

QUESTIONNAIRE FOR THE AYA

TOPICS TO DISCUSS WITH YOUR DOCTOR OR NURSE

You have an appointment soon at the hospital because you've been diagnosed with cancer. Since you're between 18 and 39 years of age, you belong to the AYA patient group. AYA stands for Adolescent & Young Adult.

When you're told you have cancer, there are so many things to think about at the same time that it's easy to forget the odd one. So, we've put together a questionnaire with a few topics as a guide. You can use this questionnaire to order your thoughts, and you can print it out and take it with you to your appointments at the hospital. You can also complete this questionnaire digitally in the patient portals of some hospitals and share it with your healthcare provider (ask your nurse or doctor if your hospital provides this).

This questionnaire serves as a starting point for the conversation with the healthcare provider you will be seeing at your appointment. This is not a fixed agenda for the conversation. You can ask whatever questions you might have, at any time during your treatment and any follow-up period.

Please note: Some cancer treatments can affect your fertility. It is important that fertility is discussed before the treatments start.



AYA 'Me and my' care needs, v. August 2022

1. General

- Who are your caregiver(s), who takes care of you or who can you turn to for support?

- What is your domestic situation (e.g. living with your parents, student residence, living with partner or alone, with young kids)?

- To whom may information be provided?

- Are other agencies / care providers involved?

2. Fertility and pregnancy

- Have you received information about the possible implications that the treatment may have with regard to your fertility or ability to have children? *Yes / No*

- Have any preventive measures been taken to preserve fertility? *Yes / No*

- Are you keen to have children now or at some point in the future? *Yes / No*

- Have you been offered counseling (information) by a fertility doctor? *Yes / No*

3. Illness and treatments

- Can you describe your illness and treatment in your own words?

- How are you coping/dealing with your illness/treatment?

- How are your loved ones coping/dealing with your illness/treatment?

- Do you use any stimulants (e.g. alcohol, drugs, smoking)?

- Are you taking any (other) medications or supplements?

4. School/education

- Are you currently in school or education?

- Do you have any questions about school or studying in relation to your illness/treatment?

5. Work and reintegration

- Do you have a full-time or part-time job?

- On what date did you first report sick?

- Do you have any questions about work and reintegration in relation to your illness/treatment?

6. Eating and drinking

- What thoughts do you have about nutrition?

- Are you worried about losing or gaining weight?

- Do you take any dietary/vitamin supplements? (see also section 17 on *complementary care* for more details)

7. Physical appearance

- Do you have any questions about hair loss, skin care, or sunbathing, for example?

- Has the illness/treatment changed your appearance? If so, how do you feel about that?

8. Sport and exercise

- Did you exercise or play sport before your diagnosis?

- Do you currently exercise or play sport?

- Would you like support with exercising or playing sport during and/or after the treatment?
Yes / No

- Are you currently experiencing fatigue?



9. Emotions

- Have you had to deal with strong emotions before in life, and how did you deal with them?

- Are you uncertain about your future? Are you afraid (of dying)? (see also section 19 on *death*)

- Can you say what gives you mental strength and stability? (See also section 10 on *meaning and purpose*)

10. Meaning and purpose

- Do you have any questions about choices that you have had to make since your diagnosis and during your treatment or that you will have to make afterwards?

- What inspires you, where do you draw strength from, or what is or are your source(s) of strength?

- Do you have a faith?

- Are 'life questions' on your mind a lot?

- Do you wonder about the meaning of life?

11. Intimacy and sexuality

- Do you have a (romantic) partner? Yes / No

- Do you have any questions about personal intimacy and sexuality, with or without a partner (a steady partner or multiple partners)?

- Are you experiencing problems or changes relating to intimacy and sexuality?

- Do you have any questions about support for problems with your relationship and/or sexuality?

12. Friends

- Do you have any questions about building or maintaining friendships?

- Has your contact with friends changed since you became ill?

- Do you feel sufficiently supported by the people around you?

- Would you like to get in contact with other AYAs? *Yes / No*

13. Family

- Do you have any questions about how to deal with or communicate with your parents, partner and/or children?

- Have the relationships changed or have you noticed tension between family members (parents, siblings, partner, young children) since you became ill?

- Do you think that your parents or loved ones are worrying too much?

- Are you worried about how to keep the family life going?

- Do you feel safe at home? *Yes / No*

- Do you feel that your caregivers are under too much strain or at risk of being so? *Yes / No*

- Is extra support needed for you or your loved ones? *Yes / No*

- With (young) children: Who has parental authority, or how is custody arranged, if applicable?

14. Benefits and allowances

- Are you entitled to a benefit or allowance? *Yes / No*

- Do you have any questions or comments about benefits and allowances in connection with your illness/treatment?

15. Mortgages and insurance

- Do you own your own home, or do you want to buy a house in the future?
Yes / No

- Do you already have life insurance? *Yes / No*

- Do you have any questions about mortgages and insurance in relation to your illness/treatment?

16. Late effects

- Do you have any questions about the late effects (physical, psychosocial) of your illness/treatment?

- Are you experiencing any (late) effects of the illness/treatment (e.g. fatigue, concentration problems, cardiovascular disease)?

17. Complementary care

- Are you using any complementary substances (e.g. cannabis oil, turmeric, St John's wort)?

- Are you using complementary interventions (e.g. yoga, meditation, mindfulness, massage, acupuncture)?

- Do you and/or your loved ones need any information about complementary care? Yes / No

18. Palliative care

Please note: This topic only applies if there is no longer any prospect of recovery from cancer. Your healthcare provider will discuss this with you and, if you do find yourself in a palliative care situation, please feel free to address the questions below, for example.

- Have you understood that there is no longer any prospect of recovery? How are you dealing with this?

- How has the knowledge that you won't get better impacted your loved ones?

- Is help needed for you and/or your loved ones (parents, partner, children)?

- Do you have any practical questions about the end of your life?

- Are you able to discuss the end of your life with your loved ones? Yes / No

- Are there any wishes you would like to fulfill at this stage of your life?

19. Death

Questions about death may be relevant even if your treatment is focused on recovery. For example, they may be about fear of dying or being confronted with the finite nature of life.

- Are you afraid of dying?



20. Topics not mentioned

Are there any topics that have not been mentioned yet but which you would like to discuss?

Footnote:

This original text was adopted at the meeting of AYA knowledge centers on June 8, 2021. This text is inextricably linked to the text on the AYA anamnesis / discussion agenda for healthcare professionals. Both documents will be revised annually. The latest version can be found at www.ayazorgnetwerk.nl Both documents are or will be soon available in the hospital information system dossier (HiX, EPIC, NeoZis, etc.) for the healthcare provider (electronic health record) and AYA (patient portal). These versions will be updated annually once the original documents have been revised.