

Space 4 AYA 2016

On Tuesday 8 March 2016 the third Dutch SPACE 4 AYA symposium 'Young & Cancer' was held at the Galgenwaard Stadium, Utrecht, the Netherlands. AYA stands for Adolescent & Young Adult, 18 to 35-year old young adults, who have been diagnosed with cancer for the first time in this life phase.

About 250 participants, including care professionals and AYAs, came together on this day to discuss the improvement of age-specific care and scientific research into 'cancer at the AYA age'. AYA ambassador Joan Strik opened the symposium and it was impressive to see how she incorporated her own experiences as chairman of the day. She shared this task with Tom van 't Hek.



'Is it an outpatient clinic or not?'

The AYA care concept and the National AYA Platform initiative

Dr. Suzanne Kaal (internist oncologist AYA, AYA Platform Radboudumc, Nijmegen) was the first speaker at the symposium. The AYA concept originated from the 'founding mothers' Prof. Winette van der Graaf and Prof. Judith Prins, of the Radboudumc. In contact with young adults it was found that there was a huge need for age-specific integrated care with attention for both medical-technical and psycho-social aspects. Kaal: "After being diagnosed with cancer, young people ask themselves what will happen to their studies,

treating specialist. How to deal with cancer and the side-effects of the treatments? These are questions for the AYA nurse specialist and the multidisciplinary team of the AYA clinic.

- The AYA4 community. This is an online hang-out for AYAs where they can meet young people in the same situation, exchange information and make contacts in a safe protected environment.
- The AYA lounge in the hospital. During treatment at the hospital AYAs can withdraw to this lounge, receive family and friends and just 'chill out'.

A national start was also made by an initiative of the AYA Platform Radboudumc in 2013, with the arrival of AYA superintendent **dr. Eveliene Manten-Horst**. This resulted in a knowledge platform 'cancer at the AYA age', the national AYA Platform. AYAs and professionals from the eight umcs and a number of general hospitals participate on this platform with the aims of distributing and establishing age-specific integrated AYA care throughout the Netherlands, stimulating scientific research at the AYA age and maintaining the quality of AYA care by means of (interdisciplinary) training and education modules. There are now two AYA clinics up and running (in the Radboudumc and the UMC Utrecht) with a third on the way. The goal is six AYA multidisciplinary outpatient clinics in the Netherlands.

whether they can go to work and whether they can still get a mortgage. Whether sex can still be fun and what the situation is with your fertility if you are being treated for cancer."

In the Netherlands 2,700 young adults (AYA, Adolescent & Young Adult) in the age group 18-35 are diagnosed with cancer for the first time. In collaboration between care professionals and AYAs, with the AYA Platform Radboudumc as an inspiring pilot, concrete care components have recently been developed and established step by step in a flexible manner. Care that pays attention to the question: 'Who are you and what do you need?' Components of the integrated AYA care are:

- The multidisciplinary AYA outpatient clinic managed by the nurse specialist. The clinic does not take over the medical-technical treatment: this remains in the hands of the

for friends and family and for care professionals) and there are three AYA lounges (in the Radboudumc, the LUMC and the UMC Groningen). The aim is to have six AYA outpatient clinics distributed throughout the Netherlands and to expand the number of lounges. A lot of energy is also being invested in setting up scientific research on 'cancer at the AYA age' and making a multidisciplinary education module 'age-specific care'. And the national AYA symposium SPACE 4 AYA, organised for the first time in the Goffert, Nijmegen in 2014, is now a permanent fixture.

Rosemarie Jansen, AYA nurse specialist, Radboudumc, and board member of the National AYA Platform: "Young people are very strong. You want to make sure that they remain strong or get strong again as quickly as possible. How does AYA care work? The treating doctor can refer the AYA to the AYA clinic and as an AYA you can make an appointment with the nurse specialist at the AYA clinic. You can do this during and also after the treatments. The nurse specialist is part of the AYA team and will listen to his or her questions as well as look for possible answers together with the AYA. Even if there are no answers, it helps to formulate the questions. This alone

already helps young people deal with cancer. AYAs might not know what their question is. An AYA questionnaire has therefore been drawn up with the help of AYAs. The list can be downloaded at www.aya4net.nl The AYA clinic covers all phases: before, after and during treatment. But also for family (parents, partners), employers and study advisors. We have built up the knowledge on what happens and can guide people who are experiencing this for the first time. As an AYA you don't know what is ahead of you. We can give you an idea of what your treatment will require from you, what you will or will not have the energy for, and what the possible alternatives are for the stages you have to go through. Also questions like "How will I get money to live from? How do I go about applying for jobs? What do I say about my illness? You can practice these conversations with us. How do I go about re-integration? What expectations should I have? What is the impact of tiredness?"

It is also unfortunately the case that 1 out of 4 AYAs die. Questions here are: "How do I want to do this? Where do I want to die? How do I go about this? How will I spend my time?" These conversations can be held at the outpatient clinic, but also if you have been admitted to hospital. They can be held anywhere, in fact, but always in consultation with the AYA and multidisciplinary team, and in close consultation with your own treating doctor. So: in analogy of 'think out of the box'; 'think out of the AYA outpatient clinic!' ●



Suzanne Kaal



Rosemarie Jansen

Music of Theatre Group Plezant

"Happiness is the greatest when connection is made at the highest level, and the soul of the one, touches the soul of the other"

Theatre Group Plezant provided the musical entertainment again in between the presentations this year. The AYA Platform and theatre group Plezant have been associated with one another for four years. Mutual inspiration results in music that touches you. "We're looking for everything of value, and that's something that AYAs know all about! You inspire us tremendously." Plezant inspires us too, by bringing out the great single 'Leef', powered by and dedicated to AYA Jip Keijzer. Plezant came into contact with the AYA Platform via Jip. On SPACE 4 AYA, in the presence of Jip's proud parents, Plezant said that the single 'Leef, powered by Jip' was being released as a cd single that day and is going to all radio stations in the Netherlands. You can download the number and all net proceeds go to stichting AYA. So download this great song for € 1.99 at <http://www.plezant.nl/product/leef-powered-by-jip/>.

Eveliene and Joan wanted to thank Plezant for this collaboration and presented **Walter Supèr** and **Tom Meulman** of Plezant with a gift. "Jip was a lovely and inspiring person who looked so much further than his own illness. He even dared to ask himself the question 'Is cancer a gift?' ", according to **dr. Eveliene Manten-Horst**, "Jip was there right at the very start of age-specific AYA care." ●

FoodforCare

FoodforCare is a unique food formula and a joint initiative by young (AYA) cancer patients, the Radboudumc and **Maison van den Boer**. FoodforCare aims at tasty, sustainable and affordable dishes with high nutritional values that improve appetite and contribute to patients feeling better. All the dishes have been specially developed with fresh, pure ingredients and contain important nutrients that the patient needs during treatment and recovery. Taste, smell, nutritional values – such as proteins and calories – and portion size are adjusted to the various patient groups. Six times a day patients can choose small à-la-carte dishes. These are provided actively by motivated food assistants who advise patients with the right ‘tone of vibe’ and encourage them to eat.

What started in 2013 as a pilot for oncology patients in the Radboudumc, has developed in 2016 into a real company with the focus on AYAs. FoodforCare is available to all care institutions and hospitals. We are also working on providing this in the home situation.

In addition to the FoodforCare Holding, the FoodforCare Foundation has also been set up. **Ralph van Renselaar**, AYA and nutritionist with his own sports nutrition company, is an enthusiastic member (secretary) of the foundation. He says this was set up for the general interest to stimulate and subsidise scientific research that focuses on the relationship between food and cancer. In addition, the foundation also contributes to the objectives of the National AYA Platform. One of the first studies it is subsidising is research into the relationship between the FoodforCare formula and patient recovery and wellbeing. ●

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Late effects after treating AYAs with cancer

Some AYAs with cancer experience negative effects from their treatment at a later age. More information on these long-term effects is being obtained by international scientific research and long-term follow-up. Based on this knowledge the risk of these effects can be reduced, for example by adjusting treatment or lifestyle.

Although most cancer treatments are successful for AYAs, as a result of treatment there is also an increased risk of negative long-term effects. In addition to psychosocial effects, there may be numerous physical side-effects. These may vary from tingling limbs and tinnitus



Winette van der Graaf

to tiredness and the development of cardiovascular diseases and secondary neoplasms. As the result of global scientific research more and more is known about the incidence and risk factors of these late side-effects in young people with cancer.

“Our research shows, for example, that AYAs have a lot of late side-effects with osteosarcomas. However, there is a lot we do not know yet, for example the role of someone’s genetic predisposition. We are currently working on getting these kinds of questions on the agenda through a European collaborative venture”, says **Prof. dr. Winette van der Graaf**, chairman of the National AYA Platform and internist oncologist at the Royal Marsden Hospital in London. During the symposium Van der Graaf was awarded the first AYA award for her special services for the national AYA Platform.

Prof. Jourik Gietema, member of the National AYA Platform and internist oncologist at the UMC Groningen, says the long-term effects of cancer treatment result from the specific combinations of the treatments given. Factors that play an important role here include age, gender, genetic predisposition and lifestyle. One of the possible long-term effects is the development of cardiovascular diseases, for example in AYAs who have been treated for testicular cancer.

Gietema: “Our research shows that twenty years after their treatment these AYAs have a slightly higher risk of cardiovascular diseases compared to a control population. Moreover, the research shows that among these young men in the period after their treatment the number of risk factors for cardiovascular diseases increases. Examples of these risk factors are obesity, high blood pressure, diabetes and a raised cholesterol level. The research also shows that AYAs who were treated for testicular cancer with cisplatin still have cisplatin residue in their blood a long time after their treatment. These raised platinum levels can cause damage to the endothelium which is associated with the occurrence of atherosclerosis and accelerated aging.” It is therefore very important to weigh up the advantages and disadvantages of a treatment carefully. Moreover, in connection with the late toxicity it is important to monitor the patient carefully for an extended period after treatment using a survivor care plan. “In Groningen we have developed, for example, the Shared-care Follow-up project, where the follow-up is carried out together with the GP”, says Jourik Gietema.¹

Another important long-term effect of cancer treatment is the development of secondary malignant neoplasms. These new neoplasms are associated with considerable morbidity and mortality. The number of patients who



Michael Schaapveld

after a first neoplasm are diagnosed later with a new neoplasm has been increasing in recent years. In the Netherlands in 1990 in 10% of all new cases of cancer a secondary neoplasm was found, while this was 17% in 2013. “It’s important here to realise that probably only a small part, possibly 5-10%, of these secondary tumours is the result of a previous treatment with, for example, radiotherapy or chemotherapy. In most cases environmental factors, lifestyle and/or genetic predisposition will have played an important role in the occurrence of the second cancer. However, clinical research shows that, for example, after radiotherapy within the radiation field there is a significantly increased risk of the development of a second tumour”, says **dr. Michael Schaapveld**, researcher at the Antoni van Leeuwenhoek hospital in Amsterdam. ●

Reference

1. Shared-care Follow-up project. Information available at www.survivorcare.umcg.nl



Eveliëne Manten-Horst en Tom van 't Hek

How do AYAs look at late effects?

Hurrah! You have finished your treatment. Unfortunately in practice this is just the start for many AYAs. You have to process what has happened to you and deal with the late effects of cancer. These involve much more than physical complaints such as tiredness and post-operative effects. AYAs are often completely unaware of the other physical effects, including the likelihood of the occurrence of cardiovascular disease or secondary tumours. The way you perceive your identity has changed and you are aware of the uncertainty of the future. There is also the social impact of cancer; friendships are put under strain and you connect with your peers in a different way.

As an AYA you are unable to move forward with your life as so many areas are out of balance at the same time and this is really frustrating. AYAs develop characteristics that they didn't know they had. Although they should be proud of it, it is also difficult as there is no choice:

allowing yourself to be vulnerable, letting go of control, living in the now, having a sense of humour and resilience. These tools reflect their environment in a special way. This can



Anna Tulkens

What can we learn from AYAs about survivorship and how?

Since 2009 a start has been made with the development and implementation of age-specific holistic care for young adults with cancer in the 18 to 35 age group in a collaborative venture of AYAs and enthusiastic care professionals in the Radboudumc. As the first spin-off of this care an AYA clinic, an AYA lounge and an AYA online community were set up. This care is now national with the start of the national AYA Platform in 2013, a knowledge and expertise network with involved care professionals, AYAs and their friends and families. The Dutch Cancer Society has also given me, **dr. Olga Husson**, a fellowship grant to conduct research. The main aim of this fellowship is to identify the components that are needed from the AYA perspective to continue offering state-of-the-art AYA care in the future. Three questions are central here:

1. Who is the AYA patient? Including: What are the physical and psychosocial problems AYAs deal with? What internal sources of strength can AYAs call on? What are the (unfulfilled) care needs? What do AYAs expect from the care system and the health care professional?
2. Which care elements foster AYA patient-centered care? Including: How is the current AYA care (age-specific clinic, community, lounge) evaluated? What elements must be present in the care system to fulfil care needs? What barriers to provide AYA patient-centered care are experienced by health care providers??
3. What (psychosocial) interventions are needed in addition to the current AYA care initiatives? Examples could be tools for self-management, communication, and survivorship care plans.

The first findings on question 1 were presented during SPACE 4 AYA. At that point 47 AYAs had completed a questionnaire about their (unful-

filled) care needs. 44% of the AYA's had one or more unfulfilled care needs during treatment, particularly in the areas of psychosocial support, answers to age-specific questions, the inability to get a referral to the AYA clinic and lack of contact with other AYAs. After treatment it was found that for 57% one or more care needs were not met, specifically in the areas of career, re-integration, sexuality, fertility, uncertainty about future, buying a house, and attention for needs of family. AYAs also indicate that more research is needed in the area of prevention (how do you get a young person to go to the general practitioner with complaints?); communication and relationships with partner, parents and friends; issues that survivors have to deal with, such as sexuality (not thinking in problems, but in solutions), fertility (what are my options?), physical activity and sport (what is good for me? The current physical activity interventions are aimed at the 'older' patient); psychosocial support for men with cancer (care does not meet the needs of men). A large national study will be conducted in 2016/2017 to answer the remaining research questions of this fellowship. ●



Olga Husson

also result in uneasiness, as there is a lot of pressure on you to always be strong or to be the example.

But on the other hand there is this healthy aversion to being pampered by your surroundings. AYAs need help dealing with this. The professional care provider should support the AYA through all these problems and be prepared to discuss them with young people, like they do at the AYA clinic. By recognising where the questions, worries or struggles of AYAs come from, and what the pitfalls are, he/she stands 'above' the AYA. In this way he/she helps the AYA to put what is happening to him or her in perspective, so you can arrive at the right care questions and set priorities together at that point in time. Helping the AYA obtain

an overview of and insight into the situation: obtaining recognition and acknowledgement and grip – all this helps.

Ideal aftercare means: more knowledge of and attention for the physical and psychosocial late effects, supervision of the AYA's study/ employer/colleagues by the AYA clinic, personalised aftercare meetings by the AYA clinic, more national recognition of the AYA clinic, and more AYA clinics in the Netherlands. In addition, AYAs need a case manager who provides an overview like a drone for, and with AYA, provision of practical information on late effects, low-threshold theme meetings, and recommended professional care providers (with knowledge of AYA problems). ●

In the spotlight

Two sponsor campaigns for the National AYA Platform hand over their cheques to SPACE 4 AYA to superintendent **dr. Eveliene Manten-Horst** and AYA **Marieke Deutz**. **Martin Schouten** and **Gert-Jan van Hunnik** took on the challenge of the ScanCovery Trail as team 33. In this 8-day ice-cold road trip adventure the team drove criss-cross through Scandinavia. In this period they covered 6,500 kilometres. Temperatures dropped to minus 40 degrees celcius. So to the question: "What was it like?" the men just laughed and said: "Really cold!" This sponsor campaign raised € 11,575!

This year for the second time the National 'HAYAcinth' action was held. On 8 January in eleven hospitals, affiliated to the National AYA Platform, hyacinths were sold by AYAs, family, volunteers and care professionals. They raised the huge sum of € 16,360 which was handed over by hyacinth grower John van der Slot and Gerard Gardien of Royal FloraHolland. The growers donated the hyacinths for free and together with a number of sponsors made this action possible. All those who contributed to this were thanked for their effort. ●

AYA care: better and affordable?

Dr. Mariska Koster of the Dutch insurance company Zilveren Kruis: "I'm going to talk about money, about the problems of funding the care."

"You are dealing with three markets, the patients, the insurance companies and the provider markets. In addition, you have the supervisory bodies. The state does want market forces, but also wants to be able to monitor the situation. And then there are stakeholder associations. These players together are the representatives of 'the money' in care. If you translate this to the citizen, you can see that he or she spends 25% of his or her income on care. Via (income) tax and via the insurance premium. If the development trend of the past few years persists, this will soon become 40 % of total income.

Basic care is a right. You are entitled to care if you have basic insurance. The care insurer has a duty of care, the duty to buy enough care so that everyone can have the care that he or she needs. The package must be effective and



Mariska Koster

efficient. This is based on knowledge of the science plus practical experience. Doctors determine whether a patient is eligible for this care. The Minister of Health, Welfare and Sport determines what is included in the

Moving forward! What can you expect from the National AYA Platform in 2016 and beyond?

Chairman for the day **Joan Strik** and superintendent **dr. Eveliene Manten-Horst** summarise the day and look ahead. The day was once more inspiring and informative and included, among other things, the call for a holistic approach to AYA care and also attention for late effects such as with a survivor care plan. In 2016, the 3rd AYA clinic will be opened in Rotterdam and perhaps even a 4th and a 5th AYA clinic!

They made the point that AYA care is multidisciplinary and that for this reason an education module has been developed for professionals from various disciplines. As fellow of the Dutch Cancer Society **dr. Olga Husson** will carry out a study into the effects of AYA care, with specific focus on the psychosocial care needs of AYAs. These needs are very different from the needs of patients who fall outside the AYA age.

Funding for AYA care is also needed. Although the fundraising activities have brought in a lot of money, even more sponsors are needed. More structural funding for AYA care is also needed.

Tom van 't Hek concluded: "The AYA platform is a powerful movement because AYAs and care professionals strengthen and embrace one another. This is an example for health care in the Netherlands." Bring on next year! ●

package. This means that the common complaint 'the insurer won't pay' is not completely true.

The care we receive is provided by a care provider and paid for by the care insurer. This does not and should not happen automatically. The Dutch Health Authority (NZA) checks the terms on the basis of which a care insurer can reimburse costs. Payment is based on 'care products': everything you can think of that happens during patient care in a hospital. From taking blood to moving the patient's bed, every care activity is linked to an amount. The difficult thing is that every broken wrist is not the same. The solution to this is an average price. And the price of these care products is negotiable.

The question is whether the help these AYAs need is included in the care products. If it is, it is a question of negotiating. But if it isn't, Zilveren Kruis can't do anything. Is this the state of science and practice? Do we want to pay for this? It is the minister who ultimately determines this. If you provide a care activity that is not included in the care products, is the hospital using the right codes? In order to solve this, Zilveren Kruis is partly dependent on the NZA. A fresh look needs to be taken at provision, as has been done for child clinics. So this is not easy." ●

Is inclusion of AYA care in SONCOS standardisation document an option?

The standardisation document of the Stichting Oncologische Samenwerking is vital for the desired quality and quantity norms for oncological care in the Netherlands. During the SPACE4AYA symposium it was discussed whether it is desirable and possible to include AYA care in the standardisation document.

The Stichting Oncologische Samenwerking (SONCOS) forms a leading Dutch platform for interdisciplinary discussion and cooperation between specialists (churgeons, oncologists and radiotherapists) within oncological care. Two of the main objectives are the definition of the conditions for good oncological care and the laying down of these definitions in a normative standardisation report. The National AYA Platform also drew up norms for the policy and the working method within the

AYA care. Inclusion of these norms in the leading SONCOS standardisation report could contribute to a broader awareness of the specific AYA care among care professionals, improvement and guarantee of care for AYAs and the training of dedicated doctors and nurses. During the SPACE 4 AYA symposium **dr. Michel Wouters**, SONCOS chairman and oncological surgeon at the Antoni van Leeuwenhoek hospital, discussed together with the public what possibilities exist within this framework.

"SONCOS is positive about the initiatives around integrated, age-specific care. Inclusion of norms for this care in the SONCOS standardisation document could result in a better awareness of the specific aspects of AYA care. Before these norms are included, however, it is important to properly lay down the definition and status of AYA care. For example, is there national cover with AYA

expertise clinics and what collaborative ventures are there? What about availability and accessibility?

I think that SONCOS can help answer these questions. Moreover, the SONCOS standardisation report is a dynamic report that in principle we can amend each year. So it is possible to write something next year that contributes to a better awareness of AYA care and its added value. So it is possible in a few years' time, when a broader platform has been created for specific AYA care, to also actually include norms for this specific area in the standardisation document", says Wouters. Superintendent of the National AYA Platform, **dr. Eveliene Manten-Horst**, added here that the National AYA Platform SONCOS can support this and can feedback to SONCOS how patients can be a vital and distinctive addition to standardisation. ●

Fertility problems in AYAs with cancer

The treatment of cancer may be linked with fertility problems. For AYAs with cancer discussion of fertility and if possible preserving this is therefore an important subject. During the recent SPACE 4 AYA symposium the complex issues of fertility and preserving fertility were high on the agenda.

Fertility and having children are important aspects of the quality of life for many AYAs. "This means that the risk of fertility problems and the available options to maintain fertility need to be discussed as early as possible in the treatment process. It is desirable that all AYAs are referred to a fertility specialist for professional counselling on options and wishes. Although we are happy to see that the number of informed AYAs is increasing every year, we know from practical experience that there are still AYAs with whom fertility is not discussed", according to **dr. Ina Beerendonck**, employed as gynaecologist Reproductive Medicine at the Radboud-umc in Nijmegen. How can the fertility of AYAs be maintained during their cancer treatment? "With post pubertal female AYAs both unfertilised and fertilised egg cells can be frozen. To do this the patient must be treated with hormone injections for two to three weeks, which with breast cancer, for example, can have a stimulating effect on the tumour cells. Although we think that this effect is limited, it is still a risk that has to be taken into account during counselling.

A second option with both pre pubertal and post pubertal women with cancer is to freeze ovarian tissue and once the cancer has been cured, to put it back in the body if the woman is then infertile. Up to now about 60 healthy babies have been born using this experimental procedure. This method does, however, involve

a 60-70% loss of egg cells. So it is always important to weigh up this loss against the loss of egg cells as the result of the cancer treatment. Moreover, with patients with leukaemia for example, there is the risk of reintroducing cancer cells with the egg cells", says Beerendonck. It is noticeable that although there are fewer male than female AYAs, more male AYAs are referred (from whom sperm cells are always frozen), while the female AYAs are not referred as often (for whom fertility preservation is used in 50% of the cases). So Beerendonck says there is still room for improvement.

To maintain and, where necessary, improve good care around fertility preservation with cancer in the Netherlands, an update of the national guideline 'Fertility preservation for women with cancer' will be published during the course of 2016. "For the first time AYAs also had a seat on the guideline committee that put together this update and will publish a version for patients. New subjects include the remaining ovarian function and fertility preservation after the cancer treatment, and the consequences and treatment of premature menopause", says Beerendonck.

To close this session a discussion was held based on a detailed mind map made by AYAs, on the theme 'The desire to have children'. This mind map gives a clear impression of how complicated this theme is with about sixty subjects that are important for AYAs. Examples of these subjects are fear, partner, heredity, identity, grief and hormone sensitivity versus the desire to have children. **Dr. Eveliene Manten-Horst**, superintendent of the National AYA Platform, says it is important that the treating doctors discuss fertility with the AYAs and refer them to a fertility specialist. They must also realise, however, that wanting to have children is ulti-



Ina Beerendonck

mately the decision of the AYA him or herself. A large Dutch study shows that making the subject available for discussion gives the AYA the feeling that he or she has some control of the situation. Also in some situations there is no option to preserve fertility. In such cases aftercare in the area of deferred mourning must be provided.

The care we receive is provided by a care provider and paid for by the care insurer. This does not and should not happen automatically. The Dutch Health Authority (NZA) checks the terms on the basis of which a care insurer can reimburse costs. Payment is based on 'care products': everything you can think of that happens during patient care in a hospital. From taking blood to moving the patient's bed, every care activity is linked to an amount. The difficult thing is that every broken wrist is not the same. The solution to this is an average price. And the price of these care products is negotiable.

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