European Network of
Youth Cancer Survivors

FROM EXPERIENCE TO ACTION:

A GUIDE TO TALKING WITH SURVIVORS ABOUT LATE EFFECTS

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Authors & Proof reading
Hannah Gsell, Carina Schneider, Anna Zettl, Ian Murphy,
Barbara Brunmair

Childhood Cancer International - Europe, Vienna, Austria

Editorial, Concept & Design
Hannah Gsell

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INTRODUCTION - Why this matters

Experiencing cancer as a child, adolescent, or young adult (CAYA) presents unique challenges which necessitate care that not only addresses medical needs but also psychological and social well-being. Although the survival rate for cancer in individuals aged 0 to 39 in Europe still varies depending on age group, cancer type, and region, medical advancements have increased survival rates in this population in recent years. However, at least 75% of survivors experience physical and psychosocial late effects of cancer and cancer therapy during their lifetime.[1, 2] This can affect hormone balance, fertility, internal organs, cognitive abilities, and mental health, among other things. Therefore, for CAYAs, comprehensive, person-centered follow-up care is crucial, with a particularly important aspect being effective, open, and compassionate communication about health, available care, opportunities, and especially the topics of late effects and long-term care.

Unfortunately, many survivors are still not (properly) informed about the fact that late effects can occur after cancer treatment, which can lead to health complications and additional psychosocial distress. Implementing person-centered approaches to follow-up care may help prevent these issues, thereby mitigating the severity of long-term consequences—or even averting them altogether in some cases.

In response to numerous reports of patients and survivors highlighting a lack of open and effective communication from healthcare providers, we have addressed this issue within the framework of EU-CAYAS-NET. Through a workshop with CAYA cancer patient advocates, we developed these Communication Guidelines. We hope they will help facilitate more effective conversations about late effects between survivors and their healthcare providers.

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[1] Oeffinger KC, Mertens AC, Sklar CA, Kawashima T, Hudson MM, Meadows AT, et al. Chronic health conditions in adult survivors of childhood cancer. N Engl J Med. 2006;355(15):1572-82.

[2] Suh E, Stratton KL, Leisenring WM, Nathan PC, Ford JS, Freyer DR, et al. Late mortality and chronic health conditions in long-term survivors of early-adolescent and young adult cancers: a retrospective cohort analysis from the Childhood Cancer Survivor Study. Lancet Oncol. 2020;21(3):421-35.

METHODOLOGY – What survivors say

This document and the recommendations were developed and written by survivors of childhood, adolescent, and young adult cancer. Through open discussions in a workshop held within the EU-CAYAS-NET network, survivors shared their experiences, challenges, and insights. The goal of this document is to support better, more transparent communication about late effects and follow-up care, based on what survivors have found helpful or lacking during their own journeys. [3]

To spark meaningful discussion, participants were asked a series of questions focused on when and how they first heard about possible long-term effects of treatment, how those conversations went, what they found helpful or lacking, and whether they felt comfortable asking follow-up questions. They also explored who should be involved in these conversations, when the topic should be introduced, and how to approach it if someone isn't ready to receive that kind of information.

Based on this we formulated recommendations that can be taken into account when discussing survivorship, late-effects, and follow-up care with CAYA cancer survivors.

Core Principles of Survivor-Centered Communication

These recommendations can be broadly categorized into four areas:

1. Survivor-centered care
2. Communication & information-sharing
3. Emotional & psychosocial support
4. Respect & empowerment

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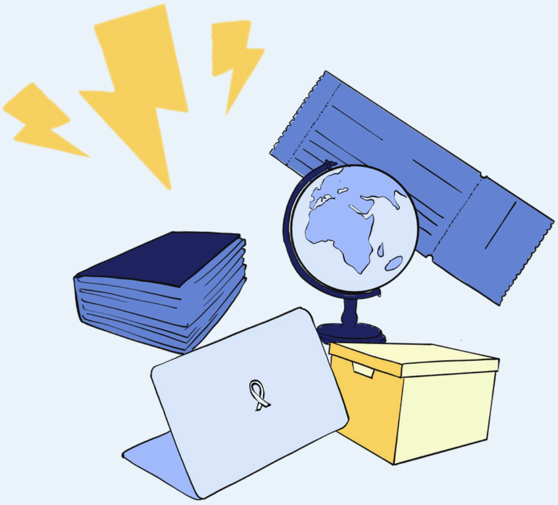
[3] Nineteen people signed up to take part. Over half of them shared that they were diagnosed with cancer between the ages of 0 and 14, while more than a quarter received their diagnosis between the ages of 19 and 30.

In the end, 12 survivors (11 women and 1 man) participated in the 90-minute online session.

Recommendations for Communication with Survivors to Prepare Them for Late Effects and Provide Support

Survivor-Centered Care

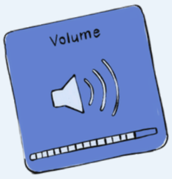
1. **Prepare Survivors for the "New" Life**
    - Avoid saying things like: "After this, you can go back to normal life." Focus on preparing us for the new life after diagnosis and treatment, addressing any new and specific needs as they arise
2. **Set Realistic Expectations**
    - Avoid "sugarcoating." Emphasize that late effects are common and will be a lifelong consideration for us. Help us to incorporate this into our health management.
3. **Emphasize Well-Being and Quality of Life**
    - Keep in mind that well-being and quality of life are essential needs, not luxuries, for us.
    - Take time to explore with us what well-being and Quality of Life mean to us, and emphasize this as a shared process to help us uncover personal definitions that may not yet be clear.
    - Remember to listen and accept our very personal definition of well-being and quality of life as this can vary widely from person to person. There is no one-size-fits-all-solution, and that is okay. Finding an individual path to personal well-being is a process.
    - Work with us to develop a concrete plan to improve our well-being and Quality of Life.



Communication and Information Sharing

1. **Provide Clear Communication Channels and Consistent Support**
    - Ensure we have a designated person with whom to discuss late effects and whom we can approach with questions regarding not only physical but also psychosocial topics.
    - Help us build a safe space for addressing uncertainties post-therapy.
2. **Tailor Communication**
    - Adapt your communication to meet the individual's specific needs. Use language everybody can easily understand.
3. **Use Consistent Terminology**
    - Use clear and consistent terminology when discussing follow-up care and late effects. Be honest and clear without minimizing the situation, but also avoid dramatizing or causing unnecessary fear.
    - Explain the importance of follow-up care for detecting relapses and for managing/preventing late effects.
4. **Check Understanding and Engage Empathetically**
    - Share information about late effects with care, ensuring we have enough time to understand and reflect before making important decisions.
    - Memory can be a fickle thing: Revisit important information at multiple timepoints and across consultations to make sure we remember the key points.
5. **Make Information Accessible**
    - Ensure information is shared and accessible through brochures, trusted websites, or other materials, allowing us to revisit and dive deeper into the topics discussed if we wish to.

Emotional and Psychosocial Support



1. **Take Concerns Seriously**
    - Avoid dismissing the issues we raise; approach each one with respect and thoughtful attention.
    - Help break the stigma around psychosocial late effects by encouraging honest conversations in a safe, supportive environment.
2. **Offer Psychosocial Support**
    - Provide options for psychosocial support, including psychologists, psychotherapists, social workers, patient associations, and peer support. Provide referrals if these services are not available on-site.
3. **Show Openness**
    - Be open to addressing any further questions that may arise, or refer to someone who can be the point of contact for additional inquiries.

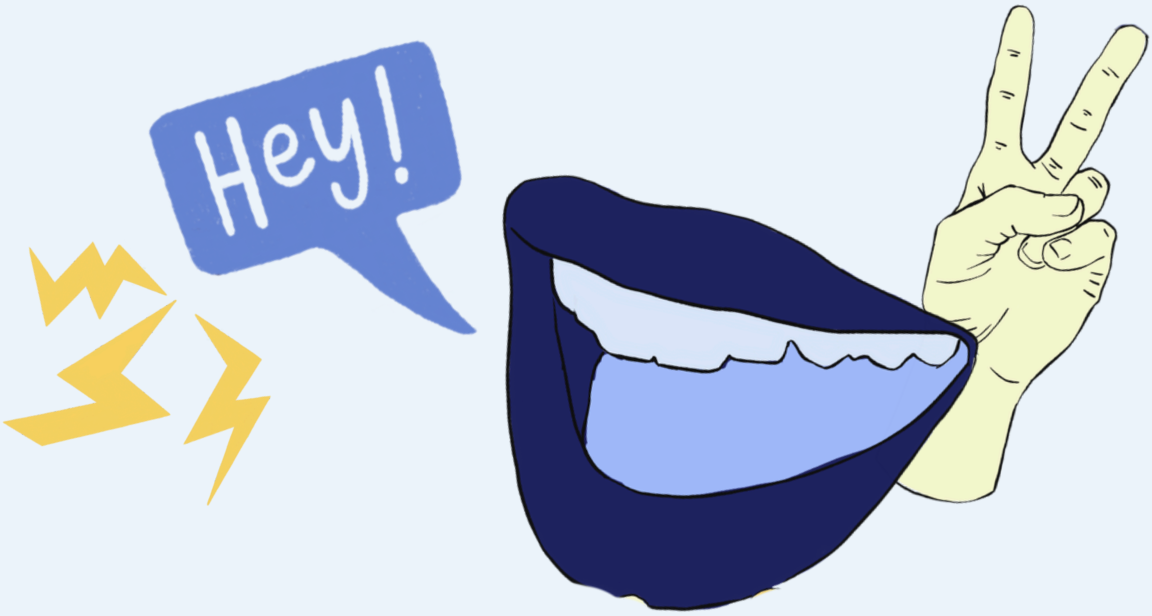
Respect and Empowerment

1. **Respect Readiness and Decision-making**
    - Allow us to decide if we are ready for new information. Respect our readiness and, if necessary, revisit the conversation in due course in an adequate setting (i.e. plan a time and space for important conversations that we are not yet ready to have).
    - Respect when we say "no," but continue to offer information at a later point, recognizing that readiness can change.
2. **Invite Feedback**
    - Invite us to provide feedback on the information shared and past conversations. This will not only help to ensure that our needs are met in terms of content and understanding, but will also help to build a trustful relationship.
    - This feedback can provide you with valuable insight into how your communication is received, enabling you to further develop and improve your own communication skills.

Final thoughts and additional tools for everyday practice

Open and clear communication can positively impact decision-making, adherence to (further) treatment, social relationships, and mental health. Although communicating about difficult topics can be hard, the approach and attitude toward communication can make all the difference.

To support these kinds of conversations—whether about serious issues or other aspects of survivorship—there are practical, easy-to-use tools available in multiple languages. These include pocket cards that can be used alongside the recommendations listed above. One pocket card focuses on **"Talking about serious matters"** and offers guidance for approaching difficult conversations with empathy and clarity. The second card outlines key **"Dos and Don’ts in communication"**, helping avoid common pitfalls and foster trustful, respectful interactions. These tools can help make communication more supportive, structured, and survivor-centered, and thus empower us in taking responsibility for our own survivorship care.



ABOUT EU-CAYAS-NET

EU-CAYAS-NET is a project, co-funded by the European Commission, which unites leading organisations from 18 countries active in the childhood and youth cancer field to map the existing resources that are helpful to young cancer patients, survivors, and their caregivers, to create new European guidelines and empower cancer survivors to advocate for their rights and needs

To best **support person-centered conversations** with CAYA cancer survivors, **practical, user-friendly tools** are available in multiple languages at beatcancer.eu. These include pocket cards that shed light on common mental health challenges and psychosocial effects while offering practical tips on how to address them. These tools can help make communication **more supportive, structured, and survival-oriented**, empowering survivors to take responsibility for their own survival care.

Find these pocketcards **here** on beatcancer.eu.

Have a look here

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