2%
POA Known/ appointed	13.7%	86.3%
Advanced Care Directives	11%	89%

**Goals of care discussion held in hospital: 86%**  
**DNR established after admission: 90%**



# “What matters most in end of life:” The Canadian Perspective

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- 5 Teaching Hospitals. (569 patients 176 family members.)
- Trust in the treating health care team.
- Avoid unwanted life support.
- Effective communication.
- Continuity of care.
- Life completion: opportunity for closure.



# Case: Lorraine 2007

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- 70 yr old lady.
  - 2008: admitted with hip fracture
  - Lab tests- anemic+....Dx MDS
  - Phx: Bypass x 2, Breast cancer ..XRT Cured+
  - Told she had 3 months to live!.
- 
- Problem: Pain due to hip fracture
  - Outcome: Discharged home, transfusions prn.



# Lorraine: 2009

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- Admitted with Pneumonia....she asked for PC consult!...to “calm the family”
- Fatigue, nausea, coughing++
- Anaemic + Low Platelets..she had given up on transfusions!.
  
- Outcome: Home again...“3 months to live”
- Transfusions restarted.



# Lorraine 2010

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- Admitted...abdominal pain...abscess
- Low platelets, low WCC, anaemic
- Fatigue no longer responding as well as before.
  
- Outcome: hoping to go home, agrees to w/chair.....transfusions will now be determined by her.
- "3months to live"



# Supportive Care In MDS

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- Symptom assessment and management e.g. fatigue.
- Clarifying goals of care and advance care planning.
- Support through various phases of illness

Questions  
anyone ?

MAY 29  
3D



