

Surviving & Thriving in times of trial



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Objectives

- To understand the challenges of MDS and aplastic anemia
 - *Reviewing stats*
 - *Examining other bodies of evidence*
 - *Trend-setting*
- To review information about stress and coping and dealing (WELL) with challenges
- A few gems about SURVIVORSHIP
or
How to plan for tomorrow when you can't be sure of today?

The incidence of MDS/AA...

is increasing due to:

- population growth
- population aging
- improved screening – earlier dx
- more sensitive technology
- better education
- less fear
- improved survivorship

This also means - living longer with the disease!

More Ontarians living with..

MDS/AA in 2012 than ever before....so – need to know the W 5 of this

Who gets it

What kind

When – child – young adult – adult – elderly

Where – epidemiological info/data

When does it recur and

How does this happen?

Mortality rates...

are decreasing due to:

- increase in average years lived (male and female)
- more treatment options
- more 'other' disease treatment options
- better education
- less fear
- earlier diagnosis – more awareness

Prevalence of MDS...

- *Number of Ontarians living with MDS/AA
INCREASING
AND more new cases diagnosed annually
AND more living a lot longer*
- *Living with blood dyscrasias presents a whole
new plethora of needs*
- *Many do not understand*
- *Tiring to have to tell them*

Defining 'Chronicity'

- Persisting for a long time; applied to morbid state where one shows little change or extremely slow progression over a long period
- Illness is 'chronic' when lasts more than 6 months
- Chronic diseases exacerbate/wain – acute on chronic – lots of fluctuation for some – stability for others
- MDS/Aplastic anemias/PNH → CHRONIC DISEASES

Miller & Keane, Encyclopedia and Dictionary of Medicine, Nursing and Allied Health, 1983

CHRONIC DISEASES

...has capacity to touch ALL aspects of individual's health –

- Physical
- Functional
- Psychological/cognitive
- Social
- Economic
- Spiritual

In essence- YOU are a SURVIVOR

- **Definition:** “From the moment of diagnosis & the balance of life, individuals with a chronic illness are survivors – When someone has a chronic illness, family members, friends & caregivers also affected & considered survivors, too”

*As in the reality show ----no one knows EXACTLY –
how long one has in this chapter of one's life*

Phases or stages

- Sometimes called trajectory- illness experience/journey
- Often have early days – a middle time – advanced/end stage
- Length varies –
- Sometimes indistinct and blur together

Whatever phase or stage..

- Stressors to face \leftrightarrow Strategies to cope
- Vary according to where one is in their illness -- May be:
 - *Physical*
 - *Psychological*
 - *Pragmatic*

What is a stressor?

- **Definition**: A stimulus perceived as challenging, threatening or demanding
- Examples of stressors for you may be:
 - Chemotherapy
 - Preparing for Bone Marrow transplant
 - Dealing with your children
 - Driving on the 401
 - Unable to carry out the garbage

Stressors differ

Different stressors = different degrees of distress
(thermometer)

- More common stressors – more options
- Less common (identified by patients) – greater distress
(eg. spiritual issues – relating to God, finding meaning,
loss of faith)
- May feel lost about what to do next

Early Days

- **Physical** – fatigue (number 1), pain esp bone (may be chronic), anemias/neutropenias, other blood related concerns, neuropathies, cognitive changes, sleep disruption, weight changes, renal failure
- **Psychological** – depression/anxiety, fear of future, changes in libido, attitudes about body/self-esteem, dealing with mortality, concentration/memory problems, coping with feelings including anger
- **Pragmatic** – social issues including work, changes in responsibilities home and elsewhere, learning a new normal, having to ask for help, loss of autonomy

Intermediate days – pre or post transplant

- Physical – fatigue may worsen - pain (not going away), resuming work or chores or continuing to let more go and losing some independence
- Psychological – anxiety re: relapse, feeling drained & dealing with limitations, feelings of isolation, responding to others' expectations, sexuality & intimacy
- Pragmatic – newest trends in disease, eligible for clinical trials if I recur, support for others (some can do this), who to see in health care system about what...?, on-going role issues, financial concerns, insurance concerns

Advancing or advanced illness

- Physical – Can be many: late effects of Rx, adjustment to new self, pain, neuropathy, weakness – increasingly taking to bed/no energy
- Psychological – Deal with anniversary dates (eg. dx), hope to live long enough for more treatment/ more choices - more living – never free of ‘cloud over my head’
- Pragmatic – F/U care/ further treatment issues, insurance, etc. Dealing with mortality – plan funeral = ensure “house in order”

Wherever you are: however you feel

- YOU need
BALANCE

AND

- YOU need
TO COPE



What is a coping strategy?

- **Definition:** A skill or set of skills that is utilized by an individual that effect his/her control over a situation and ability to deal with that situation –

May be effective or ineffective



COPING is IMPACTED by:

- Demographics – eg. age/marital status/ where you live
- Disease and treatment
- Characteristics
- Social support
- Personality

Strategies directed toward active engagement of the illness (deal with it) are associated with better psychological adjustment and Quality of Life!

COPING

- For the most part improves with age/maturity
- Takes many forms – the more/various methods of coping you possess – the better ‘coper’
- Common, effective coping strategies are faith, physical activities, distraction, acceptance, negotiation, logical analysis (head over heart), seeking guidance/support, reappraisal
- Effective coping → acceptance & peace
- Ineffective coping → depression, anxiety & anger

SOME SPECIFICS about



SPECIFIC Ways to
Cope & Hope

Strategies to Cope

- Rediscovering what is important in life
- Treating the illness as a challenge or battle to be fought and won (Sometimes aligned with resilience)
- Coming out of an illness experience stronger and better than when you entered
- Praying/Meditating/Relaxation techniques
- Fostering hope

RESILIENCE

- Concept showing that despite many catastrophic events at times, many survivors of chronic illness manifest remarkable resilience in the face of their illness
- Aligned with *hardiness* or *mental toughness* or *resourcefulness*
- Process (resiliency) not a trait & promotes well-being or protects against over-whelming odds



How to “build” resilience?

1. Maintain good relationships with family/friends/others
2. Avoid seeing crises/stressors as ‘unbearable’ events
3. Accept circumstances that can’t be changed
4. Develop and work towards ‘realistic’ goals
5. Take decisive actions in adverse situations
6. Look for opportunities of self-discovery after struggling with a loss
7. Develop self-confidence
8. Look outwards at the bigger picture (keep a perspective)
9. Maintain hope – expect good things
10. Take good care of your mind/body & spirit

COPING CHOICES

FAITH – in
something

Belief in a higher
power – a force
stronger than
you or me

Not necessarily a
formal religion –
but something to
hold onto



WW1 – NO atheists in the trenches

- Belief that God, Providence or luck would shield them from death provided security and reassurance.
- Even faith that a loving deity was behind the bloodshed and destruction imposed some sense on an other-wise unpredictable and frightening world.

HOPE – difficult
concept to describe

Does not need
to be big things or
long term dreams
or wishes –

Hope for tomorrow



HOPE

- People need to be able to make sense out of something no matter how it turns out.
- Reframe the nature of the hope as time goes by
- Hope for a cure may change to one of physical comfort, emotional calm or peaceful death.
- A belief in a personal tomorrow

LOVE – social support – people you know or don't know...

Peers – incredible to decrease the isolationism – to help you hold on –

To role model

To really understand your reality -



Love given and Love received

“Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around. It’s overwhelming to consider the continuous opportunities there are to make our love felt.”

Leo F. Buscaglia

OVERALL

Seeking Information is Number# 1 **coping mechanism** for patients – from internet, public press, media, peers, HCPs, independent research, support groups, chat rooms, etc.

(“Knowledge is power”)

Acceptance increases over time – very helpful coping – and helps decrease negative moods

Increasing social support – helpful for many

“ Cognitive restructuring”

COGNITIVE RE-STRUCTURING

- Trying to find something positive about having a chronic illness diagnosis”
- Improves – Quality of Life (Q of L)
- More of an impact on Q of L than medical factors – in other words – cope better & deal more effectively with challenges and/or stressors
- Turn things around - the eternal optimist

Nothing is stagnant ...

- Everything is **dynamic** so
- STRESSORS CHANGE and COPING MECHANISMS CHANGE, too – frequency can be hour-by-hour
- BOTH depend on where you are on a day-to-day basis
- Good days and bad days
- Unexpected – hard to plan for times/events
- Go with the flow (easier said than done)
- Gold and silver days...

Essential Components of Survivorship Care

- **Prevention** – of recurrent or new diseases
- **Surveillance** – for recurrence or complications with on-going assessment of medical & psycho-social care
- **Intervention** – for consequences of illness - medical concerns eg fatigue, pain; psychological distress eg depression; financial issues eg EI, disability in a timely fashion
- **Co-Ordination** – between specialists and primary care providers to ensure all survivor's health care needs met

As well as a survivor

- YOU are also an EXPERT in your disease
- No one else can tell you how you feel
- You really do “KNOW” best
- This comes with responsibility to
 - Tell others (needs/feelings)
 - Advocate for yourself
 - Set boundaries
 - On conversations (especially about yourself)
 - On activities
 - On expectations

New focus/emphasis on patient partnering with health care team

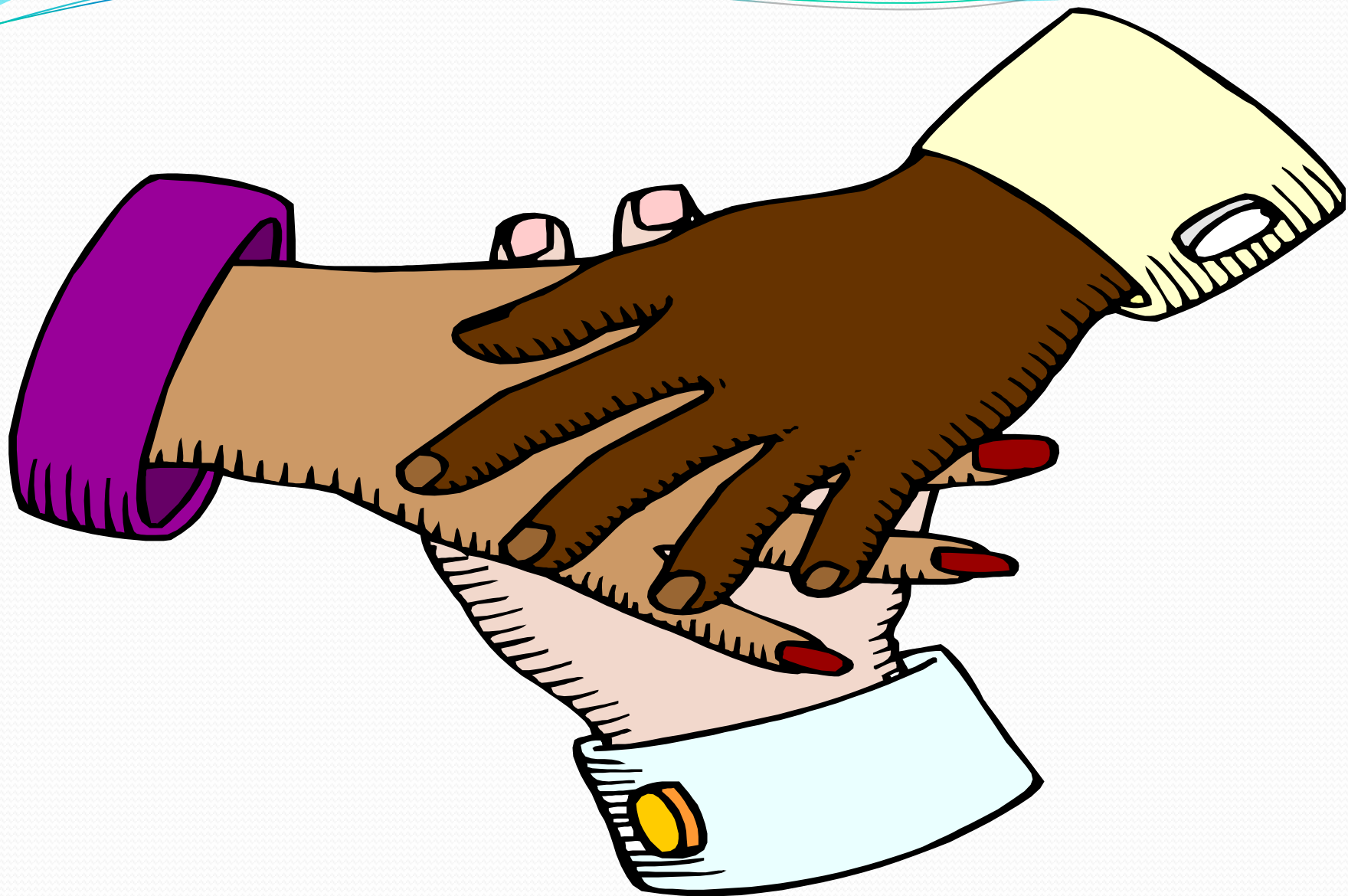
(A person who shares or takes part with other(s) *Oxford Dictionary, 2001*)

- Partners work together to achieve common goals, recognizing & respecting each other's skills & competencies & the advantage of combining resources to achieve beneficial outcomes.

Successful partnerships are non-hierarchical with shared decision-making & responsibility.

The key...is recognize that patients are experts

adapted from Coulter, BMJ, 1999



Partnership is:

A contract between two/more persons to join together money, goods, labor & skill (any or all), understanding there will be a communion of profit between them, & to enable legal trade, business or adventure.

Webster's Dictionary, 2001

Partnership

‘Being a partner:’ A relationship between persons or groups characterized by co-operation & responsibility to achieve a specific goal.

The American Heritage Dictionary of the English Language, 4th Ed., 2000

Means – ACTIVE PARTICIPATION

“Insist on being treated as a PARTNER not a statistic”

9 tips on **being an informed patient:**

1. Bring along a family member/friend
2. Talk to a nurse
4. Know your options
6. Set the terms of the relationship
5. Think through your priorities
6. Use the Internet
7. Get your medical records
8. Bring a tape recorder to your office visit
9. Find a doctor you like - don't feel obligated to stick with one you don't!

Lastly –Share your experience

- COMMUNICATION is the help of any and all
- No one can help/teach/support another unless they know there is a concern
- A problem shared is a problem halved
- Too many unique and wonderful things about you – all of us – that await to be told
- Care/treatment – perhaps resolution – may be available if you open your





With communication comes
understanding and clarity;

With understanding, fear diminishes

In the absence of fear, hope emerges;
and in the presence of hope, anything
is possible!!

Ellen Stovall, President

National Coalition for Cancer Survivorship. 2006

Strength in numbers

- A piece of string alone cannot accomplish much and has a potential to break
- Many pieces of string tied together can weave a safety net - for you/for others – try not to be isolated but stay involved/connected as much as possible
- Strength in numbers – strength in strings tied together
- The net is there for you/for your family friends –some days we need that safety and security more than others





Any Questions or
Comments??

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