

AYA community

Cancer at the AYA age isn't very common, which can make it difficult to meet other AYAs. That's where the AYA community can help you. This is an online 'place to hang' where you can meet AYAs from all over the Netherlands, share information and experiences, and ask questions, all in a safe and secure way. There are several communities: AYA4All for all AYAs, AYA4Breast for AYAs who have breast cancer and AYA4Naasten for the people close to the AYAs, their loved ones.

Go to www.ayazorgnetwerk.nl, choose the community you want to become a member of and sign up. Do you want to know how the AYA community can help you, or do you want to hear experiences from members of the community? Have a look at the website and do not hesitate to contact us.

For face-to-face meetings and fun activities you can go to the patient organization Stichting Jongeren en Kanker (www.jongerenenkanker.nl)

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 polyclinic. These spaces also make it possible to meet peers who are going through the same as you. 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

Stichting Nationaal AYA

'Jong & Kanker' Zorgnetwerk

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Young & cancer

How do you handle that?
AYA care for you!

"I really appreciate talking
to like-minded people,
it helps!"

Photography: Marlou Pulles

AYA
jong & kanker



What is AYA care?

AYAs (Adolescents & Young Adults) are young people between ages 18 and 35 who, for the first time, get diagnosed with cancer. Just like you. Suddenly, everything in your life is turned upside down and all very normal questions you might have (about for instance your education, work, insurances, sexuality, death, parents, friends, appearance, kids) are put in an abnormal context. Especially at that time, you need age-specific care and support that is coherent with your medical treatment. Care that is based in the question “Who are you and what do you need?” during, but also after cancer. That helps you pick up where you left off to the best of your abilities. Care that also takes into account the wishes and needs of your loved ones. That is AYA care.

Nationaal AYA ‘Jong en Kanker’ Zorgnetwerk (Care Network)

You’ll find AYA care in the eight university medical centres (UMCs) and the Antoni van Leeuwenhoek hospital (AvL) with AYA-poli care teams. A growing number of hospitals have people you can contact and who can point you to AYA care in the general hospital or to the nearest UMC. The eight UMCs, the AvL and the general hospitals together form the Nationaal AYA ‘Jong en Kanker’ Zorgnetwerk.

AYA-poli

AYA-poli care teams are there for every young adult in the Netherlands who have (had) cancer for the first time between ages 18 and 35. The type of cancer or treatment doesn’t matter, neither does the stage that you’re in. You can ask all your questions, especially those about the impact that the illness and its treatment have on your life, or about the choices you want to make for your future. You might have questions about your education, work, independence, relationships, fertility or sexuality. Will I get 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 that possible? Am I going to move back in with my parents? Is it a good idea to change my diet? Can I still work out? How do I tell people around me? And what if I won’t get better after all?

The AYA-poli care team consists of an oncologist, a nurse practitioner, nurses, a medical psychologist and a medical social worker.

It is not intended that the care team takes over the medical treatments or the check-up appointments. Your own attending physician will keep this responsibility. Are you being treated in a general hospital? Ask the AYA contact person in that hospital about the possibilities for AYA care. Ask for a referral from your attending physician or general practitioner. After that you can contact the AYA-poli for an appointment.

Check www.ayazorgnetwerk.nl to see where you can find AYA care near you.

“I’d grant all AYAs an AYA-poli! I feel heard and all my questions are answered.”



Ask your questions about your...

- Fertility*
- Illness and consequences of your illness and/or treatment (fatigue, concentration, etc)
- Lifestyle (sports, spirituality, mindfulness)
- Relationships
- Nutrition
- Emotions
- Reintegration and work
- Sexuality
- Insurance
- Education
- Benefits
- Death and the last phase of life
- Family and children
- Self-image
- Finances
- Late effects of cancer
- Integrative medicine (e.g. weed oil, massage)

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

Other topics can come up during or after your treatment. Sometimes a question comes up multiple times. Ask those questions when YOU want to!

At www.ayazorgnetwerk.nl under ‘patient toolkit’ you’ll find a list of questions with all the topics mentioned above you can download and bring with you to consultations with your practitioners.