

# What the F\*@%?! Managing Cancer as a Young Adult



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# Defining Young Adults

- Young Adults (YA) are defined as those age 18 to 39 years old at the time of diagnosis
- YAs are in the midst of crucial developmental changes
  - Establishing independence
  - Completing school/entering workforce/advancing in career
  - Finding life partners
  - Family building
  - May have limited income/health insurance
  - Limited experience with health system
  - Many major life decisions made during this time (Nass et al., 2015)



# Important Issues for Young Adults with Cancer

- Managing Medical Treatments & Decision-Making
- Insurance Coverage/Finances
- Late/Long-Term Effects of Treatment & Impact on Future Plans
- Emotional Well-Being & Mental Health
- Fertility
- Sexual Health
- Connecting with Other Young Adult Cancer Survivors
- Career/Education
- Body Image/Self Esteem
- Nutrition & Exercise
- Managing Relationships with Friends
- Family Dynamics

*Adapted from Nass et al., 2015*



# Managing Medical Treatments & Decision-Making

- **Social Workers and Patient Navigators** can help patients make sense of treatment options and help them come up with questions to ask their doctors.
- **Resources:**
  - Critical Mass: <https://criticalmass.org/in-treatment/>
  - Cancer Support Community: <https://www.cancersupportcommunity.org/>
  - chemoWave App - <http://chemowave.com/>
  - NCI: <https://www.cancer.gov/about-cancer/treatment>
  - NCI: <https://www.cancer.gov/about-cancer/managing-care>
  - ACS: <https://www.cancer.org/treatment.html>
  - ASCO: <https://www.cancer.net/navigating-cancer-care/managing-your-care>
  - Cancer Care: <https://www.cancercare.org/diagnosis>



# Insurance Coverage/Financial

- **Financial Counselors** can discuss insurance concerns, health care costs, and financial assistance options.
- **Patient Navigators** can discuss options that may resolve barriers such as transportation and child care.
- **Social Workers** can discuss how to apply for disability benefits or unemployment. They can also address the psychosocial distress that can accompany insurance or financial concerns.
- **Resources:**
  - Triage Cancer
    - Financial: <http://trriagecancer.org/financial>
    - Insurance: <http://trriagecancer.org/healthinsurance>
  - The Samfund: <http://www.thesamfund.org/>
  - Cancer Finances: <https://cancerfinances.org/>
  - Patient Advocate Foundation: <http://www.patientadvocate.org/>
  - Cancer Support Community
    - Insurance Checklist: <https://www.cancersupportcommunity.org/cancer-insurance-checklist>
    - Managing Cost of Care <https://www.cancersupportcommunity.org/managing-cost-cancer-treatment>



# Late/Long-Term Effects of Treatment

- **Survivorship plans** should include screenings, surveillance, and prevention based on the risks associated with their cancer diagnosis, treatments, comorbid health conditions, genetic predispositions, and lifestyle.
- Resources to look for:
  - Survivorship Clinic
  - Oncologic Dermatology
  - Physical, Occupational, Speech, & Lymphedema Therapies
  - Neurology
  - Sexual Health
  - Reproductive Health



# Emotional Well-Being & Mental Health

- Waiting for the other shoe to drop
  - Persistent anxiety and distress regarding possible recurrence, late effects, and death
  - **Therapist/Social Worker** can help these process their cancer journey through counseling and supportive resources
- Young adult patients have the capability for significant resilience:
  - Find a Therapist - <https://www.psychologytoday.com/us/therapists>
  - more gratitude for life,
  - mature more quickly,
  - **Support Groups**,
  - emotionally better prepared to handle the challenges of every day life

Zebrack, B. J. (2011). Psychological, Social, and Behavioral issues for young adults with cancer. *Cancer*, 117(10), 2289–94. doi: 10.1002/cncr.26056



# Connecting with Other Young Adult Cancer Survivors

- Social isolation and feelings of loneliness are pervasive among Young Adult cancer patients/survivors

*“Cancer is isolating. Finding others who are going through the same thing is a HUGE help to most people. I felt like I could talk to my peers and ask them questions (even medical questions) that I was afraid to ask my doctor or that I felt my doctor wouldn't know the answers to. I feel like I spoke way more about [treatment side effects] to my peers than my doctor. Often when I asked my doctor if a certain side effect was from my treatment, they would say, "I don't know" or "it isn't in the literature". But with my peers they would say, "YES I experience that too!" and it would make me feel less like things were wrong and more like they were normal.”*

*- Young Adult Patient*



# Connecting with Other Young Adult Cancer Survivors

- Connect Young Adults to online and in person programs that connect them to other young adult cancer survivors
- **Online Resources:**
  - Stupid Cancer App and Online Forum  
[www.stupidcancer.org](http://www.stupidcancer.org)
  - Lacuna Loft  
[www.lacunaloft.org](http://www.lacunaloft.org)
  - CancerCare Young Adult Groups  
[www.cancercare.org/support\\_groups](http://www.cancercare.org/support_groups)
  - Imerman Angels Peer Mentors  
[www.imermanangels.org](http://www.imermanangels.org)



# Fertility & Family Building

- **Consult** with a sexual health and fertility specialist so you can be educated on assistive reproductive technologies available as soon as possible.
- **Therapist/Social Worker** can help process and cope with the emotional burden of potential infertility and changes in future plans. Can also find resources such as support groups, therapists, and other supportive services.
- **Resources:**
  - Support Groups
    - RESOLVE: <https://resolve.org/>
  - LIVEStrong Fertility: <https://www.livestrong.org/we-can-help/livestrong-fertility>
  - Oncofertility Consortium: <https://oncofertility.northwestern.edu/>
  - Alliance for Fertility Preservation: <http://www.allianceforfertilitypreservation.org>
  - Fertility Clinic



# Sexual Health

- Changes in sexual functioning can be caused by the cancer, the treatment, or associated psychological distress -- irrespective of age, sex, and type of cancer. (Gupta et al., 2016)
- One study found that 53% of young adults aged 18 to 39 report some degree of sexual dysfunction 2 years after initial cancer diagnosis. (Acquati et al., 2018)

Gupta et al. (2016). Reimagining care for adolescent and young adult cancer programs: Moving with the times. *Cancer*, 122(7), 1038-46. doi: 10.1002/cncr.29834

Acquati et al. (2018). Sexual functioning among young adult cancer patients: A 2-year longitudinal study. *Cancer*, 124, 398-405. doi: 10.1002/cncr.31030



# Sexual Health Resources

- Sexual Health Physicians
- Pelvic Floor Physiotherapist
- MonaLisa Touch
- Moisturize!
  
- **Other Resources**
  - Will2Love: <https://www.will2love.com/>
  - Young Survival Coalition (breast cancer): <https://www.youngsurvival.org>
  - A Woman's Touch Sexuality Resources: <https://sexualityresources.com/>
  - Books: Women Cancer Sex & Man Cancer Sex by Dr. Anne Katz  
<http://www.drannekatz.com/books>



# Career/Education

- Ability to perform mental or physical tasks and overall productivity at work can be affected by diagnosis and/or treatment.
- **Discuss** your goals and needs related to work and accommodations with your physician. Social Workers, Patient Navigators, and Nursing team can help facilitate communication between patient, provider, and employer.
- **Resources**
  - Cancer + Careers: [www.cancerandcareers.org/](http://www.cancerandcareers.org/)
  - Triage Cancer: [www.triagecancer.org](http://www.triagecancer.org)



# Body Image/Self Esteem

- Some research studies suggest that cancer patients and survivors feel negatively about their own sexuality and attractiveness, and that some feel that the self they previously identified as has been lost and replaced with that of a cancer patient. (10)
- **This is NORMAL**
- **Therapist/Social Worker** can help identify, process through, and cope with these changes.
- **Support Groups** are a great way for to talk with other survivors about these concerns.
- **Resources:**
  - Look Good, Feel Better - <http://lookgoodfeelbetter.org>
  - Sephora - <https://m.sephora.com/beauty-classes>
  - Lacuna Loft - <https://lacunaloft.org/>
  - Cancer.net - <https://www.cancer.net/navigating-cancer-care/young-adults/cancer-and-your-body>



# Nutrition & Exercise

- Lifestyle interventions can lower risk of cancer recurrence, new cancers, and chronic conditions.
  - healthy diet, regular physical activity, and tobacco & substance abuse reduction
    - **Nutrition**
      - Cancer Center Dietician
      - American Institute for Cancer Research [www.aicr.org/](http://www.aicr.org/)
      - PearlPoint Nutrition Consultation [pearlpoint.org/nutritionconsult/](http://pearlpoint.org/nutritionconsult/)
      - Cancer Fighting Kitchen [www.rebeccakatz.com](http://www.rebeccakatz.com)
      - NCCN Nutrition for Cancer Survivors [www.nccn.org/patients/resources/life\\_after\\_cancer/nutrition.aspx](http://www.nccn.org/patients/resources/life_after_cancer/nutrition.aspx)
    - **Exercise**
      - 2Unstoppable [2unstoppable.org](http://2unstoppable.org)
      - Cancer to 5K [www.cancerto5k.org](http://www.cancerto5k.org)
      - First Descents [firstdescents.org](http://firstdescents.org)
      - Project Koru [www.projectkoru.org](http://www.projectkoru.org)
      - True North Treks [www.truenorthtreks.org](http://www.truenorthtreks.org)



# Managing Relationships with Friends

- **Resources:**

- Why is She Acting So Weird?: A Guide to Cultivating Closeness When A Friend is in Crisis by Jenn McRobbie
- CaringBridge.org
- LotsaHelpingHands.com
- MealTrain.org
- MyLifeline.org
- Tyze.com
- PostHope.org
- CaringVillage.com
- GiveForward.org



# Family Dynamics

- Create a support network within your identified family if possible.
- Encourage your caregivers to create their own support network as well.
- Resources
  - For Kids
    - Talking to your kids: <https://www.cancercare.org/tagged/children>
    - Resources for kids: [https://www.cancercare.org/publications/210-support resources for children and teens](https://www.cancercare.org/publications/210-support%20resources%20for%20children%20and%20teens)
  - For Caregivers
    - Publications: <https://www.cancercare.org/publications/tagged/caregiving>
    - Online Support Groups - <https://www.cancercare.org/tagged/caregiving> (YA caregiver group)
    - Mentors - <https://imermanangels.org/>



# References

1. Acquati, C., Zebrack, B. J., Faul, A. C., Embry, L., Aguilar, C., Block, R., ... Cole, S. (2018). Sexual functioning among young adult cancer patients: A 2-year longitudinal study. *Cancer, 124*, 398-405. doi: 10.1002/cncr.31030
2. Benedict, C., Shuk, E., & Ford, J. S. (2016). Fertility Issues in Adolescent and Young Adult Cancer Survivors. *Journal of Adolescent and Young Adult Oncology, 5*(1), 48-57. doi: 10.1089/jayao.2015.0024
3. Cheung, C. K., & Zebrack, B. (2016). What do adolescents and young adults want from cancer resources? Insights from a Delphi panel of AYA patients. *Supportive Care in Cancer, 25*(1), 119–126. doi: 10.1007/s00520-016-3396-7
4. Gupta, A. A., Papadakos, J. K., Jones, J. M., Amin, L., Chang, E. K., Korenblum, C., ... Giuliani, M. E. (2016). Reimagining care for adolescent and young adult cancer programs: Moving with the times. *Cancer, 122*(7), 1038-46. doi: 10.1002/cncr.29834
5. Iannarino, N. T., Scott, A. M., & Shaunfield, S. L. (2017). Normative social support in young adult cancer survivors. *Qualitative Health Research, 27*(2), 271-284. doi: 10.1177/1049732315627645
6. Nass, S., Beaupin, L. K., Demark-Wahnefried, W., Fasciano, K., Ganz, P., Hayes-Lattin, B., Hudson, M. M., ... Smith, A. W. (2015). Identifying and addressing the needs of adolescents and young adults with cancer: Summary of an Institute of Medicine workshop. *The Oncologist, 20*(2), 186–195. doi: 10.1634/theoncologist.2014-0265
7. National Comprehensive Cancer Network. (2017). *Adolescent and young adult (AYA) oncology*. (Version 1.2018). Retrieved from [https://www.nccn.org/professionals/physician\\_gls/pdf/aya.pdf](https://www.nccn.org/professionals/physician_gls/pdf/aya.pdf)
8. Richter, D., Koehler, M., Friedrich, M., Hilgendorf, I., Mehnert, A., Weibflog, G. (2015). Psychosocial interventions for adolescents and young adult cancer patients: A systematic review and meta-analysis. *Critical Reviews in Hematology/Oncology, 95*(3):370-86. doi: 10.1016/j.critrevonc.2015.04.003
9. Sansom-Daly, U. M., Lin, M., Robertson, E. G., Wakefield, C. E., McGill, B. C., Girgis, A., & Cohn, R. J. (2016). Health literacy in adolescents and young adults: An updated review. *Journal of Adolescent and Young Adult Oncology, 5*(2), 106-118. doi: 10.1089/jayao.2015.0059
10. Zebrack, B. J. (2011). Psychological, Social, and Behavioral issues for young adults with cancer. *Cancer, 117*(10), 2289–94. doi: 10.1002/cncr.26056
11. Zebrack, B., Bleyer, A., Albritton, K., Medearis, S. & Tang, J. (2006). Assessing the health care needs of adolescent and young adult cancer patients and survivors. *Cancer, 107*(12) 2915–2923. doi: 10.1002/cncr.22338



# Questions/Feedback

