Tips and Tricks for Handling Anticipatory Grief
From those who are doing it NOW
To Do:

From Amanda:

1. Build a good support system (weed out toxic people, include safe ones...it's okay if this looks different than you imagined it would)
2. Build a healthy lifestyle...in moderation (exercise, healthy eating...but go for the cake if you need to also!)
3. Sleep and rest are must dos! Schedule "rest" in your daily calendar.
4. Protect your energy-- mind, body and spirit. Say YES to only what truly matters. Everything else is an unapologetic NO. (Spoons of energy example)
5. Seek counseling or outside support to be able to enter into the painful parts of the journey-- Name the pain and be honest with yourself. There is strength in not pretending everything is okay.

From Ginny:

- Be honest with yourself and others;
- Realize not everyone can handle honesty;
- It's OK to mourn the loss of 'what was';
- It's OK to 'wallow' now and then but it's dangerous to stay there;
- Make sure your family and your treatment team know YOUR priorities.

From Ann:

- Priorities are critical. Most of mine involve experiences or family. As my oncologist said in 2009, Cancer is an excellent pruning device. Define your priorities with people, activities, etc and invest your energy there. I can be very intentional with my time and I’ve turned down friends, volunteering, etc.
- Memories— I write post cards from many places we have traveled and keep them in a red box. There are personal notes about things I hope they remember. And, some are aspirational for places I hope they visit one day in their future. I have others help me collect some postcards.
- Mental health and Faith — My faith and church are huge sources of personal peace but so is time on my knees weeding my moss garden. Defining time and outlets for faith, no matter what it looks like for you. Meditation, walks, gardening, prayer, etc.
- Invest in yourself — don’t give it all up. If you wanted to learn yoga, find a class. If quilting is your love, start a new one. If gardening keeps you outdoors and brings pleasure, build a garden. Don’t give up feeding your own interests to help distract and build your own self.
• Be kind to yourself. Don’t beat yourself up over a few pounds gained/lost, gray hair or no hair. Rest when you need it. Mourn the opportunities lost when you need to but balance it with what you do have. I mourn my career but celebrate the time with my daughters.

• Celebrate what makes you happy. Pumpkin season, birthdays, puppies, Groundhog Day, clean scans, etc. There is so much negativity in the world if your legacy is a celebratory party animal — that’s awesome.

• Prune negativity from your life. It’s not adding anything to your longevity and can dampen the quality of your life.

• Mourn. When it looked like we couldn’t have kids, the doc encouraged us to mourn and grieve. It was a good lesson. It’s unlikely I’ll meet my grandchildren and I grieve that but I’m also trying to put away a few words of wisdom and maybe a special baby story I used to tell my girls.

From Abigail:

1. Examine each part of your life and Marie Kondo it – look at it carefully, weigh whether that thing or activity or position or whatever is bringing you joy. If not, chuck it.
2. Listen to your body – if you are pushing yourself today and will pay for it tomorrow, consider whether pushing yourself is worth it.
3. Sit with your feelings and give yourself a time limit with the negative ones. For example, whenever there is bad news, I allow myself to wallow for 24 hours. After that, it’s time to get to work.
4. Learn meditation or some other method of disciplining your mind – we refer to intrusive thoughts as clouds at my yoga studio as we can’t control whether they come to us, but we can control our response and the recommended response is to simply watch them come and then watch them go.
5. Align your life with your priorities and don’t waver.
To NOT do:

From Amanda:

1. Don’t listen to others who remind you to just "be positive all the time!" (I am all for positivity and strive for that, but don’t let it become toxic and minimize what your true feelings are. Toxic positivity is real and so is spiritual whitewashing)
2. Don’t listen to others who say you MUST go see this practitioner or that one. (The advice from others is relentless. You don’t have to heed it if it doesn’t resonate with you)
3. Don’t “Just Google it” (Google is our friend until it is not. Save questions for your doctor. Avoid googling at 2am when you can't sleep!)
4. It’s okay to not listen to people who say: "Oh, my friend did THIS and now she's fine. You must do it this way." (Everyone's journey is unique. Cancer itself is unique. What worked for one doesn’t always work for another.)
5. Don’t listen to others who say: "Just relax. Most women live for years with MBC." (True or not true, not everyone is issued a terminal diagnosis like MBC patients. Yes, death is something we will all face, but MBC patients have a "clock ticking" countdown that others do not have. Additionally, living with MBC is not just about wondering when our last breath may be, it's also about the difficult journey THROUGH. Most people don't realize that because we might not have (yet) lost our hair or we try hard to integrate into a semi-normal lifestyle. This diagnosis is hard for many reasons and others do not understand)

From Ginny:

- Don't put off meaningful conversations;
- As you focus on preparations don't forget to enjoy today;
- no one else can tell you how to do this, don't let them;
- don’t let toxic people steal your joy;
- don't wait to take advantage of services like hospice.

From Ann:

- Don’t feel guilty. Don’t harbor guilt or grief for yourself or others — it only drags you down. Forgive others and self and move onward. And, you couldn’t have changed this diagnosis with diet, exercise or chanting ... cancer doesn’t work that way.

From Abigail:

- Don’t second guess yourself – make the best decision you can with the information you have today and don’t look back.
- Don’t bite your tongue so much -- say what you need to say to those around you.

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• Don’t say No to Time – children spell love “t-i-m-e.” Spend time with those you love, especially those who depend on you.
• Don’t hesitate to do all the things – don’t save a trip or experience for another time.

CHECKLIST FOR LEGACY BOXES

FROM AMANDA:

• Letters;
• Notes;
• Musings from my heart in journals to each of them separately;
• My hope is to write a book--dedicated to them-- with life lessons I've learned along the way.

FROM GINNY:

• I wrote down the things I wanted to say to people when they said something rude or 'off the wall'. As a pastor's wife I had to think carefully about my responses. I've not allowed anyone to read that journal & told my daughter she can read it when I'm gone 😊 then burn it!!

FROM ANN:

Balance is key. I want to plan ahead for my kids but some days it’s too raw or too much. It has taken me multiple trips into hallmark. I want to make sure I’m living in the present as much as possible and not living in fear or preoccupied with the end.

• Memories— I write post cards from many places we have traveled and keep them in a red box. There are personal notes about things I hope they remember. And, some are aspirational for places I hope they visit one day in their future. I have others help me collect some postcards.
• Leaving behind: lots of cards, gifts for graduation, marriage and maybe baby quilts for potential grandkids. I’ve done a video and letter through IOH but want to update this year.
• I’ve also written special girlfriends letters and left a little gift they’d remember me by. And, letters to my siblings and parents.
• I wish I could do photo albums but that is not my talent/skill set so I am trying to get them photo books for each year as it happens and a Christmas ornament to celebrate the year.
• Create Joy.

FROM ABBIGAIL:
Letters for birthdays & other important events*.
Cards for birthdays & other important events*.
Keepsakes from trips
Mementoes such as a silver dollar for the years they each lost their first tooth
*Some suggested important events for Cards …. OPEN WHEN:
  o it’s your graduation;
  o it’s your first day of college;
  o you have your first big exam;
  o before your first big presentation;
  o you are homesick;
  o you need a little extra cash;
  o you’re going to a great party;
  o you need a little parental advice
  o You have a fight with your dad;
  o You have a fight with your brother;
  o you meet someone you love
  o You got accepted into college
  o it’s the first day of Freshman Year,
  o it’s the last day of Senior year
  o it’s your first big breakup
  o you register to vote
  o it’s your college graduation
  o it’s your first professional job
  o you get your first promotion
  o you get your first car
  o you do something you regret
  o you have a headache (hangover?)
  o you move for the first time
  o you move for the second time
  o you move in with someone
  o you are thinking about proposing
  o you get engaged
  o you register for your wedding
  o wedding planning is making you crazy
  o you get married
  o you find out you are going to have a baby
  o you have your first child
  o your kid is driving you crazy
  o you have your second child
  o the kid(s) just won’t stop crying
  o you get your first pet
  o your bankroll is getting tight
  o your child goes to kindergarten
- you have your 10-year High School Reunion
- you want to know more about where you came from
- a grandparent passes away
- you’ve reached a crossroads
- you wonder what you are doing with your life
- you need someone to believe in you