

Space 4 AYA 2017

At the SPACE 4 AYA symposium, care professionals and AYAs meet each other to exchange knowledge, skills and experiences. On Wednesday 8 March 2017, the fourth national symposium was opened at the Kuip in Rotterdam by **Prof. Dr. Ir. Kees van der Hoeven**, internist-oncologist and chair of the National AYA 'Young and Cancer' platform. Van der Hoeven gave an appropriate introduction to the program by making a very impressive speech that showed his emotional involvement with the more than 300 people present. The opening was also memorable due to the introduction video with images from the AYA annual overview covering SPACE '16 to SPACE '17. The images were accompanied by the favorite AYA song 'Live' (powered by **Jip Keijzer**). The subsequent sounds from the confetti canons accompanying the launching of the new AYA website www.aya4net.nl marked a cheerful beginning of the symposium chaired by **Mr. Tom van 't Hek**.



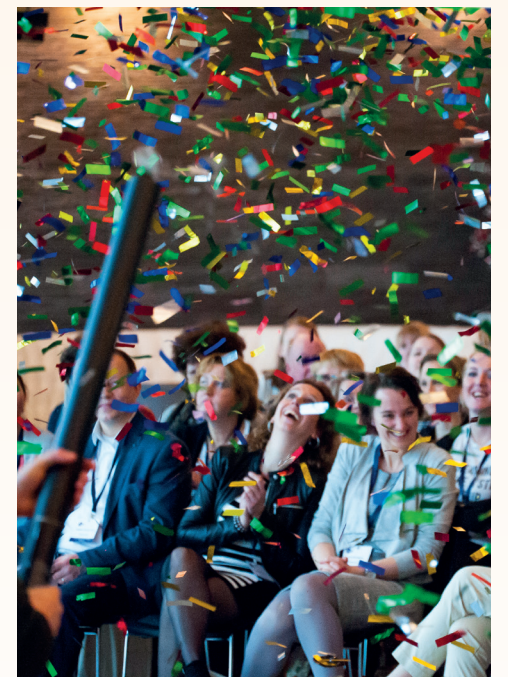
A day characterized by enrichment, broadening of horizons and connecting

It promised to be yet another wonderful day with numerous seminars about various subjects for both care professionals and AYAs. An impression of the symposium is given in this section. During the lunch break, all people present were provided with a tasty 'Food for Care' lunch. This was a good opportunity to get familiar with the 'Food for Care' concept, a unique food formula developed by AYAs which is aimed at enhancement of recovery from illness by good, healthy nutrition both at the hospital and at home. Food for Care is suitable for various patient groups, including patients with oncological problems, diabetes, kidney problems and cardiovascular disease. Food for Care is also suitable for children.

The available rooms at the Kuip were being well made use of. Sixteen different AYA-related organizations attended the information market, offering their services and presenting their goals, missions and visions. They also answered questions from AYAs, their loved ones and professionals. These organizations included patients' associations and institutions focusing on integration and reintegration after battling cancer, psychosocial care, palliative care, information provision and contacts with fellow-sufferers. As part of the information market, an 'AYA contact tools corner' was created. In this corner, the initiatives Hand-in-Hand Manual, Appetizer to contact (Match), Hoeistie.nu and the AYA Community, of course,

formed a first point of contact for AYAs struggling with the question: "How can I stay in touch with my environment while battling cancer?"

A stone's throw away, scientific research posters were being presented by doctors, researchers, paramedics, students, nurses and AYAs showing their research activities and results regarding cancer at the AYA age. The studies presented paid a great deal of attention to the psychosocial well-being among AYAs. Health-related Quality of Life yet again proved to be an important and emerging theme within the research community. The honest, open and respectful way in which AYAs and professionals interact with each



other was reflected in all aspects of this unique symposium. At the AYA 'Young and Cancer' Platform, one plus one is indeed three. The road to the best possible care is walked together. ●



Jacco van Rheenen's research group focuses on cancer, which has been made their central research theme. "With our work at the lab, we try to understand how tumors develop, grow and disseminate. We mainly use high-resolution intravital microscopy in animal models.¹ For example, by coloring cells with different fluorescent markers, we can differentiate tumor cells from healthy cells and monitor their growth and invasive behavior", van Rheenen says.

He demonstrated the application of intravital microscopy by his research group by giving two examples. The first example van Rheenen

gave involved the recent discovery of the ability of tumor cells to transfer malignant characteristics to each other, a process called phenocopying. During this process, invasive tumor cells excrete vesicles containing proteins, fatty and nucleic acids.² Benign tumor cells may include these vesicles and copy information necessary for invasive behavior. Van Rheenen states: "Hopefully, these results are useful in the development of new drugs. We also discovered that these vesicles are present in the bloodstream. By extracting and isolating them from the blood, we can non-invasively gather information about the tumor

Preclinical research leads to effective new treatments

Preclinical research is paramount for the development of new cancer treatments and diagnostic methods. During an inspiring and appealing presentation, Prof. Dr. Jacco van Rheenen, researcher at the Hubrecht Institute in Utrecht, gave some examples of how fundamental research can contribute to the treatment of cancer patients.

characteristics and give a more targeted treatment."

The second example van Rheenen gave involved research into cellular mechanisms underlying the development of intestinal cancer. The researchers described the way in which healthy and (pre)malign stem cells and their daughter cells compete with each other for the occupation of the intestinal crypts.³ The researchers also demonstrated the managing role of nutrition in this competitive process. Van Rheenen says: "It was shown that the intestinal crypts of mice with a low-calorie diet housed more stem cells than those of mice with a standard

diet. As a result, premalignant stem cells faced fiercer competition in the stem cell niche, which reduced the chance of the mice developing intestinal cancer. At present, we are examining which cellular mechanisms are involved in this process and whether there are substances which can imitate the effects of a low-calorie diet." ●

References

1. Ellenbroek SI, et al. Nat Rev Cancer 2014;14:406-18.
2. Zomer A, et al. Cell 2015;161:1046-57.
3. Ritsma L, et al. Nature 2014;507:362-5.

PROMs provide an insight into the cancer patient's perception

The patients' wishes and experiences play an increasingly important role in the provision of care. This also goes for AYA care. At the SPACE 4 AYA symposium, Dr. Olga Husson, researcher at Radboudumc in Nijmegen and Prof. Dr. Winette van der Graaf, internist-oncologist at the Royal Marsden Hospital in London, discussed the use of outcome measures reported by patients, such as questionnaires, in the treatment of cancer patients, particularly AYAs.

Patient-reported outcome measures, PROMs, provide an insight into the perception, treatment and consequences of the disease, and care of patients. "By learning the results from these PROMs, care professionals can improve the communication with their patients. These results also contribute to the choice and monitoring of treatment. The overall goal is to improve patient satisfaction and quality of life. The BREAST-Q questionnaire, for example,

is a PROM that assesses satisfaction and quality of life of patients who have undergone plastic surgery of the breast. This questionnaire covers six themes, including the physical, psychosocial and sexual well-being of the patient, according to Olga Husson. Together with Winette van der Graaf, she replaced Dr. Olivier Branford of the Royal Marsden Hospital, who was unable to give a presentation at the symposium.

Fear of cancer recurrence

The scans look promising and the doctors are satisfied: you are 'disease-free'. Everyone around you is relieved and resumes their normal lives. You are expected to do the same. But what if you are scared the disease will return? Fear of recurrence is shown to be an underestimated consequence of cancer. "Within my field of expertise, cancer-related fatigue and coping issues have been addressed for years. However, the same cannot be said of fear. Fear can be fought in various ways. For example, you can strengthen yourself by looking for information, or avoid situations you are afraid of. Usually, people find a balance between these two. However, if the balance is not right and a patient is caught up at one end of the spectrum, he or she is thought to have a severe form of anxiety." Prof. Dr. Judith Prins, Head of the Department of Medical Psychology at Radboudumc and one of the 'founding mothers' of integrated AYA care in the Netherlands, described what problems fear may cause after a patient has battled cancer. "The uncertainty of not knowing whether the cancer will return may feel like a cloud that is hanging over you. As a result, fear may become a dominant factor in your life. It may not only have a strong negative impact on your mental well-being and quality of life, but also on various behavioral aspects. For example, people tell me they are anxious to book a holiday or switch jobs, because they stay prepared for the worst."

Being young means having a whole life ahead of you. This involves making plans, setting

goals and having dreams. Therefore, it is not surprising that age is shown to be significantly associated with fear of cancer recurrence. The younger the patient, the higher his or her scores on the Cancer Worry Scale. No fewer than 62% of the AYAs who were interviewed admitted to having high levels of anxiety. This is a very substantial figure. In comparison, an average of 35% of mainly older interviewed patients with breast, intestinal or prostate cancer reported having high levels of anxiety. Apart from age, experiencing physical complaints similar to cancer symptoms is shown to be an important determinant for developing fear of recurrence.

Large parts of the audience recognized this. Another important reason for fear of recurrence mentioned by Prins are the frequent medical check-ups. "Each time I am being checked, something happens to me. It's like a reset button is being pushed. As a result, my relationships with other people need to be redefined." An AYA describes how difficult it may be to treat friends as equals and being treated as equals by them when a check-up triggers fear of recurrence. Prins: "We have conducted a study involving the people close to patients with prostate cancer. They are shown to have the same high levels of fear as the patients themselves."

"What can you do yourself to reduce fear?" Prins asked the participants. The reactions varied from gaining strength from fear, discussing feelings of fear with fellow patients

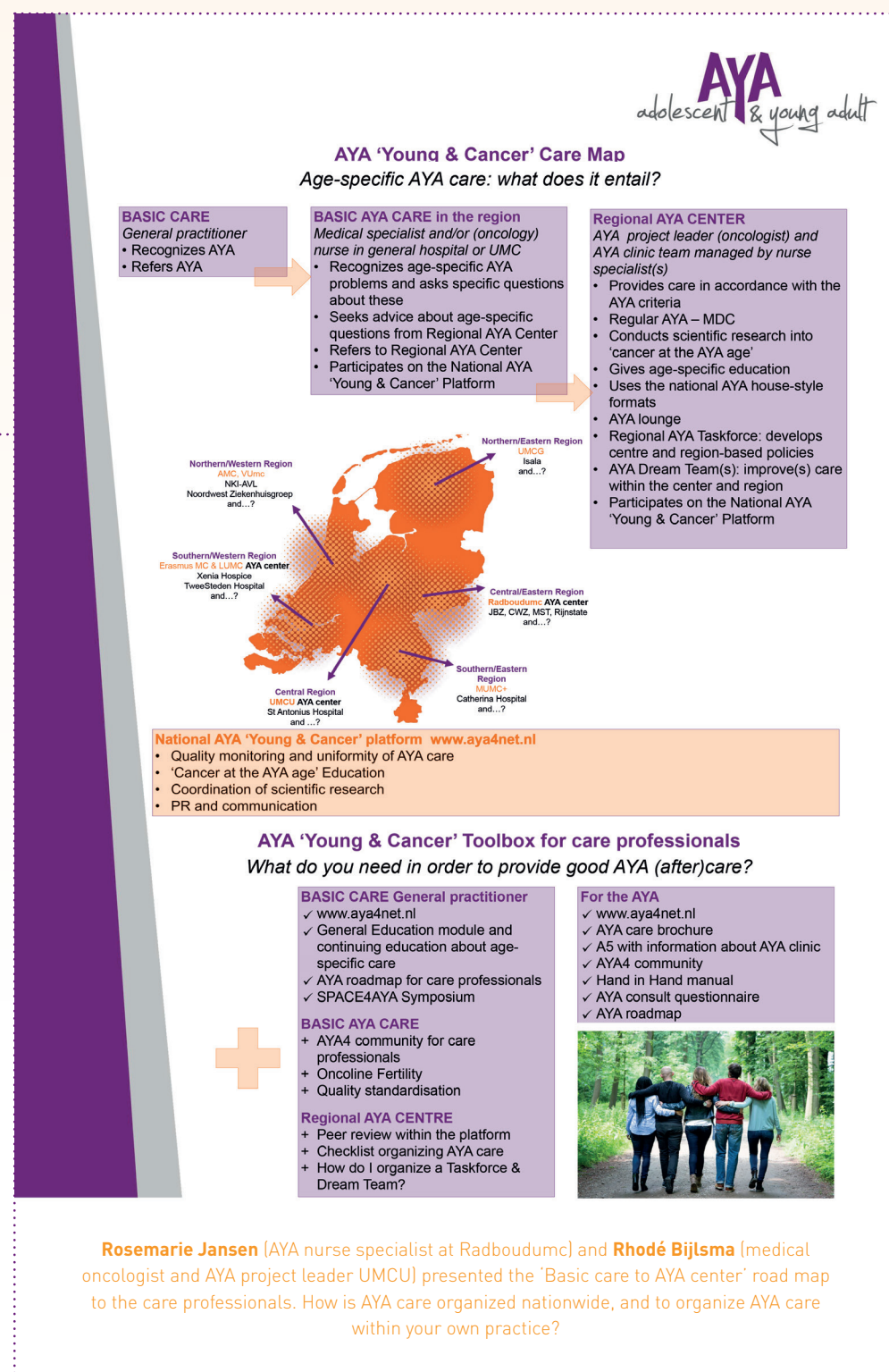
One of the results of the BREAST-Q survey was that although breast reconstruction with implants has a number of clinical and economic benefits in the short term compared to the more complex transverse rectus abdominis myocutaneous (TRAM) flap breast reconstruction, in the long term patients are more satisfied with a TRAM flap reconstruction.^{2,3} "The use of a questionnaire such as BREAST-Q gives a better insight into the patients' perception and short-term and long-term treatment outcomes. Because the BREAST-Q was drawn up in close consultation with patients, the number of questions responded to is high,

including those on delicate subjects such as sexuality", van der Graaf explains.

It is relevant to know whether the BREAST-Q is also suitable to study the perception of AYAs. "As this is presumably not the case, we are currently developing a questionnaire together with AYAs on the quality of life of AYAs with cancer", Husson says. ●

References

1. Pusic AL, et al. Plast Reconstr Surg 2009;124:345-53.
2. Hu ES, et al. Plast Reconstr Surg 2009;124:1-8.
3. Atisha DM, et al. Ann Surg Oncol 2015;22:361-9.



and professionals to accepting fear and finding rest by getting sufficient high-quality information about the disease. The theme of fear was concluded by a statement of an AYA: "Don't resist fear. You need to accept that you have a chance of recurrence. However, it doesn't matter if you are going to be 40 or 80. You can be hit by a bus anytime!" It may be helpful to get to know people of the same age and with the same disease who have been through the same as you. You may find it useful to discuss your feelings of fear and try to deal with other aspects related to

cancer. However, how do you meet them and involve the people around you in what worries you? At the SPACE 4 AYA symposium, a 'How do I meet'-corner had been set up. "Cancer often takes center stage. It is sometimes forgotten who you actually are, though. In the corner, tools are being presented which are developed for and by AYAs, aimed at involving the people around you in your disease process", says Dr. Eveliene Manten-Horst, director and quartermaster of the National AYA 'Young & Cancer' Platform and chair of the AYA parallel sessions. ●

New Oncoline guideline 'Fertility preservation in women with cancer'

Dr. Annelies Bos, gynecologist at UMC Utrecht, Rhodé Bijlsma, internist-oncologist and AYA project leader at UMC Utrecht, and Lonneke van Groningen, internist-hematologist and member of the AYA Taskforce Radboudumc, Nijmegen discussed the new Oncoline guideline. See the inserted Box.

In the Netherlands, approximately 1,800 women under the age of forty, including 275 women under the age of twenty, will develop cancer. The most common types of cancer in this age category are breast cancer, melanoma, cervix cancer, Hodgkin's and Non-Hodgkin's lymphoma and leukemia. The cure rates continue to improve, which means patients are living longer.

Patients consider the risk of fertility loss an important issue to be discussed. However, they often do not address this issue themselves. Therefore, it is the care professional's task to do so. Which interventions are available? One of the options is to surgically remove the ovaries from the pelvis and fixate them at another abdominal location if pelvic radiation is necessary. Nowadays, a more limited operation may suffice in cervical cancer. During this procedure, only the cervix including a broad margin is being removed. The uterine body is being left behind. As a result, the patient can still become pregnant. Another option is to perform an urgent IVF procedure with embryo cryopreservation and - in the absence of a partner - stimulation of the ovaries by freezing ovarian cells by means of vitrification. It

is also possible to perform cryopreservation of ovarian tissue.

An urgent IVF procedure can be started prior to chemotherapy. Embryo cryopreservation has the benefit of being the most applied procedure and of having the highest success rates. The chance of a live birth is 15 to 20% per frozen embryo. A disadvantage of this method is its time-consuming nature, the necessity of a male partner, and the temporarily higher estrogen levels due to hormonal stimulation of multiple ovarian follicles which allows tumor cells to be stimulated in patients with hormone-sensitive (breast) cancer. In the vitrification of ovarian cells, which uses a similar procedure (i.e. ovarian hyperstimulation), the chance of a live birth is 4 to 5% per thawed ovarian cell. Cryopreservation of ovarian tissue is an option, too. In this procedure, small pieces of ovarian tissue are being removed and frozen. A disadvantage of this procedure is its (still) being in an experimental stage and the chance of these ovarian tissue pieces containing metastases. Placing back ovarian tissue has not yet become a standard part of care, because the safety of this procedure cannot be fully guaranteed.

The treating doctor must discuss the subject of fertility preservation with all men and women in the fertile age who wish to have children in the future, or refer them for counseling. It is shown in practice that patients very much appreciate counseling about the various options without actually choosing fertility preservation. 'Oncology first, fertility second'. ●

How comfortable are you discussing sexuality and cancer?

This subject was discussed by **Prof. Dr. Luca Incrocci**, radiation oncologist and sexologist at Erasmus MC, Rotterdam. "Sex can give physical and mental relaxation, pain relief and rest. However, it is a difficult subject to discuss. It is still a taboo, and professionals are insufficiently trained in it", Incrocci says. He encourages patients to ask questions about sex to their doctor. He also tells them that their sex lives might be different than before they received anticancer treatment. Incrocci is a strong advocate of discussions about sexuality between the doctor and the oncological patient. Therefore, he advises medical training centers to pay attention to this subject in the curriculum. Several questions asked by patients with cancer were discussed at the SPACE symposium. When am I allowed to have sex again after receiving treatment? Am I allowed to use oral contraceptives after battling breast cancer? Can cancer change the way I feel about sex? Is cancer contagious? Can sex give you cancer? Am I allowed to have sex when receiving or after having received radiation therapy?

Anticancer therapy is often associated with changes in sexuality. These changes may include loss of libido, erectile dysfunction, pain, vaginal dryness, absence of ejaculation, changes in self-esteem or being ashamed of having a stoma or only one testicle. The AYAs expressed the importance of having an in-depth, well-structured consultation about this subject. They also stressed the importance of knowing whom they and their partners can turn to. ●

Complementary care: who is really familiar with it?

Yoga, mindfulness, massage, acupuncture, exercise programs, herbs and supplements: these are just a few of the complementary therapies available. Although many AYAs are looking for treatments to be used alongside their regular cancer treatment or are already using these, they hesitate to discuss them with their treating doctor. That is a pity, according to Daniëlle Verbeek, internist-oncologist at the Martini Hospital in Groningen. During the AYA parallel session 'Complementary Care', she discussed potentially favorable and potentially unfavorable effects of complementary therapies and shared the experience she gained at the Integrative Medicine Service at the Memorial Sloan Kettering Cancer Center (MSKCC) in New York.

Dr. Eveliene Manten-Horst started this session by quoting an AYA: "If I want to discuss complementary care options with my doctor, he says: 'Don't throw away your money. Why not buy a new pair of shoes instead?'" At the MSKCC in New York, Daniëlle Verbeek has gained experience with evidence-based complementary care implemented in both clinical and outpatient cancer care. Verbeek says: "The aim of complementary care is to supplement regular treatment strategies. Although some forms of alternative medicine are given instead of regular treatment, this is absolutely not how it should be. Integrative medicine means integrating complementary treatment methods proven to be effective into regular care while considering all aspects of the patient: physical, mental, social and spiritual. This approach is also applied in palliative care. All available scientifically-proven methods to achieve optimal health and boost an individual's self-healing ability are used. Patients with cancer find it important that symptoms of the disease are reduced, side effects of treatments are alleviated and quality of life is improved. There are also signs that some forms of complementary

medicine may have a positive effect on the course of the disease."

This sparked a discussion about weed oil. Verbeek: "Currently, there is no proven anti-tumor effect of weed oil in humans. However, it can help reduce certain symptoms such as nausea." Although some of the participants had very positive experiences with weed oil, there were also less favorable accounts. It is key for doctors and their patients to have an open discussion about complementary therapies. At the MSKCC, the Integrative Medicine Service provides information about complementary care. For instance, this Service has developed a website called About Herbs (www.mskcc.org/aboutherbs). This website is an online database aimed at introducing patients and professionals to the action mechanisms and risks of herbs and supplements, particularly if taken in combination with anti-cancer treatments.

There is room for improvement when it comes to knowledge, attitudes and referrals regarding complementary care. AYA Netherlands is a great platform to help further explore this type of care. So let's get started! ●



- 1 The treating doctor must discuss the risk of a treatment affecting the ability to have children later in life with each woman (and man!) in the fertile age with cancer who will undergo such treatment. To each patient in the fertile age with cancer who will undergo such treatment, counseling by a doctor with expertise in the field of fertility preservation should be timely offered.
- 2 Multidisciplinary consultations are important for tailoring the treatment plan, options regarding fertility preservation and planning.



Record-high proceeds of hAYAcinth action

On 13 January 2017, the national hAYAcinth action was held. Thirteen hospitals participated and were filled with hyacinths, volunteers and AYA-banners. The colorful flower bouquets were being sold like hot cakes. The proceeds amounted to more than 20,000 euros, and will all be used to improve nation-wide AYA care. The hyacinths were offered by generous hyacinth growers, and could be sold thanks to a host of volunteers. The hAYAcinth action was organized based on an idea of **Dr. Eveliene Manten-Horst**.

At the end of the fourth edition of the SPACE 4 AYA symposium on Wednesday 8 March 2017, this impressive check was being handed over. On behalf of all hyacinth growers participating entirely free of charge, growers **Rob van Haaster**, **John van der Slot** and **Gerard Gardien** gave the proceeds amounting to 20,011.15 euros to **Koos van der Hoeven** and AYA **Sophia Sleeman**. "We are very pleased to do this for the AYA Foundation. It makes us very happy", John van der Slot says.

It was a special end to a special day. A toast was made to all the brave AYAs, their loved ones who cannot be missed, the involved care professionals, the very sympathetic hyacinth growers and all the other sponsors, social partners and people who consider AYA care to be a good cause. ●

Food and cancer

In addition to regular hospital treatments, manufacturers have introduced alternative products with the alleged ability to enhance cancer treatments or even prevent cancer. **Prof. Dr. Ron Mathijssen**, internist-oncologist at Erasmus MC in Rotterdam, warns against using these alternative products as they can reduce the effects of prescribed cancer drugs. It is recommended to consult your doctor prior to starting any alternative treatment. It is shown that consuming fish oil or large amounts of fat fish like mackerel or herring when receiving chemotherapy is ill-advised because of the risk of becoming resistant. Resistance prevents the chemotherapy from being successful. It is, therefore, recommended not to consume these foods prior to, during and following chemotherapy sessions. Grapefruit may interfere with treatments, too, as it inhibits enzymes in the liver responsible for metabolizing certain drugs. As a result, the level of the drugs in the blood can become high, which may increase the chance of side effects. Alcohol may disable drug transport and therefore harm the patient when he or she is receiving anti-cancer treatment. It is recommended not to consume these products during treatment. It is often advised to maintain a healthy diet when receiving chemotherapy. But what exactly is a healthy diet? **Prof. Dr. Ellen Kampman**, a professor in Nutrition and Disease at Wageningen University and Radboudumc in Nijmegen, explains the facts and fiction that surround food. She advises to only use food supplements if you are shown to have deficiencies. An excessive supplement intake may increase the risk of developing certain types of cancer or enhance tumor growth. The World

Cancer Research Fund has drawn up dietary guidelines based on the available state-of-the-art scientific research. For more information, please go to www.wkof.nl/nl/kanker-voorkomen/verklein-de-kans-op-kanker. These recommendations also appear to stimulate recovery from cancer. For people who have or have had cancer, it is even more important to take nutrients high in proteins in combination with sufficient exercise in order to maintain muscle strength. Yogurt, fruit and nuts are good sources of protein. Questions regarding food prior to, during and following cancer treatments can be asked on www.voedingenkankerinfo.nl. Many of the patients who have been admitted to hospital do not like the 'hospital food' offered to them. Therefore, a new concept was created and developed in 2013 by the AYA & Food Dream Team led by **Dr. Eveliene Manten-Horst**. This new concept, Food for Care, was gradually implemented Radboudumc-wide in 2015 for all patients, including the children's clinic. Currently, Food for Care is available throughout the Netherlands. The Food for Care Foundation has been set up to stimulate research into the subject of cancer and food. Research is being conducted, for example, into the well-being,

fitness and physical state of patients participating in this new 'Food for Care' formula. At the Space 4 AYA symposium, **Dorian Dijk-hoorn**, physician-researcher at the Department of Gastroenterology and Hepatology at Radboudumc, presented the preliminary results of the clinical study examining the effects of Food for Care. The results, which seem to be promising, are under embargo until they are published. They will be published shortly. ●

Take home messages

- For patients: check which foods and food supplements can or cannot be consumed when receiving anti-cancer treatment.
- For care professionals: know how to inform and refer your patient.
- Create an open, safe environment, allowing this subject to be discussed more easily.



Research gives valuable information about quality of life

Research conducted by **Dr. Olga Husson** at the Department of Medical Psychology of Radboudumc, Nijmegen showed that 176 American AYAs with cancer had far worse scores on quality of life (QoL) upon diagnosis compared to control subjects.¹ "Although the QoL of AYAs had improved after one and two years, their scores were still relatively poor. This suggests that AYAs may benefit from supportive care even in the second year following diagnosis", Husson says. Husson and her colleagues found the same results in 83 Dutch AYAs with cancer. Husson explains: "Female AYAs and AYAs receiving palliative treatment in particular had lower scores on QoL." **Hanneke Poort**, who works at the same Department, studied the prevalence and potential treatment of severe fatigue in this AYA group. Poort says: "In the group of AYAs with cancer, 48% suffered from severe fatigue compared to

20% of the control subjects (n=249; p<0.001). Compared to the group of non-fatigued AYAs with cancer, the AYAs with severe fatigue reported lower QoL scores regarding the physical, mental, social and spiritual domains." The preliminary results of a subgroup analysis performed by Poort and her colleagues showed that cognitive behavioral therapy is associated with lower levels of fatigue in disease-free AYAs compared to an expectant approach.² Research conducted by **Suzanne Kaal**, internist-oncologist at Radboudumc, shows that AYAs with cancer have relatively high scores on empowerment: personal strength and resilience, social support and position within and interaction with healthcare and society. "Women have lower empowerment scores than men. Related factors included autonomy, social support and coping with problems", Kaal says. According to her, AYAs with relatively low

scores on empowerment could benefit from self-management interventions, cognitive behavioral therapy and the online AYA community, among other things.³

An important goal for cancer patients after receiving treatment is optimal participation in society by following rehabilitation therapy. "Recently, the Ciran rehabilitation foundation and Radboudumc have initiated a pilot study into the effects of aftercare and medical rehabilitation interventions on participation among twenty AYAs with cancer. The aim of the study is to improve the interprofessional collaboration between the different care levels as well as the self-management, QoL and autonomous participation among the AYAs. If the results turn out to be positive, we intend to make this type of rehabilitation care available throughout the Netherlands", says **Dr. Jan-Paul van den Berg**, rehabilitation specialist at Ciran.

References

1. Husson O, et al. J Clin Oncol 2017;35:652-9.
2. Gielissen MF, et al. J Clin Oncol 2006;24:4882-7.
3. Online AYA-community te raadplegen via AYA4net.nl

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