



A Patient's Perspective on Being Newly Diagnosed*

- Peter DeNardis, IWWMF Trustee & WM Warrior

**** Or, "Everything You Wanted to Ask about Living With
Cancer Upon Diagnosis, But Were Too Numb to Ask!"***

Patient's Perspective - Newly Diagnosed



- Dx 2003, age 43
- Married, 3 young children
- Given 6-7 years to live
- Highly symptomatic:
 - Night sweats
 - IgM > 6000 mg/dl
 - Fatigue
 - Heavy nosebleeds

Patient's Perspective - Newly Diagnosed



Tx:

- 2003 (cladribine),
- 2004 (FCR)
- 2009 (Cytosan, dex, radiation)
- 2016 (radiation)

Conditions

- Hemolytic anemia
- Cold agglutinin disease
- LPL tumors
- Peripheral neuropathy (*)
- Hypogammaglobulinemia (*)
- Drop foot



Patient's Perspective - Newly Diagnosed

LIVING WITH CANCER IS STEP-WISE PROCESS:

DIAGNOSIS

WHAT NOW?

TREATMENT

SURVIVORSHIP

LIVING

DYING



Patient's Perspective - Newly Diagnosed

DIAGNOSIS

“Why Me?”



What did I do wrong?
Did I bring this on myself?
Could I have done something
differently in my life?

“Last Holiday”

Patient's Perspective - Newly Diagnosed

DIAGNOSIS

*And yet..
Life Still
Goes On*



Source: Aquazarma blog



Patient's Perspective - Newly Diagnosed

DIAGNOSIS

DABDA – 5 Stages of Grief (Dying)

Denial

Anger

Bargaining

Depression

Acceptance



Patient's Perspective - Newly Diagnosed

DIAGNOSIS

“Why NOT me?”

***“Things don’t happen to you,
they happen for you” –
Sandra Yancey, Founder/CEO,
eWomenNetwork***

***“Lean into the suck”
– Sheryl Sandberg,
Facebook COO***

***“Pain is inevitable,
suffering is optional”
- unknown***

***“We’re all terminal; from
the moment we’re born,
every one of us begins to
die” - unknown***

Patient's Perspective - Newly Diagnosed

DIAGNOSIS

Bottom Line: Find a way to come to terms with the diagnosis and **MOVE ON!**

And, bear in mind, It's OK to Cry or Be Angry during critical moments; if it lingers, seek help, so you can MOVE ON with your life!



Patient's Perspective - Newly Diagnosed

OK...but....

WHAT NOW?





Patient's Perspective - Newly Diagnosed

WHAT NOW?

FIRST:

- *Do you want to “come out of the closet or not”?*



- How much information do you share?
- Whom do you share it with?
- When do you share it?



Patient's Perspective - Newly Diagnosed

WHAT NOW?

THEN: Start Getting ON with your life!

- *Research/Study/Read*
- *Come to terms with terminology – know the words!*
- *Know your tests, and track your test values*
- *Be in tune with your body*

Patient's Perspective - Newly Diagnosed

WHAT NOW?

THEN: Start Getting ON with your life!

- *Get a second opinion*
- *Question your doctors*
- *Verify your medications*



Patient's Perspective - Newly Diagnosed

WHAT NOW?

THEN: Start Getting ON with your life!

- ***Take Advantage of:***
 - ***Support Groups (face-to-face & online)***
 - ***IWMF Services***
 - ***IWMF Connect***
 - ***Seek and accept HELP!***



Patient's Perspective - Newly Diagnosed

WHAT NOW?

And Don't Forget:

- ***Get your financial and legal affairs in order***
 - ***Will, Living Will, Power of Attorney***
 - ***Discuss end of life issues with significant others***
 - ***Five Wishes (see: <http://www.iwmf.com/about-wm/organize-your-medical-records>)***

Patient's Perspective - Newly Diagnosed

THE TREATMENT PHASE



And This Way, I Will Keep You Vigilant and Alert!

The Pink Panther

Patient's Perspective - Newly Diagnosed

THE TREATMENT PHASE

- *It MAY be rough and inconvenient*
- *Research your options / study / read*
- *Question your doctors / don't be passive*
- *Get a support network*
- *Examine your medications & combinations*
- *Know your body*
- *Watch your symptoms and results*



Patient's Perspective - Newly Diagnosed

THE TREATMENT PHASE

- *Eat healthy*
- *Be careful with Complementary Approaches – do research, be wary of scams, and discuss supplements with your doctors*
- *Don't ignore your health; continue to get screened, tested, examined for ALL aspects of your health*
- *WM can weaken your immune system – so little infections can become BIG issues – be vigilant!*

Patient's Perspective - Newly Diagnosed *SURVIVORSHIP*





Patient's Perspective - Newly Diagnosed ***SURVIVORSHIP***

- ***Stay in it for the long haul!***
- ***Eat Well / Live Well / Exercise***
- ***Do what you enjoy***
- ***Establish a good relationship with your medical team***
- ***Be proactive and engaged***
- ***Normality is that there will be good days and bad days***
- ***Fatigue and weakness are inevitable***
- ***Rest, but don't let it become routine***



Patient's Perspective - Newly Diagnosed

SURVIVORSHIP

- The “Long Haul” also means that not only will you be mindful of IgM, hemoglobin, WBC’s, RBC’s and other test markers and results, but you’ll be on the lookout for:*
 - Hyperviscosity*
 - Hypogammaglobulinemia*
 - Hemolytic anemia*
 - Cryoglobulinemia*
 - Cold agglutinin disease*
 - Peripheral neuropathy*
 - Bing Neel syndrome*
 - Amyloidosis*
 - Transformation*
 - LPL tumors*



Patient's Perspective - Newly Diagnosed

SURVIVORSHIP

Stay In It For The Long Haul!

- ***Remember: not every ache and pain is your WM***
- ***However, don't ignore chronic, nagging aches and pains!***
- ***Keep up with health checks, screenings, scans, vaccinations, etc.***



Patient's Perspective - Newly Diagnosed

LIVING WITH WM

You NOW have a “cancer card” – use it wisely!

OFFICIAL CANCER CARD

This card certifies that

has the right to avoid heavy lifting, go to the movies,
not do the dishes, hold those closest to them a little
tighter, keep their chin up and pretty much anything
they want as long as they want due to the fact that
they or someone they love is battling cancer.

signature

date

INSERT PICTURE HERE

Patient's Perspective - Newly Diagnosed

Make the most of...

LIVING WITH WM

What WM HAS given you:

- *Time. WM is indolent and not as aggressive as some other forms of cancer.*
 - *YET – don't get "survivor's remorse"*



Patient's Perspective - Newly Diagnosed

LIVING WITH WM

What WM HAS given you:

- *Wisdom – an ability to find joy in both the small and big things in life*
- *Clarity – a stronger awareness that there's no guarantee to how long we'll be here, and a desire to fill that time with joy.*



Patient's Perspective - Newly Diagnosed

LIVING WITH WM

What should you do?

- *LIVE – live well – live happy*
- *Don't sweat the small stuff – or even the big stuff for that matter*
- *Dance naked in the rain on main street – release your tensions and frustrations*
- *Keep a positive perspective; it may not lengthen your life, but it will make the time you have left that much more enjoyable*
- *Stay Vigilant – monitor your own health*

Patient's Perspective - Newly Diagnosed

LIVING WITH WM

- **Pay it Forward!**
 - *Participate in clinical trials*
 - *Volunteer for the IWMMF*
 - *Participate in IWMMF Connect*
 - *Join a Support Group to help others facing WM*
 - *Help others in need*





Patient's Perspective - Newly Diagnosed *DYING*

At some point – we all will die....

- *but..consider....*
- *10 years ago: lifespan = 6-7 years from diagnosis*
- *Today, : lifespan = about 15 years from diagnosis*
- *So, in 2030: lifespan should = 30 years (right?)*
- *Enjoy life – do good for fellow WM'ers – and for others; after all, this is your only chance at living!*