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# Development of a AYA Team: Ensuring Age-Appropriate Cancer Care for Adolescents and Young Adults.

Donna Colabroy RN, MSN, OCN, CCM  
*Lehigh Valley Health Network, Donna\_M.Colabroy@lvhn.org*

Melissa Kratz RN, MSN, AOCN  
*Lehigh Valley Health Network, Melissa.Kratz@lvhn.org*

Amber Messinger BSW  
*Lehigh Valley Health Network, Amber.Messinger@lvhn.org*

Rose Schenk MSN

Elizabeth Rohn MSS, LCSW, OSW-C, PhD  
*Lehigh Valley Health Network, Elizabeth\_B.Rohn@lvhn.org*

*See next page for additional authors*

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**Authors**

Donna Colabroy RN, MSN, OCN, CCM; Melissa Kratz RN, MSN, AOCN; Amber Messinger BSW; Rose Schenk MSN; Elizabeth Rohn MSS, LCSW, OSW-C, PhD; and Mandy Hendricks RN MSN OCN



# Development of a AYA Team: Ensuring Age-Appropriate Cancer Care for Adolescents and Young Adults

Donna Colabroy RN, MSN, CCM, AOCNS; Melissa Kratz, RN, MSN, AOCNS; Amber Messinger, BSW; Rose Schenk, MSN; Elizabeth Rohn, MSS, LCSW, OSW-C, PhD and Mandy Hendricks, RN, MSN, AOCNS  
Lehigh Valley Health Network, Allentown, Pennsylvania

## Significance and Background

- Adolescents and Young Adults (AYA's) with cancer are a distinct patient group.
- Care management needs for the AYA patient fall between the family-centered pediatric approach, and a disease-centered adult paradigm
- Poorer overall survival trends are demonstrated in AYA patients with cancer compared to older and younger age groups.
- Factors implicated in lagging survival statistics include: inadequate access to care, lack of insurance, delays in diagnosis and treatment, lack of psychosocial support and follow-up care
- A multidisciplinary group of oncology professionals at the Lehigh Valley Health Network (LVHN) addressed the age-related needs of AYA's with cancer by developing processes to facilitate access to care, clinical trials, financial services, fertility counseling, and psychosocial support and survivorship resources

## Purpose

To develop an age-appropriate approach to patient care and management of adolescents and young adults (AYA's) with cancer.

## Interventions

- A core group of oncology certified nurses, social workers, clinical trials nurses, financial specialists and an oncology counselor developed three algorithms to delineate processes for AYA patient assessment, referrals, and interventions
- Streamlined instructions direct implementation of appropriate patient measures which can include: a fertility consult request, financial services referral, interventions for psychosocial/ behavioral concerns and others.
- A resource listing of supplemental patient support and survivorship/respite services was also created.
- Oncology clinical nurse specialists also developed a CE accredited educational offering and provided instruction in the office, infusion and radiation oncology settings to facilitate application of the process algorithms and use of the resource listing.

## Evaluation

- In the 18 months since the development of the AYA Team 47% of patients presented at Adolescent & Young Adult (AYA) Tumor Board have been consented to clinical trials.
- Eighty eight referrals have been made to fertility preservation, social work, counseling and financial services.
- Oncology nursing staff has reported increased knowledge of AYA needs and LVHN resources available for assistance as a result of educational initiatives.

## Discussion/Innovation

Delivering quality cancer care for the adolescent and young adult (AYA) is facilitated when the multidisciplinary team has increased awareness of the age-related needs of this special population.

## AYA Resource List

- Addresses AYA - specific needs
- Provides short descriptions & links to organizations that provide assistance for:
  - SSI/SSD, Medicaid
  - Peer support
  - Financial Assistance
  - Fertility Services
  - Camps, Vacations, Retreats & more
- Is a resource for staff

**AYA Resource List: For Young Adults with Cancer**

- SSI/SSD, Medicaid Information
- Vacation & Respite Programs
- Peer Support Groups
- Financial Assistance
- Fertility Services
- Camp & Retreat programs
- Transportation Assistance Programs
- Age-appropriate information re: cancer, treatment options, & potential side effects
- Psychosocial support & behavioral services
- Miscellaneous

**1. SSI/SSD, Medicaid Information:**

**Process for Applying for Social Security & Pennsylvania Medical Assistance:**

- The client & adult patient is responsible for contact. Social Security by phone (1-800-772-1223) at the first patient contact with the social worker.
- If the patient is less than 28 yrs, the pediatric social worker completes the application with the parent.
- If the patient has a prior work history, it is recommended that they apply for both Social Security Disability (SSD) and Social Security Insurance (SSI). This occurs at the first phone call. The patient should then be scheduled by Social Security for a second follow-up phone call.
- During second phone call with Social Security an interview will be conducted where details of the patient's diagnosis and work history will be requested. The social worker advises the patient what to prepare.
- While waiting for the second Social Security phone call, the patient is also encouraged to apply for Pennsylvania Medical Assistance. This also applies to patients who have primary insurance, as long as expenses may be covered by the primary insurer.
- Application for Pennsylvania Medical Assistance can be done online through PA Compass (<https://www.compass.state.pa.us/Compass/Welcome/Compass.asp>)
- When the patient has a confirmed file number with PA Compass, the social worker sends a letter with medical documentation of the patient's diagnosis. The social worker also sends any bills the patient has received with the letter. Once the patient has qualified for medical assistance, the social worker requests retroactive reimbursement of the date of diagnosis.

### AYA Algorithm

### Fertility Considerations Associated with Cancer Treatment

### AYA Psychosocial/Behavioral Considerations

### AYA Psychosocial/Behavioral Considerations

