

## KEY MESSAGES OF THE THEMATIC WORKING GROUP SESSIONS

### General:

- Need for systematic follow-up of needs in cancer patients after treatment. To date, there is **no structural organisation of supportive care/survivorship** for cancer patients in Belgium. The lack of a clear framework makes it difficult for healthcare professionals (in first and second line) to know what role they can/should play in providing follow-up care to cancer patients and their relatives. → structural funding for this is necessary
- Lack of dedicated **professional point of contact** for supportive oncological care.
- Hospitals need **multidisciplinary teams to provide follow-up** after treatment. In some hospitals this support is offered through survivorship clinics.
- Existing initiatives in hospitals working on survivorship and supportive in cancer patients should be given a place in the webtool. Such **initiatives can serve as teaching examples** for other oncological care programmes.
- We need to focus more on **identifying patients requiring further screening and assessment**. Screening and assessment should be more targeted.
- Besides the **challenges related to screening and assessment** of needs, there are also many challenges in terms of **funding** and **time investment** for providing supportive care.
- We should invest more in **health promotion** after treatment (e.g. by an oncocoach).
- The BeONCOsup project could be an opportunity to further **create awareness** among primary care providers about the importance of supportive oncological care.

### For specific needs:

#### *Fatigue*

- **The Multidimensional Fatigue Index (MVI)** is an important tool for measuring fatigue in cancer patients.
- **The app Untire** is an important tool for teaching cancer patients how to cope with fatigue.
- Attention to the essential role of **physiotherapists and oncodietitians** in supporting cancer patients with fatigue symptoms.
- There seems no gap in the offer of supportive oncological for fatigue in cancer patients, but the **offer is highly fragmented**.

#### *Pain and cognitive impairment*

- **The visual analogue scale (VAS)** is described as a tool that is easy for both caregiver and patient to use and allows for pain assessment in an easy way.
- For cognitive problems in cancer patients, the following assessment tools can be used: **FACT-COG and MoCA**
- An important challenge for professionals concerns **understanding and assessing the different pain mechanisms** and tailoring treatment to these mechanisms. → refer to specialists on pain mechanisms
- **Lack of therapeutic measures to treat pain in cancer patients**. For many patients, the standard treatment is not enough, patients do not tolerate the standard treatment.

- **Communication regarding pain is also a major challenge for professionals.** Communication about pain should start early in the treatment process and should be adapted to the patient's needs.

### *Physical activity*

- **Increase workforce:** Need to train more professionals with expertise in exercise and physical activity in cancer patients, especially for the paediatric population.

### *Nutrition*

- The webtool should indicate the distinction between accredited dietitians and nutrition coaches. These coaches do not have a qualification that is recognised. There should be a **clear reference to accredited dietitians** with experience working with people with cancer.
- There seems to be a **lack of awareness about the crucial role dietitians** play in nutritional counselling of cancer patients.
- **Limited knowledge about after treatment anti-cancer diets.** Many patients seek information on the internet, but it is very important to guide patients in this and provide them with evidence-based information. So far, there are no good websites to which patients can be referred.

### *Oncopsychology*

- There is a **need for a clear guideline for (onco)psychologists on what they can and should provide for cancer patients.** Until today, it is not clear to what extent follow-up should be provided, how screening should be organised, etc. Currently (onco)psychologists mainly see patients once they have been diagnosed but there is a lack of structural follow-up.
- A need for better clarification of the role of other care providers (oncocoaches, social workers, etc.) in providing support for psychosocial needs.

### *Sexuality*

- **Discussing sexuality with cancer patients remains difficult** for many healthcare professionals. The webtool should therefore provide guidelines on communication or other tools to support healthcare professionals in this regard.
- Currently, not every hospital has a sexologist. This can be a **major barrier in treating sexuality needs in cancer patients** and in organising multidisciplinary teams to follow up on needs and problems related to sexuality.

### *Return-to-work*

- For RTW-related aspects, there is a **lot of legislation underlying the rights and obligations of patients and employers.** It is not possible for healthcare providers to inform patients about all this legislation and understand which legislation is most relevant for patients depending on their situation. Therefore, the webtool provide links to existing sources of information + provide short descriptions of the info that can be found there.

### Social care

- Attention to **patients with low health literacy, different cultures**, etc.
- **Problems with insurances**: although things are sometimes clearly related to the cancer story and a direct consequence of it (e.g. dental care), they are still not reimbursed by insurances.
- **Families with young children** often have it very difficult, e.g. caretaking for the children. Often difficult to rely on the network.

## LIST WITH THE IDENTIFIED NEEDS

Theme	Needs and problems
Cancer pain	Cancer pain
Fatigue and sleep	Cancer-related fatigue
	Insomnia/Chronic insomnia/Insomnia syndrome
	Sleep-related movement or breathing disorders
	Excessive sleepiness, hypersomnia
	Lack of energy
Oral health problems	Halitosis
	Altered smell, taste changes
	Dental problems
	Xerostomia
	Trismus
	Oral mucositis
	(Chronic) dysphagia/swallowing issues
Respiratory problems	Chronic salivary gland dysfunction
	Pulmonary fibrosis
	Asthma
	Chronic cough
	Emphysema
	Pneumonitis
	Pulmonary hypertension
	Bronchiolitis obliterans syndrome and Idiopathic pneumonia syndrome
	Breathlessness
	Swelling problems
Lymphoedema	
Musculoskeletal problems or bone and joint problems	Osteoradionecrosis (ORN)/Jaw osteonecrosis
	Muscle fibrosis → (muscle) weakness
	Cervical dystonia
	Osteoporosis and osteopenia
	Shoulder dysfunction
	Amputation
	Dermatologic problems
Skin fibrosis	
Loss of body hair/persistent alopecia	
Acneiform rash	

	Pigmentary changes
	Nail toxicity
	Chronic radiation dermatitis
	Compromised wound healing
Fertility and gonadal dysfunction	Psychosocial problems related to fertility
	Early onset of menopause
	Premature ovarian failure
Sexuality	Sexual functioning : <ul style="list-style-type: none"> <li>• Problems getting or maintaining erection/problems with ejaculation</li> <li>• Pain with sexual activity/dyspareunia</li> <li>• Disturbance of libido</li> <li>• Problems with orgasm</li> <li>• Vaginal stenosis</li> </ul>
	Changes in intimacy and sexuality : <ul style="list-style-type: none"> <li>• Difficulty becoming sexually aroused /Feeling uneasy with sex/ Avoiding sex/ Problems enjoying sex / Low or lack of interest in sex/intimacy</li> <li>• Feeling guilty for not fulfilling sexual needs of partner</li> <li>• Relationship difficulties</li> <li>• Concerned about the ability to have children (psychosocial support related to fertility)</li> <li>• Sexual identity development, initiating intimate and emotional relationships</li> <li>• Concerns about dating, marrying, and having a family later in life</li> </ul>
Endocrinological problems	Gynecomastia
	Pubertas praecox
	Thyroid gland abnormalities
	Growth hormone deficiency
	Cortisol deficiency
	Diabetes mellitus
	Hypothalamic-pituitary dysfunction
Metabolic problems	Sarcopenia
	Sarcopenic obesity
	Metabolic syndrome
	Cachexia
Nephrotoxicity	Long-term renal dysfunction
Hepatology	Liver fibrosis/liver cirrhosis
	Focal nodular hyperplasia and steatosis
Genetic counseling	Genetic counseling
Neurological/cognitive symptoms	Cancer-related cognitive impairment (CRCI)
	Neuropathy
Cardiotoxicity	Cardiotoxicity
Urinary tract problems	Bladder/urinary symptoms
	Haemorrhagic cystitis/radiation cystitis/chronic cystitis
Gastro-intestinal symptoms	Late enteritis/colitis/proctitis/gastritis/esophagitis

	Oesophageal stricture/stenosis
	(Chronic) diarrhoea
	Bowel incontinence and fecal leakage
	LAR-Syndrome
	Constipation
	Living with a stoma
	Symptoms of the upper gastrointestinal tract: heartburn, acid or bile reflux, burping/belching, dysphagia, dry mouth, early satiety, oral flatulence, halitosis, odynophagia, jaundice, gastric stasis, pain, regurgitation, vomiting, weight loss, hypersalivation
	Other symptoms of lower gastrointestinal tract : bloating, abdominal or anorectal pain, nausea, tenesmus and bleeding, steatorrhea, irregular defecation
Ophthalmological, ORL problems	Eye problems (e.g. Legal blindness, keratoconjunctivitis Sicca, double vision)
	Tracheostomy and laryngectomy
	Diminished voice quality and function
	Hearing problems (e.g. hyperacusis, tinnitus)
Haematological/vascular symptoms	Anaemia
	Neutropaenia
	Thrombocytopaenia
	Low Platelet Count (bleeding)
	Raynaud's disease
Prevention and overall health and well-being promotion	Cutting down alcohol
	Cutting down smoking
	Physical activity
	Skin protection/sun safety
	Nutrition and weight management
	Prevention and detection of cancer recurrence
	Prevention and early detection of new primary cancers (second cancers)
	Immunization: administration of vaccines
Psychological consequences following cancer	Distress
	Fear of recurrence
	Adjustment disorder
	Emotional fatigue
	Depression
	Other uncertainty and fears
Changes in body image	Changes in body image : feeling unattractive due to scars, weight issues, hair loss, skin changes, amputation, other changes in appearance, feeling old, Feeling the own body cannot be trusted, reduced self-esteem, etc.

<p>Difficulties in resuming family and social roles after cancer/relationship with others</p>	<p>Difficulties in resuming family and social roles after cancer/relationship with others :</p> <ul style="list-style-type: none"> <li>• Shifts in being a parent during and after cancer (shift in relationship with children)</li> <li>• Relationship difficulties with partners (shift in relationship with partner)</li> <li>• Shifts in (family) roles and dynamics (e.g. familial expectations for life to return rapidly to normal and for the cancer survivor to resume all prior responsibilities and role)</li> <li>• Concerns about being treated differently or discriminated against; stigma and taboos</li> <li>• Difficulties in relationships with friends and family</li> </ul>
<p>Existential needs</p>	<p>Existential needs :</p> <ul style="list-style-type: none"> <li>• Process of finding meaning after cancer</li> <li>• Seeking a deeper meaning in having (had) cancer</li> <li>• Changes and adjustments in (religious/spiritual) beliefs</li> <li>• Re-evaluating priorities, patterns and goals in life</li> <li>• Fear of death and dying</li> <li>• Social isolation, loneliness</li> </ul>
<p>Need for social support</p>	<p>Need for socio-aesthetic support</p>
	<p>Need for home care</p>
	<p>Need for care aids (e.g. stoma)</p>
	<p>Lack of insight in social rights</p>
	<p>Taking care of children</p>
	<p>Transportation problems</p>
	<p>This section will contain more needs in the future or could alter in the future</p>
<p>Return-to-work</p>	<p>Return-to-work :</p> <ul style="list-style-type: none"> <li>• Practical concerns regarding return-to-work (e.g., transportation, caregiving responsibilities, health insurance coverage, financial toxicity)</li> <li>• Work ability impairments (cognitive tasks, long periods of standing, use of hands)</li> <li>• Reduced functioning at work/ diminished work productivity/ having (had) cancer decreased work performance</li> <li>• Working on relationship with colleagues (shifts in relationship with colleagues)</li> <li>• Need for flexible working conditions</li> <li>• Vocational identity and career readiness (AYAs)</li> <li>• Etc.</li> </ul>

Education/schooling	Education/schooling: <ul style="list-style-type: none"> <li>• Return to school/education</li> <li>• Social interactions with peers: struggling to rebuild friendship, peer rejection, social isolation, loneliness</li> <li>• Weaker academic functioning due to learning difficulties, poor concentration, fatigue or physical limitations</li> <li>• Social anxiety, disease burden (physical symptoms, neurological problems, changes in appearances) --&gt; lowered confidence/insecurity</li> <li>• Behavioural deficits</li> <li>• etc.</li> </ul>
Financial effects of cancer	Right to be forgotten
	Problems with getting a loan, mortgage, or (travel)insurance
	More needs could be added in the future
Vacation and leisure time	Vacation and leisure time
AYA	Mention information specific for AYA
Elderly	Mention information specific for elderly
(Psychosocial) support for relatives/wellbeing of relatives	Mention information specific for relatives