

## When a Young Adult Gets Cancer: From Her Perspective

Valerie Powell

1. What do survivors wish that caregivers knew? What were presenting symptoms?
  - a. Nodule behind ear, no pain, 7 years
  - b. Follow-up, had CT scans, checked on it
  - c. Began working in rad onc in March 2017
  - d. Results came back--took them to rad onc to review
  - e. Nothing showed up--ENT to follow
  - f. Surgery for precaution--July 2017
  - g. Complete parotidectomy
  - h. Dr made rounds--we found more than we thought, suspected malignancy
  - i. Asked lots of questions--shook by diagnosis
2. Final diagnosis, final staging?
  - a. Stage II because of size of tumor
  - b. Typically in men over the age of 40-50
  - c. Adenoid cystic ca is rare--no spread, no nodes
  - d. Stuck to facial nerves
3. Cancer in my own family, shock after diagnosis? Interpretations of docs conversation completely different? Is there a disconnect between caregivers and patients? How can we do better?
  - a. Information will not always be absorbed, due to shock of diagnosis
  - b. Cancer is not always a death sentence
  - c. Resources for coping
  - d. What mattered most was genuine support, take time to listen, empathize, let's you talk about your feelings, have that moment to get out thoughts
  - e. Take a few extra minutes, see where patient is mentally and emotionally
4. What treatment options were presented? Meet with surgeon, what choices were given?
  - a. Adenoid cystic ca is not receptive to chemo
  - b. Radiation or no radiation [surgery only]
  - c. Did not want to lose hair; mother had chemo for breast cancer and she didn't want to go through that process
  - d. Trusted doctors in UAB rad onc department
5. Profound grief at diagnosis? Describe that?
  - a. Shock and fear
  - b. Trying to make sense of things, what is to come
  - c. New emotions
  - d. Future was robbed from her ... feeling like cancer was a death sentence
  - e. Taken long time to understand that she didn't do anything to get cancer and can't control anything to prevent
  - f. Mental and emotional struggle was worse than physical
  - g. Trying to figure out whys--book says trying to figure out why is like playing God
  - h. Stay healthy emotionally and mentally
6. What about radiation? What were treatments like? How did side effects impact you?
  - a. Radiation is harder than you think
  - b. Had to have mouthpiece made---moving tongue out of way

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- c. Immobilization mask
  - d. Simulation was terrifying--aquaplast mask
  - e. Immobilization necessary for precision
  - f. Keep you in same position and protect healthy tissue
  - g. Treatment took about 15-20 minutes
  - h. Memorize movement of machines, smells, noises
  - i. Smell comes at beginning of treatment, taste in mouth
  - j. 2-3 weeks before side effects presented
  - k. Fatigue hit hard, work was difficult
  - l. Week 3-4 started losing taste, sweets became awful tasting
  - m. Week 4--noticed skin toxicity, slough off, gum up
  - n. Ulcers on her tongue [left side]
  - o. Ear was very dry, crusted over, swollen
  - p. Radiation just isn't pleasant
  - q. mucositis , thick saliva, sticky and gooey
7. What does it smell like?? Interesting from patient's perspective. 1.5 years out. What do emotions mean?
- a. Since finding normalcy, different normal
  - b. Trying to connect and be who she was before ... people have different reactions to her now
  - c. People have removed themselves or act differently because they cannot relate
  - d. Introvert, but loves deep conversation
  - e. Further she gets out from treatment, she wants to have long conversations and learn about them
  - f. Or at Wal-Mart or the doctor's office, being more in touch with simple things
  - g. Cancer makes you realize that you are mortal
  - h. People and experiences have become really important
8. What advice would you give to young survivors? What would you tell young cancer survivors?
- a. Attitude and support from people around you
  - b. Faith
  - c. Keep your head strong
  - d. Don't love the word 'fighting', take day at a time
  - e. Learn about yourself, how your process and feel and learn
  - f. Normal reaction is to hide and accept, but there's a better way to deal--reach for stars
  - g. Believe that you are going to be OK, there's more to life to do
  - h. Keep your thoughts positive
  - i. Be forward-looking, move and push towards better day
  - j. Talk about feelings, emotions, attitude
9. Surrounded by support team [family]. What about healthcare team? Radiation therapists were angels. What about support from healthcare team?
- a. Team is also co-workers

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- b. Particularly RTTs and nurses have gone above and beyond
  - c. First 3 weeks felt like there was no end
  - d. Support, she was fragile
  - e. Take extra time with her to talk and listen
  - f. Time is main theme, show that you care
  - g. Attitude and compassion that they provide
  - h. Excited to see patients after treatment
  - i. Placed in her path to take care of her through darkest days of her life
  - j. It meant the world to her to have people who care
10. Faith and prayer? Describe how this experience has affected your faith or how faith affected experience? Coping?
- a. Faith affected how she moved through things and the experience affected her faith
  - b. Faith got her through this, not always strong
  - c. Didn't understand, but rested in right people at the exact right time
  - d. People and timing, details
  - e. Her heart couldn't have handled knowing diagnosis before surgery
  - f. Changed the way she looked at things retrospectively
  - g. This happened, but all these things happened to get to this point
  - h. Knowing that people around her were praying, lifted her, understanding
  - i. Patients have different experiences
  - j. Gotten her through the hardest days, changed her, matured her