

SUPPORTIVE CANCER CARE IN BELGIUM: STATE OF PLAY AND FUTURE DIRECTIONS. CONFERENCE REPORT

22 MARCH 2024

Supportive cancer care in Belgium :
State of play and future directions.

15:30 | Eurostation
20:00 | 1, Ernest Blérot
Room Storck

BeONCOsup


Date: 22.03.2024

Venue: Eurostation 1, Ernest Blérot, Room Storck, 1070 Anderlecht

Attendees: 73

EVENT OVERVIEW:

Due to improved diagnostics and treatment, **more and more people are surviving cancer**. In Belgium, there were 472,360 people alive at the end of 2020 who had received a cancer diagnosis between 2011 and 2020. However, these successes bring new challenges, with a growing need for attention to (chronic) symptoms during and after treatment, which is essential for ensuring a good quality of life of cancer patients and their relatives. There is growing awareness that supportive care is crucial for the well-being of cancer patients. Nevertheless, patients don't have equal access to this support, partly due to unclarities for professionals regarding the available and accessibility of the supportive care offer. Supportive cancer care also remains under the radar in the absence of a coordinated policy, very few initiatives have been taken to formally organize supportive care (especially in the aftercare phase).

This event brought together professionals of Belgian institutions and patients to foster dialogue and exchange about the current and future organisation of supportive cancer care, strategies to improve the organisation of supportive care in cancer, and to gain insight in the experiences of patients with supportive care services.

15:30 – 16:00	Registration
	Welcome and introduction
16:00 – 16:20	<i>Marc Van den Bulcke</i> (Belgian Cancer Centre - Sciensano) <i>Anouk Waeytens</i> (Cabinet of Minister of Social Affairs and Public Health)
	Keynote speeches: Supportive cancer care - Survivorship: where are we now?
16:20 – 17:05	<i>Jean Klustersky</i> (Cancer Supportive Care Task Force - BSMO) <i>Florence Van Ryckeghem</i> (Cancer Survivorship Task Force - BSMO)
	Keynote speeches: Patient perspectives on supportive cancer care
17:05 – 17:35	<i>Kayla Rifaâd</i> <i>Marieke Colpaert</i>
	Presentation: Belgian Handbook for (Hemato)-Oncological Supportive Care
17:35 – 17:50	<i>Sofie Theys</i> (Belgian Cancer Centre - Sciensano)
	Presentation: Belgian Network of Oncological Supportive Care
17:50 – 18:00	<i>Régine Kiasuwa Mbengi</i> (Belgian Cancer Centre - Sciensano)
	Reception with presentation of Belgian initiatives regarding oncological supportive care
18:00 – 18:50	<i>Ann De Zitter</i> (Axxon) <i>Andrea Cornez & Jerome Van Lindth</i> (Bao Academy) <i>Juliette Berguet</i> (Baob Brussels) <i>Nathalie Deleu & Isabelle Paelinck</i> (Oncobulle) <i>Régine Simonis & Alexandra Paye</i> (Oncococon) <i>Nathalie Vanlaer</i> (UZ Brussel - CHU Brugmann)
	Roundtable: State of play and future directions for supportive cancer care and survivorship in Belgium
18:50 – 19:50	<i>An Lebacq</i> (Stichting tegen Kanker/Fondation contre le Cancer) <i>Bernard Willemart</i> (Espace bien-être l'Essentiel - Namur) <i>Christel Fontaine</i> (BSMO taksforce Supportive Care - Survivorship) <i>Dirk Van Gestel</i> (Belgium Board of Oncology) <i>Michiel Daem</i> (Universitair Ziekenhuis Gent) <i>Hans Neefs</i> (Kom Op Tegen Kanker) <i>Magali Mertens</i> (ASBL Travail et cancer) Excused
	Closing remarks
19:50 – 20:00	<i>Karin De Ridder</i> (Wetenschappelijk Directeur, Epidemiologie en Volksgezondheid – Sciensano)

1. General introduction



Anouk Waeytens reflected on the importance of supportive cancer care, stating that it is a cornerstone of modern oncology. From managing symptoms and treatment side effects to providing psychosocial support and enhancing communication and socio-professional integration, **supportive care plays a vital role in improving the quality of life** for those affected by cancer. She reflected on the importance of the BeONCOsup project in supporting professionals in offering guidance and resources to navigate their patients and their families through the challenges of their journey. She also emphasized the pivotal role of supportive care in enhancing communication and decision-making among patients, families, and healthcare providers by facilitating open and honest conversations about treatment options, goals of care, and end-of-life preferences.

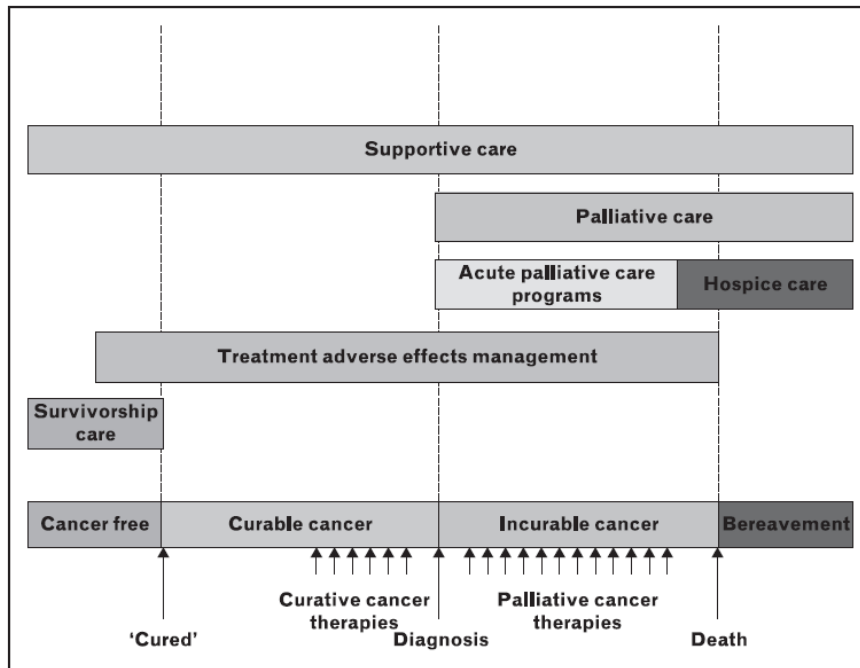


Marc Van den Bulcke further welcomed the participants to the event and reflected on the EBCP as well on the next plan of the European Commission on mental health that is in the pipeline and could be an opportunity to set up as well supportive care initiatives for oncological patients.

2. Keynote speeches: Supportive cancer care - Survivorship: where are we now?



During his presentation, **Prof. Dr. Jean Klastersky** discussed the history of supportive care in oncology and new emerging concepts. He stressed that autonomy for the patient is an essential part of supportive care. Key areas in which medical expertise should be available in order to provide adequate supportive care were discussed. The introduction of immunotherapy broadened the spectrum of complications that were unknown before and had as a consequence that medical professionals had to learn a new approach of medicals related to immune adverse events. Dr. Klastersky further clarified the **concept of supportive cancer care**. It is an umbrella concept that applies to the entire duration of the disease, addresses all the aspects of the patient, needs multiple competences, and requires international dimension. Supportive cancer care includes support aimed at the well-being and autonomy of the patient with advanced cancer with **attention to early palliative supportive care** for the incurable patient still receiving anti-cancer therapy and palliative support for cancer patients not receiving anti-cancer therapy and considered near to the end-of-life.



Hui et al., Curr Opin Oncol, 2014

Dr. Klastersky stressed the importance of **advance care planning in practice**, yet it is rarely discussed between patients, their relatives and healthcare professionals and usually takes place in the last months of life, in ICU and with physicians who are not part of the patient's primary care team. One of the reasons is that conversations about prognosis are difficult for patients and clinicians. A recent paper by Jackson et al. (NEJM 2024, 390: 63-69) gives more insight into communication about serious illness and end-of-life. In the presentation the role of the **MASCC** (Multinational Association of Supportive Care in Cancer) was further highlighted. The MASCC is a group of professionals that began to research ways to prevent or mitigate the symptoms and side effects that accompany the disease and its treatments. Joining forces, they created an international, multidisciplinary organization to address and promulgate evidence-based practices of cancer supportive care. Towards the end of the presentation the concept of **integrative medicine** was discussed. Integrative medicine can support the needs of cured/stabilized patients. At the end a new comprehensive and stratified concept for supportive care in cancer patients was introduced.



During her presentation, **Dr. Florence Vanryckeghem** started with introducing the definition of survivorship care. A key aspect is regaining as much as possible the important aspects of life before cancer and finding new ways to move forward in a satisfied way. Survivorship is also unique for each individual and caregivers, family, and friends are also part of survivorship. **Survivorship is not survivorship without quality of life.** Some facts related to survivorship were presented: the total cancer mortality rates in the EU declined by 5% in men and 4% in women between 2015 and 2020, Belgium belongs to the top 10 worldwide number of survivors (1076/100000 inhabitants), 67% of the survivors is older than 65 years etc. Dr. Vanryckeghem stressed in her presentation the care survivorship has to involve, including regular controls, monitoring of long-term consequences, prevention, evaluation and management of cancer-related symptoms, coordination between 1st and 2nd line, information about aftercare, encouraging of healthy lifestyle measures, and reintegration work life tailored to the patient. (As a physician it is not enough to ask oneself is the patient disease free, but is my patient free of side effects and satisfied with his/her life?) Further in the presentation some important aspects in survivorship were highlighted such as the changes in family and relationships, fertility/becoming pregnant after cancer, finances and insurances (right to be forgotten), etc. and some symptoms as a consequence of cancer and/or its treatment such as peripheral neuropathy and fatigue were discussed. The importance of telehealth (always in combination with real life contact) and

integrative oncology in survivorship were stressed. Towards the end of the presentation important **challenges in survivorship** care were addressed such as the challenge to identify exact needs, the need for a landscape review of who and what services are available, the access to evidence-based integrative care in survivorship, etc. There is a need for more action and to further organise supportive care - survivorship in Belgium, need for a network of survivorship experts, further development of clinical practice guidelines, specialized working groups, etc.

3. Keynote speeches: Patient perspectives on supportive cancer care



Kayla Rifaâd shed her light as a patient on her experiences with supportive care during and after her treatment. First, she talked about the difficulties and needs she experienced during her treatment. She stressed the difficulties related to isolation, pain, fear of dying, sleep, cognitive difficulties, administrative work related to the disease and some important needs she had such as the need to talk about beliefs, need for appropriate social support, comfortable care, etc. What Kayla experienced as very positive during her treatment was the support from her psychologist who was a liaison person to support her and responded to her needs, requests and difficulties. What she experienced as negative during her treatment relates mostly to the social support. Kayla highlighted the difficulties for her and her family/relatives during that period and the stress/emotional overload she and her family/relatives had to deal with. The administration related to the disease trajectory was most of the time very unclear (Who to go? Where to go? When to go?) and also information related to finances was vague (What kind of aid? Public/private!). After her treatment and during remission Kayla indicated that she experienced difficulties related to fatigue, conflict with family, being alone, death, managing her emotions/stress, managing her anxieties related to disability, work, etc. She stressed the need for psychological support for assimilating the process, understanding and mourning. She also stressed the need for reassurance, presence and support, follow-up and accompaniment. Towards the end of the presentation Kayla summarized the most important difficulties she experienced as a young person with cancer: administrative, financial, social isolation, pain, menopausal symptoms, infertility, sexuality, bereavement, etc. Some important unmet needs for Kayla were the isolation and the lack of facilities for young people and/or immunocompromised people. Follow-up should be tailored to experience and based on active listening. She also missed more psychological support from professionals afterwards. At the end of the presentation Kayla formulated **recommendations based on her experiences with the support:**

- 1) for the social support there should be better coordination and communication between departments, there is a lack of information (“Administration robs patients of their last remaining strength”);
- 2) lack of structures for adolescents and young adults after treatment – hospitalisation. Suggestion to create a specific team for young people in the hospital with a referral doctor, a referral nurse, a referral psychologist, a referral social worker;
- 3) for young people: inclusion of a patient expert to support the medical team and the patient;
- 4) for young people: an established structure for gradual readaptation to active and professional life in each region;
- 5) in general : a comprehensive document given directly on admission, explaining the first steps to be taken during hospitalisation and/or diagnosis, have social workers on the front line at the hospital communicating directly with the appropriate services, create a database for Belgium that brings together all the information needed to ensure that treatment and the post-cancer period runs smoothly, including a list of facilities with professionals who can provide practical help and a list of associations adapted to the disease.



Next **Marieke Colpaert** told her story about her disease trajectory and her experiences with supportive care. Marieke first gave some background details related to diagnose, therapy, rehabilitation and follow-up. In what followed Marieke first talked about her experiences with the supportive care she received. What she clearly missed was more information at the start of the process on sexuality and body image. Fortunately, she had received consultations with a psychologist who also happened to be a sexologist (partner therapy provided a strong foundation). During her chemotherapy Marieke performed supervised sports thanks to AZ Groeninge's test project 'Sterkker onderweg'. What she missed was the automatic referral to exercise therapy as she herself had to find out the offer. The exercise therapy brought multiple positive aspects for Marieke: it made sure she didn't 'sink' after third chemo, but stayed as 'strong', it was a way of gaining control as it was the only thing in her hands, for the rest she had to let go (which is not simple). It was really assuring that the sports was supervised ("so you know what you do is safe"). Something what was really missed during treatment was the AYA support. Afterwards Marieke found support via Warriors against Cancer: an open house in Kortrijk for cancer patients where you could mainly find young people and where everything is young at heart. Further, expertise or support regarding cancer in a young family were important unmet needs that Marieke experienced. A lot of attention goes to people with a child wish but people who have already young children are not that well supported. A lot of services do not provide help before 8 AM or after 5PM. Next Marieke talked about her experiences with survivorship. After the oncological rehabilitation she felt on her own, without guidance on how to keep sporting and perform exercises. She indicated the need for more formal structures (with professional trainers) related to sports and exercise therapy after oncological rehabilitation because the step to regular sport clubs is not easy. Marieke also expressed her need for more attention to the psychological (fears, brain fog, etc.) rehabilitation in oncological rehabilitation programmes. To conclude Marieke formulated **recommendations based on her experiences with the support:**

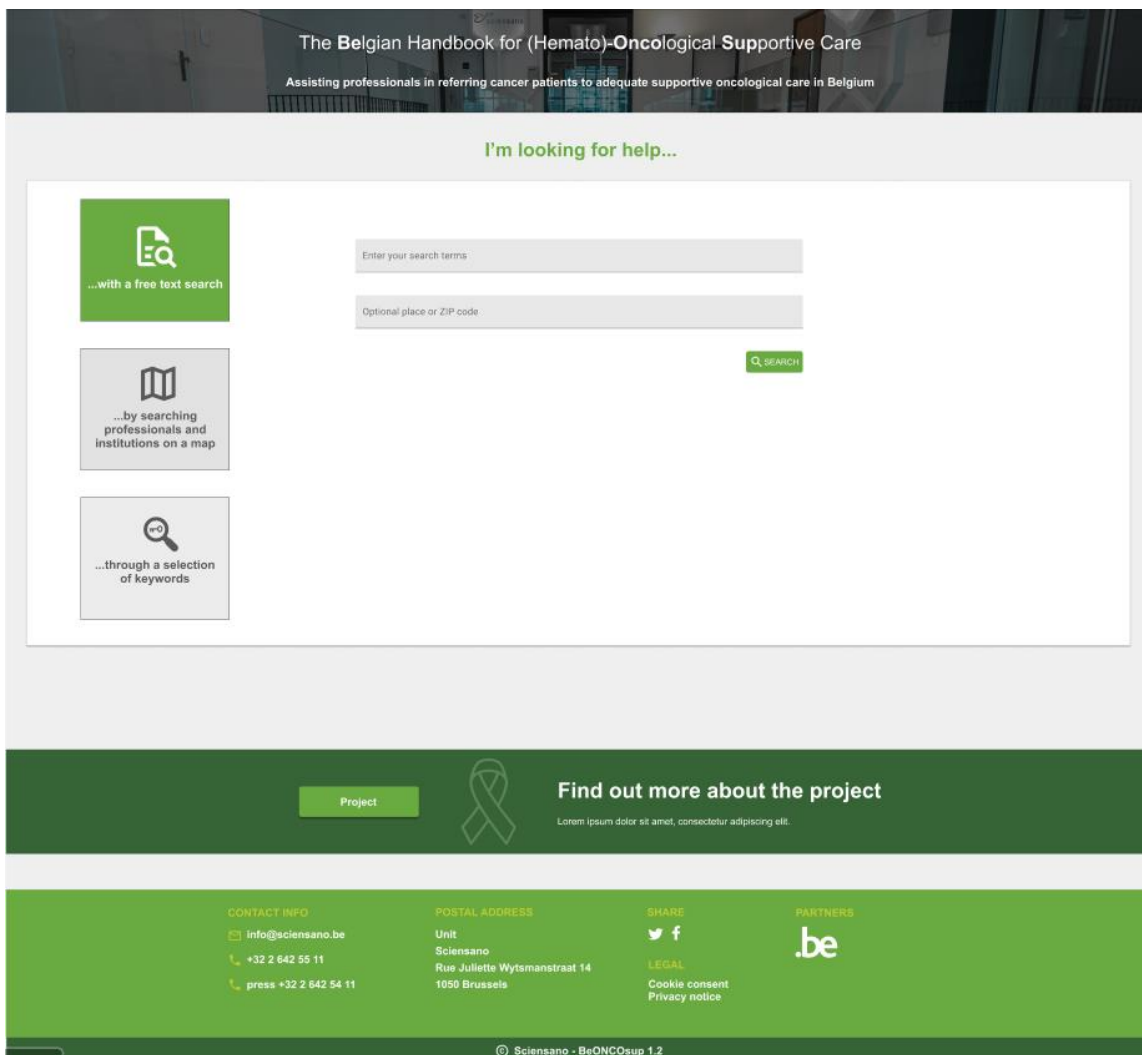
- 1) a standard offer of Mindfulness Based Stress Reduction (MBSR) training in every hospital;
- 2) access to a dietician or lifestyle coach after treatment. Dietician support during chemo is limited to 'not losing too much weight', but for breast cancer patients it is often a matter of being supported afterwards due to the changing hormones and weight gain;
- 3) more attention to partners and children and family support during and after treatment;
- 4) need for the right, tailored information (Marieke wrote a book called 'op de tast' which bundles information on female sexuality after cancer);
- 5) a follow-up consultation for cancer patients of a least one hour;
- 6) free consultation with an oncosexologist and a multidisciplinary approach for sexuality in an intimacy clinic.

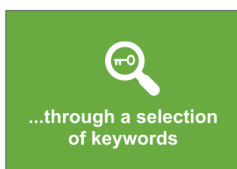
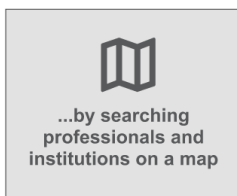
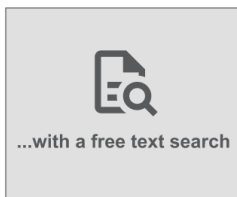
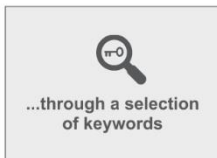
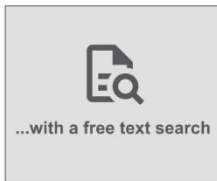
4. Presentation: Belgian Handbook for (Hemato)-Oncological Supportive Care (BeONCOsup)



Sofie Theys presented the BeONCOsup project in which the Belgian Handbook for (Hemato)-Oncological Supportive Care is developed. The idea for the BeONCOsup project arose, on the one hand, on the basis of the general policy note of the cabinet of the Minister of Social Affairs and Public Health (28 October 2022) which described the need for more integrated (oncological) care and more attention to aftercare in cancer patients. On the other hand, results of several scientific projects, co-organised by the Sciensano Cancer Centre, indicated a lack of knowledge among the professionals on available supportive care and specific oncology services for cancer patients (during follow-up). There

is a clear need for a systematic and quality approach that fills in the gap of who can be referred to whom and for what. The Belgian handbook will be developed as an innovative webtool that provides a reliable and up-to-date overview of providers and services offering supportive care for the needs of (hemato-)oncological patients in Belgium. The webtool will also provide support for detecting and assessing care needs, and will support patients and relatives with (low health literacy) by including relevant resources that helps them in understanding their supportive cancer care needs. The development process will also provide the opportunity to identify gaps in the supportive cancer care for Belgium. Currently the first phase of the project is completed in which the structure and preliminary content for the webtool are developed. In phase 1, working groups were organised to map care needs of cancer patients (preliminary focus on the needs after cancer treatment) and thereafter eleven need-specific thematic working group sessions were organised to discuss for each of the needs together with professionals, experts, patient experts, and patient organisations the following content: guidelines, tools, supportive care. By the end of phase 1, a validated list of needs for cancer patients (preliminary focus on the needs after cancer treatment) was developed and a preliminary structure of the webtool was designed. Here below can be found some screenshots of the first mockup of the website. This mockup intends to give an idea of how the webtool will look like and thus not provide content yet. In phase 2 we will continue with an in-depth mapping/collection of information on professionals and institutions providing the supportive care, guidelines and identification/assessment tools for the needs, and relevant sources for patients (with low health literacy). In phase 3, we will build the electronic database with all the contact details for the professionals and institutions providing supportive care.





- Sexuality: sexual functioning
- Fertility
- CRF
- Cognitive dysfunction
- Pain
- Oral Health
- Hearing/voice/vision problems
- Mental Health
- Healthy lifestyle/tertiary prevention
- Palliative care
- Education
- Return to work
- Social, administrative, financial and legal care
- Sleep problems
- Nutrition
- Dyspareunia
- Fertility
- CRF
- Cognitive dysfunction
- Pain
- Oral Health
- Hearing/voice/vision problems
- Mental Health
- Healthy lifestyle/tertiary prevention
- Palliative care
- Education
- Return to work
- Social, administrative, financial and legal care
- Sleep problems
- Nutrition

The Belgian Handbook for (Hemato)-Oncological Supportive Care
Assisting professionals in referring cancer patients to adequate supportive oncological care in Belgium

Dyspareunia

- Description
- Guidelines**
- Tools
- Specialists and supportive organizations
- Information for patients

Dyspareunia (*diss-per-ee-nia*; 'dis-per-OO-nee-a') is painful **sexual intercourse** due to medical or psychological causes. The term dyspareunia covers both female dyspareunia and male dyspareunia, but many discussions that use the term without further specification concern the female type, which is more common than the male type. In females, the pain can primarily be on the external surface of the **genitalia**, or deeper in the pelvis upon deep pressure against the cervix. Medically, dyspareunia is a pelvic floor dysfunction and is frequently underdiagnosed.[1] It can affect a small portion of the vulva or vagina or be felt all over the surface. Understanding the duration, location, and nature of the pain is important in identifying the causes of the pain.

Numerous physical, psychological, and social or relationship causes can contribute to pain during sexual encounters. Commonly, multiple underlying causes contribute to the pain. The pain can be acquired or congenital. Symptoms of dyspareunia may also occur after menopause. Diagnosis is typically by **physical examination and medical history**.

Underlying causes determine treatment. Many patients experience relief when physical causes are identified and treated.

In 2020, dyspareunia has been estimated to globally affect 35% of women at some point in their lives.[2]

Signs and symptoms

Those who experience pelvic pain upon attempted vaginal intercourse describe their pain in many ways. This reflects how many different and overlapping causes there are for dyspareunia [3] The location, nature, and time course of the pain help to understand potential causes and treatments.[4]

Pain due to a long penis or a small vagina

Some describe superficial pain at the opening of the vagina or surface of the genitalia when penetration is initiated. Others feel deeper pain in the vault of the vagina or deep within the pelvis upon deeper penetration. Some feel pain in more than one of these places. Determining whether the pain is more superficial or deep is important in understanding what may be causing the pain [5] Some patients have always experienced pain with intercourse from their very first attempt, while others begin to feel pain with intercourse after an injury or infection or cyclically with menstruation. Sometimes the pain increases over time.[citation needed]

Pain may distract from feeling pleasure and excitement. Both vaginal lubrication and vaginal dilation decrease. When the vagina is dry and undilated, penetration is more painful. Fear of being in pain can make the discomfort worse. Pain may continue despite the original source being removed, due to the learned expectation of pain. Fear, avoidance, and psychological distress around attempting intercourse can become large parts of the experience of dyspareunia [6]

Physical examination of the vulva (external genitalia) may reveal clear reasons for pain including lesions, thin skin, ulcerations or discharge associated with vulvovaginal infections or vaginal atrophy. An internal pelvic exam may also reveal physical reasons for pain including lesions on the cervix or anatomic variation.[7]


When there are no visible findings on vulvar exam that would suggest a cause for superficial dyspareunia, a cotton-swab test may be performed. This is a test to assess for localized provoked vulvodynia [6] A cotton tip applicator is applied at several points around the opening of the vagina; the patient reports the resulting pain on a scale from 0-10.

Project  Find out more about the project
Lorem ipsum dolor sit amet, consectetur adipiscing elit.


The Belgian Handbook for (Hemato)-Oncological Supportive Care
Assisting professionals in referring cancer patients to adequate supportive oncological care in Belgium

Dyspareunia

- Description
- Guidelines**
- Tools
- Specialists and supportive organizations
- Information for patients

 **Belgian guidelines**


There were no guidelines found relevant for the Belgian healthcare context.

 **European guidelines**

Préservation de la santé sexuelle et de la fertilité en cas de cancer ([link to guideline](#))

Organisation : Institut national du cancer (INCa)

Extra information : The guideline is written in French and addresses sexuality and fertility in cancer patients.

 **Non-European guidelines**

NCCN Clinical Practice Guidelines in Oncology: Survivorship

Organisation : National Comprehensive Care Network (NCCN) Guidelines

Extra information : The guideline is written in English and addresses amongst others sexuality in cancer patients.

Erectile Dysfunction: AUA guideline

([include link to guideline](#))

Organisation : American Urological Association (AUA)

Extra information : The guideline is written in English and addresses erectile dysfunction in cancer patients.

The Belgian Handbook for (Hemato)-Oncological Supportive Care
Assisting professionals in referring cancer patients to adequate supportive oncological care in Belgium

Dyspareunia

- Description
- Guidelines
- Tools**
- Specialists and supportive organizations
- Information for patients



Screening tools

Female Sexual Function Index (FSFI)

Aim/domain : Sexual desire, arousal, lubrication, orgasm, satisfaction, dyspareunia, relationship with partner.
Target group : Not specifically developed for cancer patients but validated in patients with breast cancer.
(include link to tool)

The Gynaecologic Leiden Questionnaire (GLQ)

Aim/domain : Female sexual desire, arousal, satisfaction, dyspareunia, relationship with partner and female orgasm.
Target group : (Gynaecological) cancer patients
(include link to tool)



Assesment tools

Arizona Sexual Experiences Scale (ASEX)

Aim/domain : Sexual functioning: sex drive, arousal, vaginal lubrication/penile erection, ability to reach orgasm, and satisfaction from orgasm.
Target group : Not specifically developed for cancer patients; but validated in patients with breast cancer
(include link to tool)

Sexual Function and Vaginal Changes Questionnaire (SVQ)

Aim/domain : Sexual interest, lubrication, orgasm, dyspareunia, vaginal dimensions, intimacy, sexual problems of partner, sexual activity, sexual satisfaction, and body image.
Target group : Gynecological cancer patients
(include link to tool)



Communication tools

The Belgian Handbook for (Hemato)-Oncological Supportive Care
Assisting professionals in referring cancer patients to adequate supportive oncological care in Belgium

Dyspareunia

- Description
- Guidelines
- Tools
- Specialists and supportive organizations**
- Information for patients



Professionals that could be referred to

Physiotherapist specialized in pelvic floor therapy

Role : Application supporting professionals in discussing sexuality with special attention to non-native speaking patients
Costs : Professionals working with non-native
Professionals :

Wolters B.

☎ 0475/65.32.16

✉ info@boukewoltershaptonomie.be

Wolters B.

☎ 0475/65.32.16

✉ info@boukewoltershaptonomie.be

Wolters B.

☎ 0475/65.32.16

✉ info@boukewoltershaptonomie.be

Gynecologic oncologist

Role : explain role
Referral : refer to professionals in hospital
Professionals :

The Belgian Handbook for (Hemato)-Oncological Supportive Care
Assisting professionals in referring cancer patients to adequate supportive oncological care in Belgium

Dyspareunia

Description Guidelines Tools Specialists and supportive organizations **Information for patients**

Websites

<https://www.alliesoverkanker.be/leven-met-kanker/kanker-en-seksualiteit>
Language: explain
Which information is given: explain

Podcasts

<https://www.dsherontdekkingsvanhaarzelf.nl/>
Language: explain
Which information is given: explain

<https://open.spotify.com/show/0mrq8uUUMigSArDTcmJoy>
Language: explain
Which information is given: explain in French and addresses sexuality and fertility in cancer patients.

Brochures

<https://www.kanker.be/sites/default/files/publication/4-3-5-NL-Kanker-en-intimiteit-04-2015.pdf>
Language: explain
Which information is given: explain

5. Presentation: The Belgian Network for Supportive Care (BelNetSup)



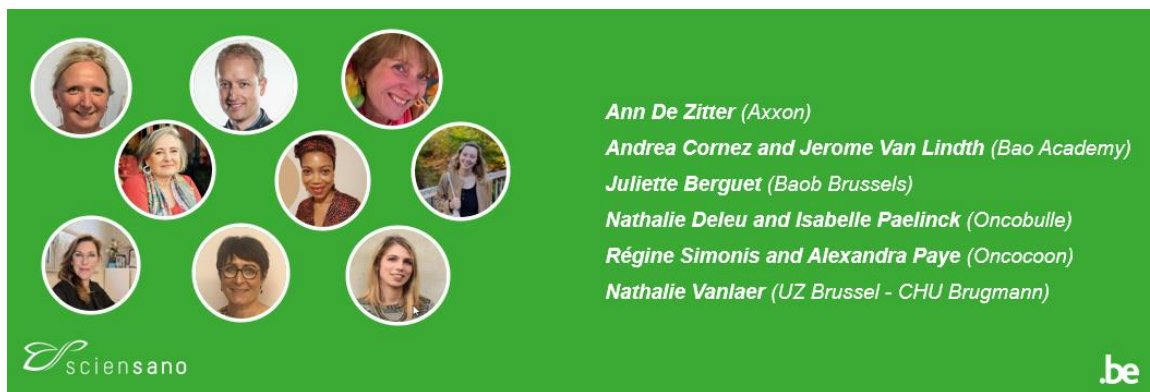
Régine Kiasuwa Mbengi started with introducing the idea for creating The Belgian Network for Supportive Care (BelNetSup). As for today, many multidisciplinary initiatives exist for providing supportive care for cancer patients. The idea of the network is to **support improvement and create collaboration and cooperation between initiatives where necessary and useful** (not to undo what does exist). The network should also interact with comprehensive initiatives that exist at the EU level. In order to build something that is useful, and that could support and help the professionals and ultimately the patients and their relatives, we need to look at what we know, what is observed in terms of needs and gaps and we need to find the right framework in which the work can be done. It will be of high importance to ensure the sustainability of the network, and to find a win-win situation, where the network can function but also bring added value to the healthcare and social security system in general (in terms of supportive care, we can argue that all these developments can serve the other patients suffering from other (chronic) diseases). In her presentation Régine provided 3 examples of frameworks on which the BelNetSup could rely on: the EBCP with the Joint actions Jane 2 and EUnetCCC, the MASCC, and the inter-federal plan for the integrated care. In what followed Régine talked about 3 key aspects on which for the future will have to be found consensus : **missions and objectives of the network, structure of the network and its members.**

- Regarding the missions and objectives accessibility should be at the heart of the work of the network. There is also a great need to create more collaboration and cooperation between initiatives. Another important objective of the network is to facilitate and promote the creation or to generate (new)knowledge. The BelNetSup will be used as a platform to share best practices, to constantly identify the remaining unmet needs (of both patients and professionals), learn from each other, think together and develop a vision to provide high quality and efficient care. In the presentation the process that could be used by the network to achieve different goals and develop different initiatives was explained.

- Regarding the members of the network we should think about a good geographical coverage and make sure we have a multidisciplinary group. The profile of members should be diverse including healthcare professionals and organizations/societies, healthcare centers (ie. 86 OCPs), scientific societies and relevant research groups, patient organizations, NGOs etc.

6. Networking reception

Seven organisations that organize or provide supportive care for cancer patients presented and explained the important work that they do during the networking reception of the event. The organisations with their representatives are listed here :



7. Round table: State of play and future directions for supportive cancer care and survivorship in Belgium



An Lebacqz, who is an expert on care and support at Stichting tegen Kanker/Fondation contre le Cancer, talked about two projects they organise to support cancer patients. The first project is the one led by expert Frédérique Bernard who is mainly working on physical activity but also has expertise related to intimacy and sexuality in cancer patients. Frédérique has established a **national expert working group on physical activity** in which quality criteria are developed and in which is strived for recognition and structural reimbursement. For the moment, healthcare professionals need to be creative in finding ways to get reimbursements, so it is really an effort to make this much more easy for the healthcare professional and for the patient. Just recently the report of the Foundation and the national working group on physical activity in cancer was published: <https://kanker.be/press-release/onco-revalidatie-lichaamsbeweging-als-bondgenoot/>. The second project is about the **cancer care homes** (Inloophuizen/Maisons de Ressourcement). Cancer care homes together with the Foundation try to convey the message to policymakers that these homes really have an important role to play in the supportive care, and can help, together with patient organisations, patient expert organisations etc. patients getting access to supportive care in Belgium. As for today also more and more professionals are becoming implicated and are supporting the approach of the homes. To end, An indicated that the care is there, there is a good offer of supportive care but we need to help patients to find more easily their way and for that a transversal operation and a multidisciplinary approach are necessary. The BelNetSup can definitely be a good facilitator to supporting patients in getting access to care.



Dr. Bernard Willemart, who is the head of the service of the nuclear radiotherapy and onco-haematology in Namur and responsible for the initiative of **L’Espace L’Essentiel**, talked about the organisation and provision of supportive care in the hospital of Namur. They foresee supportive care for over 20 years including aesthetic care, massage therapy (pilot with the Foundation in 2009) hypnosis, and sophrology. Five years ago a new center was created within the hospital of Namur called L’Espace L’Essentiel, a center for oncology patients and their family accessible wherever the patient is treated (Liège, Bordet, etc.). The center is based on **integrative medicine** and they organise collective and individual activities during and after treatment (until 1 year for collective and until 3 years for individual activities). In the center they start from needs of the patient to propose activities. For the future there exist important challenges related to finding budget for continuing the activities within the center. It is foreseen to perform also more evidence-based studies for the future around integrative medicine.



Prof. dr. Christel Fontaine, who is a medical oncologist at UZ Brussel and who was also responsible for the BSMO supportive care task force, first talked about a study of the supportive care task force in which they mapped available settings for supportive care and current practices in Belgium (<https://researchportal.vub.be/nl/publications/supportive-care-for-cancer-patients-a-survey-of-available-setting>). Only half of the centers have a dedicated supportive care center. Further Dr. Fontaine highlighted the **lack of well organised supportive care in practice** and stressed the **need for dedicated centers and a clear framework**. During treatment, there is a need for a multidisciplinary oncology consultation in which different disciplines are gathered together to discuss supportive care (until now no financial support). For supportive care after the treatment there is also a lack of a framework for integrative cancer care. In the United States they have already for 20 years integrative cancer centers.



Prof. dr. Dirk Van Gestel, who is Medical Director of Oncology, Director of the Radiotherapy department at the Institut Jules Bordet and chair of the Belgian Board of Oncology, talked about the provision of supportive care in the Institution of Jules Bordet. IJB is a **cancer dedicated center** and foresees already since a long time (1980s) supportive care. The IJB has now a unity with 100 beds for palliative and mainly supportive care with dedicated nurses, a mobile team etc. Prof. Van Gestel stressed the importance of supportive care as the trajectory of cancer patients has changed enormously. Patients have totally different needs and by foreseeing a unit dedicated to supportive care those needs can be met. The unit for supportive care consists of dedicated oncology nurses for accompanying the patients, 30 onco-psychologists of whom a lot also perform intensive research, patient experts who guide the patients, etc. IJB will also foresee an integrative home together with the psycho-oncology department in which intensive research into integrative oncology will be done.



Michiel Daem, who is a clinical nurse specialist and nursing consultant for patients with brain tumors at the Ghent university hospital, talked about **the role of the clinical nurse specialist and nursing consultant in providing supportive care** to cancer patients and the holistic and broad view they can add (support with psycho-oncology, fatigue, sexuality problems, intimacy, etc.). Michiel further explained the follow-up care that is foreseen in the Ghent university hospital. There is a survivorship consult foreseen for cancer patients to really focus on the follow-up care and the needs and problems they have. Further, a **survivorship compass** was created for different types of cancer and a general leaflet on important needs and problems that need follow-up in cancer survivors → all information can be found here : <https://www.uzgent.be/patient/zoek-een-arts-of->

[dienst/kankercentrum/kankercentrum-voor-verwijzers/zorg-na-kanker/tools-voor-een-nazorgconsult](https://www.vieetcancer.be/dienst/kankercentrum/kankercentrum-voor-verwijzers/zorg-na-kanker/tools-voor-een-nazorgconsult).

Michiel further stressed the importance of working together in an integrated manner with professionals in the first line ; we should think about what care can/should be provided in hospitals and what care can/should be provided by professionals working in the first line and how we can work better together. To end, Michiel indicated that at the moment **finances and legislation are lacking** for providing care that addresses the needs of the growing group of survivors. Now payment is foreseen for each new diagnose but the group of survivors is becoming large, and growing very fast so we absolutely need the support of onco-psychologists, oncology nurses, etc.



Hans Neefs, who is a researcher and policy advisor for Kom Op Tegen Kanker, is for several years doing research on the topic of survivorship care and follow-up after treatment. During his talk he explained what over the years has been done related to the topic. More than five years ago a public campaign to raise awareness for unmet needs of cancer patients after treatment was started. Following that, a round table ‘Zorg na kanker’ was organised together with the Cancer Center of Sciensano and the Belgian Board of Oncology (formerly the College of Oncology). Since then not much has been changed as the follow-up is still mainly organised from the medical perspective and there is still no systematic attention for recovery rehabilitation and survivorship issues. During his talk, Hans formulated some recommendations for the next generation of policy makers. The first aspect he stressed is that of **screening and assessment of patients’ needs in follow-up care**. This could perhaps be organised with a nurse in the hospital, or with a general practitioner in the home setting. It should be combined with other types of monitoring and support that already exists nowadays such as the digital tools and the projects that are running on measuring patient reported outcomes. The second important point Hans raised was that of the **organisation of follow-up care**. It will be complex as you have different groups of patients (survivors) and some will need longer and more specialized follow-up while for others initiatives or strategies like tailored patient education and information will be sufficient.



Magali Mertens, excused.

<https://vieetcancer.be/>



Q&A session

- A patient from the public stressed the importance of involving patients in the BeONCOsup project and to make also a version suitable and consultable by patients.
- Stefan Gijssels (Expert Patient Centre) further stressed the importance of tailor-made initiatives and develop them by type of disease. This discussion also raised the point of care centralisation in oncology and should prompt us, given the evidence-based and financial challenges to reflect on centralisation of the more complex supportive cancer care.

8. Closing remarks



Dr. Karin De Ridder, is a physician and the current scientific director of Epidemiology and Public health at Sciensano, and formerly worked as a rehabilitation specialist and as a public health officer. In her closing remarks, she raised important points for debate and further reflection. First, the importance of a more integrated approach for care and the systematic involvement of primary care. To give an example, Dr. De Ridder explained the way follow-up in Norwegian hospitals is organised. For every patient (who need social, psychosocial or medical rehabilitation) and their relatives that leaves the hospital a multidisciplinary consult is organised in which needs and problems are thoroughly discussed. After the consult, contact is taken with the municipalities to organise together the return to home of the patient and to look what is necessary for further follow-up. In Belgium this is not done systematically yet, which creates a big gap in the follow-up of the needs of patients and their caregivers. **Every patient with a chronic disease (who have or are at risk of having limitations in their physical, mental, cognitive or social functioning) has the right to a care plan and has the right to an integrated and formally organised follow-up.** Second, she emphasized that psychosocial support should be organised from the start, should be family-centred, and ideally a roadmap for psychosocial support needs to be developed. It should pay high attention to emotional, spiritual, social struggles of both the family and their relatives and address caregiver/partner/family support. Healthcare professionals should also be aware of how and what they communicate to patients and their caregivers and should avoid the use of hollow words and phrases (e.g. “you should take care of yourself”). A caring attitude is essential and professionals should focus on increasing the knowledge, skills and confidence a person and his family has in managing their health and care. Professionals should be aware not to consider words as “self-management” and “empowerment” as empty buzzwords. **“Empowerment begins when you feel heard, seen, respected and recognized (Manu Keirse)”**. Dr. De Ridder further talked about the distressing impact of the name *palliative care* compared with *supportive care* as the name palliative care can be perceived as distressing and reducing hope by patients and their caregivers, while the term '*supportive care*' gives confidence and hope that support will be there when needed. The topic of access to care was also addressed. From her own experience as a caregiver, Dr. De Ridder stressed the complexity of gaining access to social care and the administrative burden for the caregiver to receive support. This adds to stress and tiredness the caregiver (e.g financial stress, difficult dynamics within the family etc.) already experiences. Ideally, a dedicated 'social office' (front) that combines the different types of agencies should be created in the future (back offices). To end, Dr. De Ridder stressed the importance of public health officers as they can think broader and above specific diseases. Supportive care is necessary in a lot of fields and for all chronic diseases. In the future, the handbook for supportive care (BeONCOsup) can pave the way for more attention to supportive care for all chronic diseases.

9. Some pictures







CONTACT INFORMATION

Régine Kiasuwa Mbengi • BeONCOsup@sciensano.be • +32 2 642 5765

Sofie Theys • BeONCOsup@sciensano.be • +32 2 642 5889

Website : <https://www.sciensano.be/en/projects/belgian-handbook-oncological-supportive-care>