Adolescent and Young Adult Cancer Awareness Social Media Toolkit







Adolescent and Young Adult Cancer Awareness Social Media Toolkit April 2021

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Tip: Viewing this PDF in Google Chrome? Use "Ctrl+Click" on links to open them in a new tab.

This work was supported by Cooperative Agreement #NU58DP006461-03 from the Centers for Disease Control and Prevention (CDC). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of CDC.

ABOUT THIS TOOLKIT

This toolkit is designed to help stakeholders implement evidence-based practices when communicating about adolescent and young adult cancer. It can be used throughout the year or for specific health observances like National Young Adult Cancer Awareness Week in April, National Cancer Survivors Day in June, or back-to-school in the fall.

Don't have the time or capacity to implement this toolkit? Don't fret!
You can still engage your audience by retweeting messages from
abcurrenger: actual color: a

WHO SHOULD USE THIS TOOLKIT?

Public health professionals, cancer control professionals, cancer centers, coalitions, community-based organizations and other stakeholders can use this toolkit and adapt its messaging for their unique audiences and areas of expertise.

SOCIAL MEDIA 101

This toolkit offers recommended posts for <u>Facebook</u>, <u>Twitter</u>, and <u>LinkedIn</u>. For information about social media platforms, key terms, and strategies to promote health observances using social media, please review the social media guide available at http://bit.ly/GWCCSMTKs.

ABOUT ADOLESCENT AND YOUNG ADULT CANCER

Over 89,000 adolescents and young adults (AYA) are diagnosed with cancer every year in the United States (National Cancer Institute, 2020). AYA typically refers to patients 15 to 39 years old (Burkart et al., 2019). The Centers for Disease Control and Prevention (CDC) reports that cancer is a leading cause of disease-related

death for this age group (CDC, 2015). In addition, the economic burden of cancer survivorship is particularly significant for AYA survivors; the average excess economic burden placed on a cancer survivor is estimated to be over \$16,000 per year (Guy et al., 2013). While insurance protections in the Patient Protection and Affordable Care Act (ACA) increased insurance coverage rates among young adults diagnosed with cancer between the ages of 18-25, uncertainties in the future of the ACA may contribute to financial distress for AYAs diagnosed with cancer (Parsons et al., 2017).

Until recently, AYA patients with cancer and survivors were not considered a distinct demographic group, and were often lumped together with childhood or older adult patients with cancer and survivors. Improvements in outcomes for AYA patients with cancer are being seen, yet inequities in survival within this population still exist. There are calls for continued

focus on improving care and outcomes for AYA individuals with cancer and survivors (Close et al., 2019). With over 90% of adults ages 18-29 using social networking sites, social media can be an effective way to reach AYA patients, survivors and their families (Perales, Drake, Pemmaraju & Wood, 2016). Diverse channels of communication, like Instagram, Twitter, and other social media channels can also be effective ways to reach an AYA audience (Cheung & Zebrack, 2017).

BEST PRACTICES FOR COMMUNICATING ABOUT ADOLESCENT AND YOUNG ADULT CANCER

AYA survivors have distinct needs that are different from those of childhood cancer survivors and older survivors. Limited awareness of AYA risk, treatment, and other unique care needs hampers research, education, and communication efforts tailored to this population (U.S. Department of Health and Human Services (HHS) & LIVESTRONG Young Adult Alliance, 2006). Raising awareness about AYA cancer issues is a first step toward increasing national focus and resource allocation to address gaps in care (Johnson, 2013). Spread the word about AYA cancer issues to educate and inform your audience.

Your organization's communication efforts can be most effective when they:

- Treat AYA survivors as a distinct group with unique needs
- Acknowledge and address psychosocial support needs
- Emphasize survivorship follow-up and resources
- Promote quality physician training to support AYA survivors
- Refer AYA patients with cancer to clinical trials

MESSAGES SHOULD...

1. Treat AYA survivors as a distinct group with unique needs

- **Promote resources that address these unique concerns.** Some of the issues that are particularly salient for AYA patients are self-esteem and identity development, returning to normalcy, psychological distress, psychosexual identity, and fertility, financial strain, and insurance concerns (Warner et al., 2016; Shay, Parsons & Vernon, 2017; Hydeman et al., 2019; Elsbernd et al., 2019).
- Emphasize peer support groups, whether online, via telephone, or in-person, to
 meet this need. AYAs use in-person groups, social media, and online forums to
 exchange support, cope with emotions, describe their experiences, and establish their
 identity as a member of the community (Penn & Kuperberg, 2018). Make sure to
 emphasize COVID-19 safety and social distancing precautions if promoting in-person
 support groups.
- Highlight resources that increase awareness of job protections and information that support AYA survivors returning to work. Many AYA survivors report cancer's negative impact on their ability to work and may not be aware of legal and

- employment protections available to them (Scardaville et al., 2019; Warner et al., 2016).
- If it is possible to do so, sponsor informal social activities such as meet-ups and retreats while adhering to COVID-19 safety and social distancing guidelines.
 Group gatherings can help promote a healthy lifestyle and reduce stress for AYA survivors (Penn & Kuperberg, 2018).

2. Acknowledge and address psychosocial support needs

- Educate patients about how to obtain psychosocial support and other services. Survivors who report any psychosocial care are more likely to report satisfaction with how their needs are met (Forsythe et al., 2013). Despite this fact, over 50% of survivors report not receiving this form of care (Forsythe et al. 2013).
- Refer patients to psychosocial support services throughout the continuum of care. AYA patients experience high levels of distress at diagnosis and when they transition to survivorship. AYAs also experience poorer health-related quality of life compared to AYAs who have not received a cancer diagnosis (Burkart et al., 2019).
- Focus on AYA-specific concerns, such as vocational rehabilitation, social reintegration, and involvement. Psychosocial interventions should "include programmatic components that alleviate distress, but also promote potential for positive growth and successful achievement of normative developmental tasks" (Zebrack, Kent, Keegan, Kato & Smith, 2014, p. 8).
- Encourage survivors to take part in activities that restore a sense of normalcy to life whenever possible (Penn & Kuperberg, 2018).

3. Emphasize survivorship follow-up and resources

- Inform patients that they can ask their doctor or other health care professional about survivorship care plans. Having a written survivorship care plan may help address specific AYA cancer survivors' needs. (Shay, Parsons & Vernon, 2017; Hydeman et al., 2019).
- Make sure patients are provided with information about their treatment as well as their practical follow-up care needs. AYA cancer survivors have expressed needing information to address concerns around late-effects of treatment, recurrence, fertility, physical and psychosocial effects of treatment, follow-up care, and financial toxicity (Shay, Parsons & Vernon, 2017; Hydeman et al., 2019; Elsbernd et al., 2019).
- **Tailor resources for your audience.** AYA survivors want resources and support for their age group (Cheung & Zebrack, 2017).
- Provide patients with resources on financial assistance. Survivorship care can
 include more than just treatment effects and screening recommendations. It can also
 include information about managing long-term financial toxicity (Cheung & Zebrack,
 2017).

4. Promote quality physician training to support AYA survivors

- Educate primary care providers about the unique needs of AYA survivors.

 "Providers caring for AYA patients at diagnosis through survivorship must keep abreast of the evolving AYA literature and guidelines and, most importantly, have the common goal of improving the health and quality of life for AYA patients through survivorship and survivorship care" (Burkart et al., 2019, p.7).
- Ensure that providers are aware of and are up-to-date on appropriate clinical trials that may benefit their AYA patients. AYA cancer treatment is evolving and clinical trials are becoming more available (Burkart et al., 2019; Close et al., 2019).
- Provide targeted information on modifiable risk factors to reduce cancer risk and collaborate with other health providers to support behavior change (Burkart et al., 2019). AYA cancer survivors are likely to smoke the same amount and have the same level of physical activity as those who have no history of cancer (Burkart et al., 2019).
- Remind providers about the unique needs of AYAs and encourage specialized training to meet these needs. Age-based cancer care can support developmental milestones during adolescence and young adulthood (Close et al., 2019).
- Ask patients who should be involved in decision-making and make every effort to honor those requests. Parents, family members, or caregivers involved in care decisions may be important for some AYA patients (Siembida et al., 2020).

5. Refer AYA patients with cancer to clinical trials

- Refer AYA patients with cancer to centers that offer clinical trials. AYAs have seen some gains in clinical trial enrollment compared to younger or older patients with cancer, but disparities still exist (Parsons et al., 2019; Close et al., 2019). Clinical trials for adolescents with cancer are available at the Children's Oncology Group (COG) member institutions.
- Refer adolescents with cancer to COG member institutions, when possible, to increase access and enrollment in clinical trials for this population.
- Improve AYA enrollment in clinical trials. Research shows that decreased enrollment in clinical trials is an important factor in AYA patients with cancer having lower cancer cure rates than patients in other age groups (Shaw, Hayes-Lattin, Johnson & Bleyer, 2014).
- Educate stakeholders about the importance of increasing clinical trial availability for AYA patients. Increase the number of clinical trials available to AYA patients with cancer (Siembida et al., 2020; Close et al., 2019; Fern & Taylor, 2018).
- A variety of barriers and facilitators can affect an AYA's decision to enroll and adhere
 to clinical trials. Address barriers to clinical trials by: 1) establishing a trusted
 patient-provider relationship, 2) having a provider recommend clinical trials,
 ideally with support from a nurse navigator, 3) balancing autonomy and
 dependency in decision making and 4) making sure consent forms are clear and
 meet the needs of AYA patients (Siembida et al., 2020, Fern & Taylor, 2018).



Tip: These correspond to the strategies above.



Tweets	Facebook Posts	Message Category
#DYK over 89,000 adolescents & young adults are diagnosed w/ #cancer each year in the U.S.? Learn more about #AYAcancer: http://bit.ly/2FAwpGP	Over 89,000 adolescents and young adults are diagnosed with cancer every year in the United States. Learn more here: http://bit.ly/2FAwpGP	1
#AYAcancer survivors have unique needs & concerns, like fertility, financial issues & social support. @CancerCare has resources to help: http://bit.ly/2DRGXEM	Adolescent and young adult cancer survivors have unique needs, from fertility issues to financial concerns—thus, ageappropriate content is critical. These resources from CancerCare can help: http://bit.ly/2DRGXEM	1,2
Age-appropriate resources are critical for #AYAcancer survivors. These from @LLSusa can help: http://bit.ly/2BIW4L7	Did you know that many adolescent and young adult cancer survivors report a lack of age-appropriate resources? This list from the Leukemia and Lymphoma Society can help: http://bit.ly/2BIW4L7	1,3
#BreastCancer is one of the most common #cancers in women 25-39. Learn more from @YSCBuzz: http://bit.ly/2DANeob	Did you know that breast cancer is one of the most commonly diagnosed cancers among 25- to 39-year-olds? Young Survival Coalition has more information: http://bit.ly/2DANeob	3
You may have heard about BRCA genetic testing—but could it be right for you? Learn from Amy's story & talk w/your doc: http://bit.ly/2n6UXQy #BringYourBrave	"Cancer runs in Amy's family: her grandmother had both breast and ovarian cancer, and encouraged her family to learn about their risk." Learn more about genetic testing for BRCA gene mutations from Amy's story and talk to your doc about whether it's right for you: http://bit.ly/2n6UXQy	4,5
This video from @theNCI covers what adolescents & young adults need to know after a #cancer diagnosis: http://bit.ly/2DJnKUU #AYAcancer	What do adolescents and young adults need to know after a cancer diagnosis? This video from the National Cancer Institute covers the basics. Number one? You're not alone: http://bit.ly/2DJnKUU	2,3

Tweets	Facebook Posts	Message Category
Janna was 32 when she was diagnosed w/#cervicalcancer. Her advice? Regular checkups can save your life: http://bit.ly/2N3ifaj #AYAcancer	"I was scared and angry when I received my diagnosis, but I decided to face it head on." Janna was just 32 when she was diagnosed with cervical cancer. Her advice? Take your regular OB/GYN appointments seriously—it could just save your life: http://bit.ly/2N3ifaj	4
Looking for work during or after #cancer treatment can seem daunting, but @CancerAndCareer's resume review service can help you move forward: http://bit.ly/2GfDZrw	Do you have questions about looking for work after a cancer diagnosis? Cancer and Career's resume review service can help polish your resume, answer your questions, and build your confidence: http://bit.ly/2GfDZrw	2,3
Looking to find other young adult #BreastCancer survivors? @YSCBuzz has you covered: http://bit.ly/2F7BO7V	Young Survival Coalition connects young adult breast cancer survivors. Gain perspective and insights from stories about survivors just like you: http://bit.ly/2F7BO7V	1,2,3
Treatment side effects can impact you at work. These tips from @CancerAndCareer can help you cope: http://bit.ly/2rBqn6r #youngadultcancer	"Cancer can drain you physically and mentally, but there are ways to bolster your inner reserves. Specially tailored food and fitness plans can ward off fatigue and other side effects. Plus, there's your psyche – the most important weapon in your arsenal against the disease." Read on: http://bit.ly/2rBqn6r	2,4
You're not alone. @theNCI has tips for confronting some of the challenges of #AYAcancer: http://bit.ly/2FAwpGP	A cancer diagnosis as an adolescent or young adult can leave you feeling alone, but this info from the National Cancer Institute can help you find support: http://bit.ly/2FAwpGP	1,2
Looking for a support group to meet others dealing w/#AYAcancer? @StupidCancer has you covered: http://bit.ly/2E7ppBA	Hanging out with other adolescent or young adult cancer survivors can make you feel less alone. Stupid Cancer can help you locate a support group in your area: http://bit.ly/2E7ppBA	1,2

Tweets	Facebook Posts	Message Category
Eating well & getting active are especially important for #AYAcancer survivors. Get started today w/these resources from @AmericanCancer: http://bit.ly/2rCCUXm	Taking the first steps toward eating healthy and getting active can seem overwhelming, especially if you're a cancer survivor. But don't worry, the American Cancer Society has resources to get you started on the path to wellness: http://bit.ly/2rCCUXm	3
#Cancer is something you should never have to face alone. @StupidCancer has resources that can help you connect & get support: https://bit.ly/2wMMH0p	Facing a cancer diagnosis in the prime of life can bring up a lot of emotions and fear. Stupid Cancer has a number of ways to help you process these feelings by finding others who understand what you're going through. Learn more: https://bit.ly/2wMMH0p	1,2,3
#AYAcancer treatment comes w/a lot of questions. Questions from @ulmanfoundation can help you talk with your doc: https://bit.ly/2KbJGJU	Going through cancer treatment as an adolescent or young adult can seem overwhelming. These questions from the Ulman Cancer Foundation can help you organize your care by asking the right questions with your care team: https://bit.ly/2KbJGJU	4
#DYK adolescents and young adults w/ #cancer have unique needs? @NCCNnews has a resource guide for patients: https://bit.ly/3crXNad	Adolescents and young adults (AYAs) with cancer are often lumped in with pediatric patients or older adults, but they have unique needs. This guide can help AYA patients take charge of their care: https://bit.ly/3crXNad	1
Thinking about joining a #cancer clinical trial? Check out this guide from @theNCI to help you take the first steps: http://bit.ly/2msvYo4	Thinking about joining a cancer clinical trial? This guide from the National Cancer Institute can help you learn how to search for clinical trials and decide which one may be right for you: http://bit.ly/2msvYo4	5

Tweets	Facebook Posts	Message Category
Looking to find clinical trials for adolescents with #cancer? Visit the Children's Oncology Group to find #clinicaltrials for this population: https://bit.ly/3gD9T35	Clinical trials for adolescent patients with cancer are available at the Children's Oncology Group (COG) member institutions. Visit COG to find clinical trials for this population: https://bit.ly/3gD9T35	5
What's being done to close the gap & improve #AYAcancer care? This update and next steps aim to keep moving the conversation forward: https://bit.ly/3asfdC1	Adolescent and young adult cancer survivors haven't seen the same gains in treatment and care as other groups. This report provides next steps to close the gap: https://bit.ly/3asfdC1	1,4
Should you join a #clinicaltrial? Watch this short video from @theNCI which explains possible benefits of participating in a trial: https://bit.ly/2xDLEjV	Clinical trials can be a valuable opportunity for patients with cancer, but there's a lot of misinformation out there. This short video from the National Cancer Institute explains benefits of participating in a trial and next steps you can take: https://bit.ly/2xDLEjV	5
Health insurance can be a major concern for #AYAcancer survivors. @TriageCancer can help: https://bit.ly/2xVyE9j	Worried about health insurance after a cancer diagnosis? Triage Cancer has you covered with health insurance resources and practical advice: https://bit.ly/2xVyE9j	3
#Healthcare professionals: Adolescents & young adults affected by #cancer have unique care needs. Learn more from @NCCNnews: http://bit.ly/2DGrtCN	Healthcare professionals: Did you know the National Comprehensive Cancer Network has guidelines on caring for adolescents and young adults with cancer? Create a free account to access: http://bit.ly/2DGrtCN	1

Tweets	Facebook Posts	Message Category
What are #clinicaltrials? Why are they important for #AYA #cancer patients? Watch this quick video from @theNCI about clinical trials: https://bit.ly/2VoU2wD	Cancer clinical trials are at the heart of delivering breakthrough treatments to patients and saving lives. However, trials need more young adult patients with cancer to participate in them. This short video from the National Cancer Institute aims to spread the word about clinical trials: https://bit.ly/2VoU2wD	5
Finding out you have #cancer is overwhelming at any age, but especially if you're young. This resource directory from @ulmanfoundation can help address your concerns and get you connected: https://bit.ly/3bv9M70	"You're looking for help, and we want to help you find it." This resource directory from the Ulman Foundation covers everything from financial aid to fertility preservation: https://bit.ly/3bv9M70	1,2
Young women w/#BreastCancer have unique concerns. #YSCBuzz has meet up groups just for you: http://bit.ly/2Brl4WM	Local Young Survival Coalition's Face 2 Face networks are support and social networks that bring together young women at all stages of a breast cancer diagnosis, treatment, or recovery, to learn from each other: http://bit.ly/2Brl4WM	1,3
#AYAcancer survivors have unique concerns when it comes to the sexual impacts of #cancer. This paper can help clinicians address these important needs: http://bit.ly/2GgAd10	Healthcare professionals: Adolescents and young adult cancer survivors have unique needs when it comes to the sexual impacts of cancer. This paper for clinicians can help assess and treat these concerns: http://bit.ly/2GgAd10	1,4
#Healthcare professionals: Stay up to date about #AYA #cancer treatment, side effect management, and survivorship through @ASCO eLearning: https://bit.ly/3ciVtBU	Are you a health care professional caring for an adolescent or young adult (AYA) who has had cancer? Stay up to date on the needs of AYA cancer patients and survivors through ASCO eLearning: https://bit.ly/3ciVtBU	4

SAMPLE TWEETS AND FACEBOOK POSTS FOR COVID-19

Tweets	Facebook Posts	Message Category
Finding credible resources for #AYAcancer patients and survivors during #COVID19 can be difficult. Check out these programs for patients, by patients: http://bit.ly/30c05WO	Finding credible resources and information for AYA patients with cancer and survivors during COVID-19 can be difficult. Check out these programs for patients, by patients: http://bit.ly/30c05WO	1,2,3
Managing #AYA patients with #cancer and survivors during #COVID19 provides many challenges. Use these resources from other #heatlhcare leaders for helpful hints: https://bit.ly/3rcPXcs	Managing and treating AYA patients with cancer and survivors during COVID-19 provides many unique challenges. Use the resources from other healthcare leaders for helpful hints: https://bit.ly/3rcPXcs	4
Check out information and support resources around #COVID19's impact on #AYA patients with #cancer, survivors, and caregivers from these advocacy groups: http://bit.ly/3c0fSNR	Check out information and support resources around COVID-19's impact on AYA patients with cancer, survivors, and caregivers from these advocacy groups: http://bit.ly/3c0fSNR	1,2,3
#Healthcare professionals: The earlier you can detect #cancer, the better the outcome for the patient. Learn how to promote cancer screening even during #COVID19: https://bit.ly/31gQD4Y	Healthcare professionals: The earlier you can detect cancer, the better the outcome for the patient. Learn how to promote safe cancer screening during COVID-19: https://bit.ly/31gQD4Y	4
#Cancer patients and survivors, including #AYAs, may be at a higher risk of serious infection if they get #COVID19. Lower your risk of infection by following @CDCgov guidance: http://bit.ly/2JPXH3p	Cancer patients and survivors, including adolescents and young adults, may be at higher risk of serious infection if they get COVID-19. Lower your risk of infection by following this CDC guidance: http://bit.ly/2JPXH3p	3

SAMPLE LINKEDIN POSTS

LinkedIn Message	Message Category
Healthcare professionals: Caring for an adolescent or young adult (AYA) who has had cancer? Stay up to date on the needs of AYA patients with cancer and survivors through ASCO eLearning: https://bit.ly/2Vv9Ei6	2,3
Healthcare professionals: Did you know adolescent and young adults (AYA) who have cancer have unique care needs? The National Comprehensive Cancer Network has guidelines on caring for adolescents and young adults with cancer. Create a free account to access: http://bit.ly/2DGrtCN	4
Adolescent and young adults who have received a cancer diagnosis have a variety of unique needs and concerns. This resource directory from the Ulman Cancer Foundation can help healthcare professionals and patients: https://bit.ly/3bv9M70	1,4
Young people living with cancer are a special demographic that may be more vulnerable to the effects of COVID-19 than peers their age. Providers must pay attention to their unique needs, particularly mental health, when providing care during the pandemic: https://bit.ly/3kGb017	1,2
National Young Adult Cancer Awareness Week in April is a great time to spread the word about adolescent and young adult (AYA) cancer with this summary from the National Cancer Institute: http://bit.ly/2FAwpGP	1



Remember that other suggestions on social media strategies, links to images and graphics, analytic tools, and a glossary of social media terms can be found in the GW Cancer Center's Social Media Guide at http://bit.ly/GWCCSMTKs

ADDITIONAL TOOLS AND RESOURCES

Tool	Description
Breast Cancer in Young	This CDC source outlines risk factors and breast cancer
<u>Women</u>	screenings for young women.
Breast Cancer in Young	These bilingual infographics raise awareness about breast
Women- Bring your Brave	cancer among younger women and promote CDC's Bring
Campaign	your Brave Campaign and CDC's Spanish information on breast cancer.
Long-Term Follow-Up	The Children's Oncology Group developed these guidelines
Guidelines for Survivors of	to help raise awareness of late effects and improve follow-up
Childhood, Adolescent,	care of young cancer survivors throughout their lives.
and Young Adult Cancers	
National Comprehensive	These guidelines are for adolescents and young adults who
Cancer Network: AYAs	are dealing with cancer. They can also be helpful for
with Cancer Guide	caregivers, family, and friends and include information related to diagnosis, treatment, side effects, and survivorship.
Nurse Oncology	This 5-part video series addresses unique challenges that AYA
Education Program: At	patients with cancer face in regards to physical, emotional,
the Crossroads: Cancer in	and practical needs.
Ages 15-39	
Promising Policies and	This publication provides information about indoor tanning
<u>Practices for Cancer</u>	among minors and potential strategies for reducing this
<u>Prevention: Indoor</u>	behavior in the community.
Tanning Among Minors	
Support for College	This guide includes extensive and empowering information,
Students with Cancer	online resources, support organizations, and an inspiring
	'insider perspective' from an incredible young student
	currently undergoing treatment for cancer. This guide is for
	those trying to pursue their dream of higher education-
TI D 1. 11 "	despite their battle with the Big C.
The Road to Wellness:	The Geographic Health Equity Alliance has developed a new
Driving Tobacco and	educational supplement aimed at teaching young people and
Cancer Off the Map	parents about the harms and effects of tobacco use.
2020 Special Section:	The 2020 Special Section profile from the American Cancer
Cancer in Adolescents	Society is for adolescents and young adults ages 15-39. It
and Young Adults	includes data on incidence, mortality, survival, and treatment
	while discussing unique challenges affecting these patients.

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