

A Conversation Guide for care providers

AYA Compass

Adolescent & Young Adult 16-35 years of age

The AYA Compass is an instrument that AYAs and their care providers can use to discuss the impact of cancer and its treatment on various aspects of life. It also helps them to identify needs and obstacles and to pay attention to what is going well.

Foreword

AYAs (Adolescents and Young Adults, young people between the ages of 16 and 35 years) feel the impact of their illness and treatment in all areas of their lives. They are faced with a variety of challenges and obstacles, and needs change throughout the illness and its treatment phases.

A holistic approach is recommended, but for the AYAs, and for their care providers, it is often not easy to clarify expectations and decide which needs take priority.

The AYA Compass is based on a number of internationally recognised tools, such as the HEEDSSS Assessment (Goldenring et al., 1988 & 2004), the CanTeen Psychosocial Assessment (2011), the 'AYA anamnesis' from the Stichting Nationaal AYA [National AYA Foundation] and the IAM Assessment from the Teenage Cancer Trust.

(References: See the list at the end of this Conversation Guide.)

Importance of the AYA Compass

The AYA Compass maps out a complete picture of the personal situation of the AYA. It brings difficulties and care needs to light but also identifies the AYA's sources of support. By exploring needs, wishes and expectations using the AYA Compass, you contribute to empowering the AYA while, at the same time, helping to create a clear framework for individual challenges.

Using this AYA Compass is valuable at various points throughout the course of care and treatment. At the time of the diagnosis, it becomes a starting point for an individual care plan. During the treatment phase, it provides direction in offering age-specific care, and at the end of treatment, it is the basis for an aftercare plan.

A report of the AYA Compass conversation can be added to the AYA's electronic patient record (EPR). If the AYA completes more than one AYA Compass conversation during the treatment phase, then these reports in the EPR provide an overview of the changes in the perceptions and the needs of the AYA throughout the illness.

Discussing the outcomes of the AYA Compass with the multidisciplinary group of care providers allows you to put the interests of the AYAs first and to optimise their care. You also raise awareness about AYA care while increasing the shared knowledge about the various psychosocial concerns of AYAs that can (in)directly influence (medical) treatment and follow-up.

Getting started

This Conversation Guide will support you in using the AYA Compass. The process you go through using the AYA Compass is just as important as the actual outcome of the conversation.

The AYA Compass is composed of several themes that relate to various areas of the AYA's life. **Get familiar with the various themes.** How you discuss the themes is up to you. For some of the themes in this Conversation Guide, we have formulated several sample questions to get you started. Adapt these to your own style and to the age of the AYA.

You may occasionally run into **barriers or encounter personal boundaries** while caring for AYAs. You may not feel sufficiently familiar with the age-specific needs of AYAs, or you may encounter an especially complex situation. In that case, consult those colleagues who are also involved in AYA care or seek the advice of an AYA Reference Team, such as the one at UZ Gent. Information and education on age-specific care for AYAs are also spearheads of organisations such as Care4AYA vzw (www.care4aya.be), Kom op tegen Kanker (www.allesoverkanker.be), Cédric Hèle Institute (www.chicom.be) and Stichting tegen Kanker (www.kanker.be).

Points of special interest

Before you start using the AYA Compass, we would like to explain some basic conditions and important points.

THE FOUNDATION

- **The AYA is more than his/her/their illness.** The AYA is, first and foremost, a young person who lives within a unique context and who is suddenly faced with cancer.
- **By using this AYA Compass, the AYA determines the direction the conversation takes, and the care provider navigates along with the AYA.** In other words, hand the control over to the AYA, allow the AYA to determine the focus of the conversation, and ask permission to enquire about specific topics.
- Try to use the AYA Compass during an **individual conversation** with the AYA, without the presence of parents, partners, or other people. Involve loved ones in a separate conversation.
- It can be very uncomfortable for the AYA to share personal information with a care provider. Acknowledge this and be understanding. Clarify what you aim to do with the AYA Compass and reassure the AYA that it is a regular **part of the AYA care process.** It helps AYAs to know that it is normal to talk about these themes and that an AYA Compass is also used with other AYAs.
- Be sure to **point out that what the AYA tells you is confidential and subject to rules of privacy.** Explain very clearly what happens to the info from the AYA Compass and who within the team has access to it.
- **EVERYTHING IS OPEN FOR DISCUSSION;** no question is abnormal or inappropriate!

SETTING

- Make sure you have **sufficient privacy and a quiet space** where you will not be disturbed.
- **Provide for the necessary time** but adapt to the AYA's capabilities. For example, it may be desirable to spread the AYA Compass over several visits if the AYA is very tired or in pain.

COMMUNICATION

- Avoid jargon and use clear, **understandable vocabulary**. Adapt your information and communication style to the AYA's developmental level.
- A smooth, youthful style can be a good idea but, above all, **be authentic**. If you use a style that is too overly artificial, you might make the wrong impression and that could make it harder to build trust.
- Be attentive to the AYA's **body language** and (emotional) reactions. Sometimes these say more than words.
- Have **integrity** and always respond professionally and competently, especially on more sensitive topics such as sex, substance use, or mental health.

APPROACH

- Investigate to what extent the AYA feels **informed** and whether he/she/they have accurate information. If necessary, explain difficult topics repeatedly.
- Together with the AYA, discuss **what kinds of care will be provided**, in what order, and which concrete steps, such as a referral to a specific healthcare provider or an AYA Reference Team, will be taken.

- Schedule a **follow-up** conversation with the AYA.
- Make agreements and give them, in a **short summary**, to the AYA. This could, for example, take the form of an electronic report that the AYA can access at a later date on the digital collaboration platforms CoZo or Mynexuz.be.
- Explain how **AYAs can share information and track appointments** within CoZo or Mynexuz.be. Help the AYA log into these digital patient portals.
- Give your **contact details** to the AYA and explain how you and your fellow caregivers can most easily be reached.
- If the AYA would benefit from peer contact, refer them to the Support4AYA sessions at Het Majin Huis in Ghent (www.uzgent.be/aya), the online AYA platform at www.care4aya.be, the KOTK-meetings initiatives [Kom op tegen Kanker ontmoetings-initiatieven] via www.allesoverkanker.be, and the patient organisation FLAYA at www.flaya.org.
- The theme 'The finite nature of life' is also covered in this AYA Compass. However, if the AYA is receiving palliative care, then he/she/they have needs that require a more specific approach. Clarify the palliative care options, such as the option to receive guidance from a palliative support team, a palliative home care service and/or care providers who work on 'Advanced Care Planning'.

The AYA Compass

The AYA Compass highlights themes that AYAs face in their living environments. Not all the themes require the same amount of attention at all times. An exploration of the various life domains will quickly identify the most important needs and what kinds of support and care should be prioritised.

Introduce the AYA to the AYA Compass and try to gauge his/her/their willingness to work with it. Give the AYA Compass to the AYA ahead of time (e.g. in the waiting room) in preparation for the conversation. Allow the AYA to tell you which themes he/she/they definitely want to discuss during the conversation. This way, you can immediately answer questions or address concerns that the AYA may have

already had for some time.

Also ask the AYA to indicate how concerned he/she/they are about these themes: ranging from not concerned to very concerned.

We recommend always using the AYA Compass in a **face-to-face conversation** with the AYA. If this is not possible, have the AYA indicate which themes he/she/they would like to discuss in a separate meeting and then schedule this meeting. For example, an AYA may feel hesitant to talk about a theme such as sexuality in the presence of his/her/their parent(s). During the conversation with the AYA, only move on to the non-priority themes once all the priority themes have been discussed. Pay special attention to topics, such as fertility, that should be discussed at specific moments throughout the care process, and initiate these topics yourself if the AYA does not consider them a priority. At the end of the conversation, give the AYA a blank copy of the AYA Compass for a next conversation. A digital AYA Compass is currently being made. This digital version will be available to patients of UZ Gent via the electronic patient platform. To check on the progress of this version, consult www.uzgent.be/aya.

Guiding questions by theme

MY ILLNESS, TREATMENT, AND FOLLOW-UP

Relationship with care providers

- Do you have any questions about your illness, treatment, or the care you are receiving?
- Do you know who to turn to with your questions? Have you been given their contact information?
- What do you think is important when it comes to the relationship with your care provider?
- What does quality care mean to you?
- How outspoken and assertive are you towards your care providers?
- Are you currently being supported by other care providers outside the hospital?
- Do you have a good, trusting relationship with your GP (if you have one)? What role do you think your GP should play in your care?
- Do you have questions about the collaboration between your healthcare providers, both inside and outside of the hospital?

Information

- How do you handle information? Where do you get your information? Do you look things up on the Internet?
- Do you need more wide-ranging and detailed information?
- Would you rather be informed gradually, bit by bit, or would you rather have all the information right away?
- What information may we give to your partner, parents, family, and others?
- Do you need help figuring out what you want and which issues you want to discuss?
- Do you or your family experience language difficulties when talking to the care provider? Would you like to use an interpreter (by phone) or an intercultural mediator?

Alternative treatments

- Do you use supplemental remedies such as vitamins, herbal preparations, etc.?
- Do you use alternative medicine therapies, such as homeopathy, acupuncture, osteopathy, etc.?

PRACTICAL AND FINANCIAL

Personal

- What is your family situation?
- Do you have housing issues?
- Are you having trouble getting to the hospital?
- Do you need practical support, such as household help or adapted tools or materials?

Administration

- Do you have financial worries? Can you still afford the things you need?
- Do you need any financial-administrative support?
- Do you have any questions about your national health insurance, other insurance, or benefits?

Studies

- What effect does your diagnosis and treatment have on your studies?
- How are your fellow students and teachers handling the situation?
- Would you like the hospital to inform your fellow students and/or teachers about your diagnosis and the care you are receiving?
- How will you schedule your study activities, internships, and exams? Is it possible to postpone any of these, if necessary?
- Would you like to receive guidance to help you continue, re-start or end your studies?
- Are you aware of the support you can get through the hospital school, Bednet or from the student administration service of your college/university?
- Do you need certain certificates or specific documents for your school?

Work

- How does your work currently fit into your life?
- Have you told your employer and/or colleagues about your diagnosis yet? How did you experience their reactions?
- Do you completely understand what kind of paperwork you must complete for your absence from work?
- What challenges do you see, and can something be done about them now? Do you know who to turn to?
- What are your conditions for continuing to work?
- Do you see opportunities for adapted work at your current job?
- Is there someone at work you can talk to about your illness and its treatment?
- What do you need to get back to work?
- Do you need guidance or counselling to get back to work or to find a new job?
- Are you aware of the options for (re-)entry into the workforce?

PHYSICAL WELL-BEING

- Do you currently have any physical complaints?
- How severe are your physical symptoms?
- How is your energy level?
- Are you having trouble sleeping? Can you identify causes for the changes in your sleep or your energy level (e.g. pain, worry)?

THOUGHTS AND FEELINGS

- What thoughts, phrases and words are going through your mind at the moment?
- Are you experiencing anxiety? Anger? Sadness? Loneliness?
- Do you know how to cope with your thoughts and feelings right now?
- Have you ever before had to deal with major, life-changing events in the past?
- How do you handle difficult situations?
- Do you have experience with depression or suicidal thoughts?
- What is your biggest worry right now?
- Is there anyone you can go to with your thoughts and feelings?
- Would you like support from a psychologist, psychiatrist, social worker, or sex therapist?

RELATIONSHIPS WITH OTHERS

Children

- Are you worried about your child(ren)?
- Do you need support in the form of child care?
- How do you talk to your children about your illness and treatment?
- Would you like a healthcare provider to talk to your child(ren)?

Informal carers

- Who do you think is(are) the most suitable informal carer(s)?
- Can you turn to them when you are struggling or when you have questions?
- How would you like the communication about your illness/treatment to go with the loved one who is caring for you?
- Is there anything missing in the informal care you are receiving?
- Do you think your carers need some guidance of their own?

Caring for others

- To what extent do you have to care for your parents, grandparents, or others?
- Do you care for any animals?

Partner

- Does your illness/treatment affect your relationship with your partner? How?
- Do you feel you can talk about anything with the people around you?
- Do you need to talk to a care provider, individually or as a couple?

Parents

- How would you describe your relationship with your parents?
- Are there topics you would rather keep to yourself and not discuss with them?
- Would you like to call in professional counsellors?

Friends and colleagues

- Do you feel understood by your friends/colleagues?
- Are there things that are difficult to share with them?
- Do you need advice or practical tips for staying in touch with them or for communicating with them?

- How would you like to see your friends in hospital, and how can the hospital make this more pleasant for you?
- Are you active online? What do digital contacts or friendships mean to you?

Fellow cancer patients

- How do you feel about contact with other cancer patients?
- Would you like to share your room with another AYA during your hospital stay (if possible)?
- Do you know about initiatives like FLAYA, the youth arm of Kom op tegen Kanker, or the digital platform from Care4AYA?
- Would you like to participate in activities with fellow cancer patients?
- Would you like help in contacting other cancer patients?

LIFESTYLE & INTERESTS

- Would you like to change something about your lifestyle, and do you want help with that? For example, things like quitting smoking, dealing with alcohol and drugs, exercising and staying fit, healthy eating, etc.
- If you smoke, drink alcohol, or take drugs, how do you see your use of these substances during your treatment?
- Are you taking other medications that have nothing to do with your diagnosis and treatment?
- Do you need information about the effects of certain substances on the course of your illness and treatment?
- What do you think about your eating/drinking habits? Do you have questions?
- Do you have any questions about sunbathing during your treatment?
- How will you continue to exercise/play sports during your treatment?
- Do you need more info and/or an adapted training schedule from a physiotherapist or sports instructor?
- Would you prefer to exercise alone or with fellow cancer patients?
- Are you interested in participating in an oncological rehabilitation programme?
- Which free-time activities give you the most pleasure and energy?
- Do you think it is possible to continue these activities?
- How important is contact with your friends? How do you see that during your treatment?
- How active are you online?

FAITH, SENSE OF PURPOSE, AND CULTURE

- What do religion and spirituality mean to you?
- Do you need to deepen your sense of purpose or religion, and if so, who or what can help you do that?
- How will your cancer diagnosis be handled within your community?
- Are you experiencing difficulties dealing with your illness and treatment within your community or difficulties talking about it?

- Do we, here at the hospital, sufficiently understand what you think is important within your culture?
- What should care providers take into account when it comes to your customs, traditions, and cultural background?

FERTILITY

- Do you currently have a desire to have children?
- Do you have questions about the impact of your illness and treatment on your desire for children or family planning? What do you know about this?
- With which care provider would you prefer to speak about this?
- Have measures already been taken to preserve your fertility?
- Do you know which contraception is best to use during your treatment?
- How do you see your desire for children after treatment?
- Do you want support and guidance in becoming pregnant in a healthy way?
- Do you need information and/or guidance from your partner?
- Would you like information on alternative forms of parenthood, such as adoption, foster care, etc?
- Do you have questions about using contraceptives in combination with your treatment?

INTIMACY AND SEX

- Are you currently sexually active?
- Are you experiencing changes in your sexual functioning?
- Does your illness/treatment affect your experience of intimacy and sexuality?
If so, how are you handling this?
- Do you feel like you have sufficient information about the possible consequences of your treatment on your sexual functioning?
- Do you need support from a healthcare provider, e.g. a sex therapist?

SELF-IMAGE AND APPEARANCE

- How do changes in your appearance due to the illness and treatment affect you?
- Do changes in your appearance/self-image affect your functioning and/or your identity?
- Do your illness and treatment have an effect on your self-confidence?
- Do your illness and treatment influence the way you interact with others (e.g. your partner, friends, strangers)?
- What could be an important support for you in dealing with these changes?
- Are you aware of initiatives like 'Look good, feel better', free wellness treatments, etc.?

MY FUTURE

End of treatment

- How do you see the end of your treatment?
- What do you expect from your recovery/rehabilitation?
- Do you feel like your life needs a new direction?
- What is important to you in the period following the cancer treatment?
- What are your expectations and preferences for the rehabilitation?

Fear of relapse

- Are you afraid of relapsing?
- Are the people around you anxious? How are you handling this?
- What helps you deal with fears?
- Do you need any psychological help or other support?

Long-term consequences

- Are you worried about the long-term or late effects of your illness and treatment?
- Are you currently suffering from specific consequences of your cancer treatment?
To what extent are these consequences currently affecting your life?
- Do you need more information about this?

THE FINITE NATURE OF LIFE

- Do you feel adequately informed about the options in case of incurable illness?
- How are you handling the uncertainties of life expectancy?
- Do you think about death or the possibility that you may not recover? Do you ever wonder about the chances of dying?
- Are you someone who likes to hear stats on the probability of survival/death?
- Do you have questions about the end of life?
- Are you aware of the options for palliative care and advanced care planning?
- Are you aware of the different types of living wills, such as the negative living will, the euthanasia living will, organ donation, or donating your body to science?
- Have you thought about your estate, your last will and testament, or your funeral?
- Do you have questions about your digital legacy, or what will happen to your social media after your death?
- Would you like to record certain wishes or end-of-life arrangements?
- Can you talk about this topic with your partner/parents/children/family/friends?
- Would you like help making your wishes known?

Colophon

The AYA Compass and Conversation Guide for care providers have been developed by the AYA Reference Team at UZ Gent. In collaboration with AZ Jan Palfijn Gent, AZ Sint-Lucas Gent, AZ Maria Middelaes Gent, UCVV Gent, Care4AYA vzw and primary care partners, within the context of the AYACare@Gent project. This project was achieved with support from Kom op tegen Kanker.

More info:
www.uzgent.be/aya
www.care4AYA.be
www.allesoverkanker.be/jong-en-kanker
Contact: AYA Reference Team UZ Gent: ayateam@uzgent.be

The AYA Compass and Conversation Guide were created in the context of knowledge dissemination based on scientific research, without the goal of generating profits. All rights reserved. No part of this publication may be reproduced or stored in an automated database or be made public, in any form or by any means, without the prior written permission of the AYA Reference Team at UZ Gent and Care4AYA vzw.

Responsible publisher: Care4AYA vzw / Nathalie Belpame
January 2023 © Care4AYA

References

CanTeen (2011). Adolescent and Young Adult Oncology Psychosocial Care Manual. Australia: CanTeen
Goldenring, J., & Cohen, E. (1988). Getting into adolescent heads. Contemporary Pediatrics Available.
Goldenring, J. M., & Rosen, D. S. (2004). Getting into adolescent heads: an essential update. Contemporary Paediatrics-Montvale 21 (1), 64-92.
Nationaal AYA 'Jong & Kanker' Zorgnetwork (2018). Compass and interventions basic AYA care according to the 'I & my' care concept (via <https://ayazorgnetwork.nl/>).
Teenage Cancer Trust (2017). The IAM Assessment (via <https://tyaiam.co.uk/>).