A Patient’s Perspective on Being Newly Diagnosed*

- Peter DeNardis, IWMF 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 (Cytoxan, 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

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
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**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?
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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
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](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
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
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!
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.
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 IWMF
  - Participate in IWMF Connect
  - Join a Support Group to help others facing WM
  - Help others in need
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!