Connect with other AYA's

Cancer at the AYA age isn't very common, which can make it difficult to meet other AYAs. It may feel like you're the only one going through this at your age. Connecting with other AYAs can help. To get in touch with fellow young cancerpatients and -survivors you can go to patient organisation Stichting Jongeren en Kanker. Check the events calendar on www.jongerenenkanker.nl for fun onand offline activities and meetings.

Your loved ones

It's inevitable that your cancer diagnosis also affects your loved ones (parents, partner or siblings). It can be helpful for them to meet others in a similar situation. Hence the AYA Zorgnetwerk and the Stichting Jongeren en Kanker regularly organize (online) meetings for parents, partners, etc. These can also be found on www.jongerenenkanker.nl/events.

AYA lounge

More and more hospitals are putting up special AYA spaces where you can chill with your loved ones in between treatments or visits to the policlinic. These spaces also make it possible to meet others who are going through the same things as you are.

During your stay at the hospital, ask the nurses or your attending physician if there is an AYA lounge, or check www.ayazorgnetwerk.nl.

Contact

Do you have questions about AYA care? Do not hesitate to contact us:

Central coordination AYA Zorgnetwerk

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What is AYA care?

AYAs (Adolescents & Young Adults) are young people between ages 18 and 39 who get diagnosed with cancer. Just like you. And you'll have many questions which are completely normal in this abnormal situation you find yourself in. Questions about your disease and its impact on your education, job, insurance, mortgage, sexuality, death, parents, friends, appearance, fertility or kids. At this time in your life especially, you need age-specific care and support that is inextricably linked to your medical treatment. Care focusing on "Who are you and what do you need?" during, but also after cancer. Helping you pick up your life to the best of your abilities. Care that also takes into account the needs of your loved ones. That is AYA care.

AYA 'Young & Cancer' Care Network You'll find AYA-poli's in the seven university medical centres (UMCs) and the Antoni van Leeuwenhoek hospital (AvL). In a growing number of hospitals there are AYA nurses available to help you with all the questions you might have around your diagnosis or, if necessary, they can refer you to the nearest AYA-poli. The hospitals delivering AYA care work closely together, forming the AYA 'Young & Cancer' Care Network. Together, we make sure you can count on the right care, on the right moment, at the right place!

AYA care is here for you

AYA care is meant for all young adults in the Netherlands who have (had) cancer between the age of 18 and 39. The type of cancer or treatment doesn't matter, neither does the stage of your cancer. You can count on specially trained healthcare professionals to help you with al your questions. Especially those about the impact that the illness and its treatment may have on your life or about the choices you want to make towards your future. For example questions about your education, employment, independence, relationships, fertility or sexuality. Do I have a right to sickness benefits if I have a part-time job? Do I want to cryopreserve my eggs or sperm before my cancer treatment starts and is this even possible? Shall I move back in with my parents? Should I change my diet? Can I continue my sports? How do I tell the people around me about my cancer? And what if I don't survive after all?

In case the hospital you're being treated is part of the AYA Zorgnetwerk, you'll be offered AYA care.

Are you not sure whether you are able to receive AYA care at your hospital? Ask the assigned contact person for AYA care about the possibilities. You can find these contacts on www.ayazorgnetwerk.nl/zorgkaart. With a referral from your attending physician or general practitioner it's also possible to make an appointment at one of the AYA-poli's.

The care teams of the AYA-poli's at the UMCs and the AvL consist of an oncologist, nurse specialist, medical psychologist, medical social worker and nurses. It isn't the intention of the AYA care team to take over your medical treatment or check-ups. Your own attending physician will stay in charge of the medical aspect of your treatment.

Check www.ayazorgnetwerk.nl to see where you can find AYA care in your region.

"I'd grant all AYAs an AYA-poli! I feel heard and all my questions are answered."



Ask your questions about your...

- Fertility and pregnancy*
- Illness, treatment and consequences (e.g. fatigue, concentration, etc.)
- Education
- Work and reintegration
- Nutrition
- Appearance (e.g. possible changes and body image)
- Sports and movement
- Emotions
- Spirituality (e.g. questions about the meaning of life or religion)
- Intimacy en sexuality
- Dealing with friends
- Family and children (e.g. parents, siblings, partner, young kids)
- Benefits and compensations
- Mortgages and insurances
- Long-term effects of treatment
- Complementary care (e.g. CBD oil, massage, mindfulness)
- Palliative care (when curative treatment is not an option)
- Death

*Unfortunately, some cancer treatments can affect your fertility. Therefore, it is important that the specialist talks about fertility to you before your treatment starts. Notify your specialist about this.

Various topics can come up during or after treatment. Sometimes the same question arises multiple times. Ask those questions when YOU want to!

At www.ayazorgnetwerk.nl under the button 'patiënt' you'll find a list of questions (in Dutch) with all the topics mentioned above to download an bring with you to consultations with your practitioners. This list will also be available on your digital patient portal soon.