LET'S TALK ABOUT ...

Mental Health & Psychosocial Care during and beyond childhood, adolescent and young adult cancer

A SET OF EU-CAYAS-NET POCKET CARDS FOR GUIDANCE AND AWARENESS

European Network of Youth Cancer Survivors

LET'S TALK ABOUT ...

- 10 Key points on Mental Health
- Talking about serious matters
- Do's and Don'ts in communication
- Social dimension
- Education support
- Career support
- Fear and hope
- Grief & depression
- My right to grieve

"MENTAL HEALTH IS MORE THAN THE ABSENCE OF MENTAL DISORDERS"
WHO, 2022

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Childhood Cancer International Europe

Medical University of Vienna

10 KEY POINTS TO TAKE CARE OF YOUR MENTAL HEALTH

DURING AND BEYOND CANCER

Cancer in young people can leave a lasting impact. While the focus is often on physical health, it's important to also prioritize mental health during and beyond cancer.

Acknowledge your emotions
It is normal to feel a range of emotions, including anxiety, sadness, and fear. Acknowledge these emotions and seek support when needed.

Find a support system
Having a support system can provide emotional and practical support. This can include family, friends, and support groups.

Prioritize self-care
Taking care of your physical health through exercise, healthy eating, and sleep can improve mental health outcomes.

Seek professional help
Mental health professionals, such as psychologists and counselors, can provide specialized support for young people and their families.

Educate yourself
Learning about mental health during and beyond cancer can reduce stigma and increase access to resources.

Stay connected
Social activities and hobbies may improve social support and reduce feelings of isolation.

10 KEY POINTS TO TAKE CARE OF YOUR MENTAL HEALTH

DURING AND BEYOND CANCER

Relaxation exercises
Mindfulness practices, such as meditation and breathing exercises, can reduce stress and improve emotional well-being.

Involve healthcare professionals
Get in touch with a healthcare professional about your mental health and any concerns you may have.

Advocate for yourself
Don't be afraid to speak up and advocate for your mental health needs. It is ok if you need someone supporting you with that.

Take it one day at a time
Living with and beyond cancer is a journey, and it is important to take it one day at a time. Remember that you don't always have to hink positively. Despair and hope can alternate and that's okay!

SEE POCKET CARD "THE BALANCING ACT BETWEEN FEAR AND HOPE"

Contact / Notes

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TALKING WITH YOUNG PEOPLE ABOUT SERIOUS MATTERS

Communication about difficult topics is not something that can be avoided, but the approach and attitude can make a difference.

1 **Be at Eye Level**
Physically and symbolically.

2 **Appreciate**
Show willingness to enter the young person's world, try to accept their reality as they see it and hear their fears and their losses as they feel them. Appreciate their points of view – don't judge or underestimate them.

3 **Involve**
Give young people a voice: Talk TO, not ABOUT them! Encourage age appropriate, active participation.

4 **Listen**
Listen carefully: WHAT is being said HOW? Especially at untypical times & unexpected places.

Find more information on: **beatcancer.eu**

RECOMMENDATIONS FOR ANYONE INVOLVED IN A CONVERSATION

5 **Adapt Language**
Use gentle & careful language oriented to the DEVELOPMENTAL STAGE of the young person. Consider both verbal & nonverbal communication (e.g. facial expression, gestures, body posture).

6 **Respect Emotions**
Take emotions seriously. Name emotions, respect them, don't minimize.

7 **Be sincere**
Young people expect honest answers to honest questions in order to build trust.

Contact / Notes . . . . . .

TALKING WITH YOUNG PEOPLE ABOUT SERIOUS MATTERS

IT IS OKAY TO BE OVERWHELMED AND LOOK FOR HELP WHEN COMMUNICATING.

RECOMMENDATIONS FOR ANYONE INVOLVED IN A CONVERSATION

8 Show Openness
Signal that all questions are good & welcome. Be open to discuss difficult topics instead of making them taboo. Pay attention to small signals.

9 Orient yourself to Questions
Be guided by questions from the young people. They naturally seek the amount of information that is right for them in order to feel safe. Don't over- or under-challenge.

→ E.G. WHAT DO YOU ALREADY KNOW?
WHAT AND HOW MUCH
DO YOU WANT TO KNOW?
WHAT EXACTLY ARE YOU WORRIED ABOUT?

10 Give Space & Time
Offer a protected, age-appropriate environment. Consider attention span and give time to process. Schedule multiple sequential conversations.

11 Use Tools
Provide books, drawings, applications, visual models, etc. to encourage under-standing and processing in order to support informed and shared decision making.

12 Plan & Act
Discuss concrete next steps & plan together to ensure self-efficacy and healthy coping. Give confidence & security.

13 Involve Family & Social Network
Open communication has proven to be a protective factor for everybody involved. A trusted person can be a valuable source of support during difficult conversations.

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DO'S AND DON'TS IN COMMUNICATION

RECOMMENDATIONS FOR ANYONE INVOLVED IN A CONVERSATION

Before engaging in a conversation with people living with and beyond cancer, ask yourself ...

- How am I feeling today? Am I capable to support?
- What is my role in this person's life?
- What does that imply for the conversation?
- What does this person expect from me?
- If it was me, what would I want from this conversation?
- What do I know (or think I know) about this diagnosis?
- What kind of question can I ask? Do I need to ask this?

Contact / Notes

KEY TAKE AWAYS

- It is ok to not know what to say (and to express that openly)
- It is ok to ask a difficult question, but give the person the space to leave it unanswered
- Accept the person's experience, not what you think it is
- Be curious
- Be patient
- Try to be comfortable with silence, non-verbal communication can also be effective and comforting

Find more information on: **beatcancer.eu**

TIPS TO IMPROVE COMMUNICATION

POOR COMMUNICATION CAN AFFECT DECISION-MAKING, ADHERENCE TO TREATMENT, SOCIAL RELATIONSHIPS & MENTAL HEALTH.

What to say DO's

- **Tailor communication**
  Consider individual age, cognitive development, social aspects and recognize their unique needs and abilities
- **Acknowledge emotions**
  Be empathetic, but avoid excessive empathy
- **Support decision-making**
  Provide all information needed to make an informed decision
- **Be honest and transparent**
  Portray information in a constructive hopeful manner

What NOT to say DON'Ts

- **Blame**
  "What have you done to get cancer?"
- **Compare**
  "I met someone with cancer and he passed away."
- **Impose**
  "You should be grateful! At least you are alive!"
- **Label**
  "Fighter" "Hero" (There is no one-size-fits-all)
- **Use toxic positivity**
  "Stop worrying, in a few months you will look completely normal."
- **Depersonalise or minimize**
  "At least you do not have the most aggressive type of cancer."

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THE SOCIAL DIMENSION

Childhood, adolescent and young adult cancer can lead to social challenges.

Socio-economic factors
- Education
- Employment
- Material living conditions (e.g. income, availability of food & clothing)
- Living circumstances (e.g. housing condition & quality)
- Legal status

Socio-cultural factors
- Language
- Country of origin
- Ethnicity

Contact / Notes

Social work complements medical, psychological and nursing care with the aim of providing advice and support with social challenges.

Social relationships
- Interpersonal relationships
- Social networks
- Social support

Socio-ecological factors
- Environmental factors (e.g. urban vs. rural, climatic conditions, air quality)
- Mobility (e.g. availability of transport, accessibility of workplaces, schools, healthcare facilities)

THE SOCIAL DIMENSION

What's needed?

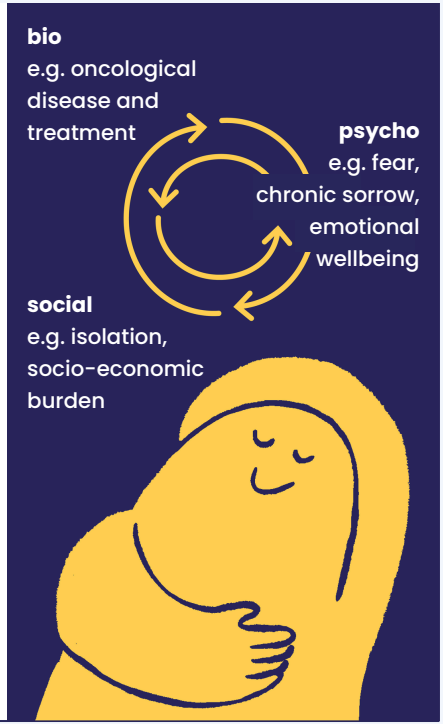
- **Bio-psycho-social** treatment concepts
- Social screening/assessment, counseling & interventions **for all young persons and their carers** during treatment and in follow-up care
- **The right to be forgotten**
  = ending discrimination against cancer survivors when accessing essential financial services.
  - Stop unfair treatment of survivors seeking for financial services because of their medical history.
  - Provide legal rights for long-term survivors not to disclose their cancer history to financial entities.
  - Guarantee having access to insurance and prevent the insurance rates or bank loans from rising.

Bio-psycho-social treatment concepts are a multi-dimensional approach to health and disease.

Not only somatic, but also psycho- social aspects must be included in the consideration of health and disease.

Treatment on all three levels

Find more information on: **beatcancer.eu**



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EDUCATION SUPPORT

Young people living with and beyond cancer may face restrictions in their education due to their disease, treatment or late effects.

NORMALITY WHEREVER POSSIBLE — SUPPORT WHEREVER NEEDED

OUR GOAL: EDUCATION THAT SUITS ABILITIES, PERSONALITY AND FUTURE PLANS

What's needed?

- **Surveillance** and **support** over the **entire course of education**
  … for young people living with and beyond cancer, their caregivers, teachers & peers
- **Easy access** to meaningful information on all legal and practical support option
- Dedicated professionals in follow-up care with the necessary **knowledge, skills and time** to coordinate communication between young person/family, school and healthcare team

Contact / Notes

- Find key points for education support on the back
- Find support material in different languages on: **beatcancer.eu**

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6 STEPS TO IMPROVE EDUCATIONAL SUPPORT

COPE WITH LIMITATIONS — BENEFIT FROM STRENGHTS

NO FAVOURITISM, BUT REDUCTION OF DISADVANTAGES

#1 Get clear overview of personal **STRENGTHS and DIFFICULTIES.**
→ e.g. through neuropsychological assessment

#2 Consider **DISADVANTAGE COMPENSATION:** they are particularly important if limitation in one area (e.g. memory) would lead to disadvantage in other areas (e.g. maths).

#3 **PERSON-CENTERED support:** Use legal options and/or disadvantage compensation – tailored to individual needs.

#4 Be **TRANSPARENT:** plan and discuss support options **TOGETHER.** Communicate and collaborate with all parties involved (young person, carers, siblings, peers & teachers).

#5 Provide **EMOTIONAL SUPPORT:** allow feelings of anxiety, uncertainty & fear of being different and make use of support.

→ **= Compensation for disease related disadvantages to ensure equal opportunities**

- Separate, quiet rooms for exams
- Room for breaks
- Use of learning materials that support memory (e.g. mathematical formula collection)
- Extra time for exams
- Reduction of tasks or homework
- Multimodal learning materials, materials for planning & structure

#6 Focus not only on performance, but also on a **SENSE OF BELONGING** and social situation; prevent bullying.

LET'S MAKE CAREER SUPPORT A PRIORITY

What's needed?

- Continuous surveillance and **longterm support** in follow-up care...
  - ... for young people living with and beyond cancer, their care-givers & employers
- **Easy access** to meaningful information on all legal and practical support options
- Dedicated professionals in follow-up care with the necessary **knowledge, skills and time** to coordinate communication
  - ... between young person/family, workplace, healthcare team and career support providers
- **Peer-support** programmes

Young people living with and beyond cancer may face restrictions in their careers due to their disease, treatment or late effects.

Very often they are under- or over-estimated due to the lack of knowledge of others and may therefore end up in inappropriate work situations.

- Find key points for career support on the back
- Find support material in different languages on: **beatcancer.eu**

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KEY POINTS ON VOCATIONAL SUPPORT

NORMALITY WHEREVER POSSIBLE— SUPPORT WHEREVER NEEDED

COPE WITH LIMITATIONS — BENEFIT FROM STRENGHTS

#1 Get clear overview of work-related **STRENGTHS and DIFFICULTIES**
→ e.g. through neuropsychology or occupational medicine

#2 Analyse **WORKING CONDITIONS** to identify where adaptations can be made.

#3 **PERSON-CENTERED support:** tailored measures & adaptations to individual needs. Consider bio-psycho-social background and **PLAN AHEAD.**
→ — Adjustment of working hours
— Framework conditions or type of activity
— Provision and use of appropriate tools & aids
— Room for rest & more ...

#4 Clarify **LEGAL ISSUES:** employment and social law.

#5 **TRANSPARENT:** plan and discuss support options **TOGETHER:** Communicate with all parties involved. (young person, carers,employers, collegues, career support providers)

#6 **EMOTIONAL & SOCIAL SUPPORT:** Focus not only on performance. Allow feelings of e.g. uncertainty, fear of being different & grieving about initial plans.Consider social situation. Preventbullying.

GOAL: VOCATIONAL SITUATION THAT SUITS ABILITIES, PERSONALITY, PASSION AND FUTURE PLANS

THE BALANCING ACT BETWEEN FEAR AND HOPE

Negative feelings are part of being human in order to adequately process (traumatic)experiences.

- Fear is a **natural and important reaction.** It is a force that drives us to cope with real threats.
- **Occurring at a moderate degree fear ...**
  - has a protective function through a performance-enhancing effect.
  - sharpens our senses & activates our survival mechanisms.
  - can lead to personal maturation.

Find more information on: **beatcancer.eu**

IT IS NORMAL THAT FEAR AND HOPE, WORRY AND CONFIDENCE CAN ALTERNATE IN THE SHORTEST POSSIBLE TIME OR THAT THEY ARE PRESENT AT THE SAME TIME. THE ABILITY TO SUSTAIN THIS DUALITY "DOUBLE AWARENESS" IS CONSIDERED TO REPRESENT AN OPTIMAL PSYCHOLOGICAL ADAPTATION TO DISEASE OR CRISES.

Hope is a multidimensional and highly individual feeling, which is subject to continuous adaptation.

- Hope is a **confident inner orientation** that something desirable will occur in the future, without having certainty about it.
- It can be accompanied by fear and worry.

"HOPE IS DEFINITELY NOT THE SAME THING AS OPTIMISM. IT IS NOT THE CONVICTION THAT SOMETHING WILL TURN OUT WELL, BUT THE CERTAINTY THAT SOMETHING MAKES SENSE, REGARDLESS OF HOW IT TURNS OUT."
Václav Havel

ABOUT "GOOD" AND "BAD" FEELINGS

There are no bad feelings. Every emotion has its justification and function and should be allowed to be felt and expressed.

Feelings that subjectively feel right and coherent lead to greater well-being, regardless of whether they are considered to be "good" or not.

What's needed?

- ! Continuous **Mental Health surveillance** during treatment and in life-long followup care
  - → … for people living with and beyond cancer & their families/friends
- ! **Easy access** to psychosocial treatment and other support options
- ! Dedicated professionals with the necessary **knowledge, skills and time**
- ! **Peer-support** programmes

Positive attitude vs. "Toxic positivity"

Positive attitude and optimism are generally associated with higher well-being …

BUT

… when used to suppress negative emotions, it can do more harm than good.

THE FORCE OF "HAVING TO BE GRATEFUL" CAN LEAD TO PRESSURE AND FEELINGS OF GUILT. TRAUMATIC EXPERIENCES SHOULD HAVE A PLACE AND BE DEALT WITH.

Contact / Notes . . . . . .

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THE FINE LINE BETWEEN APPROPRIATE, HEALTHY PROCESSING AND EMOTIONAL DISORDERS

While grief is a natural response and part of life, depression requires special support. The difference between grief and depression can be nuanced – and there are characteristics that apply to both states:

GRIEF

- Distress is related to loss or being separated
- Tearfulness
- Longing for the lost person/function/thing
- Emptiness
- Often comes in waves

- Sadness
- Loss of interest in activities & social life
- Fatigue
- Appetite ↑↓
- Sleep ↑↓

DEPRESSION

- Distress is related to a generalized lowered mood
- Thoughts of self-harm/suicide
- Often consistent, sustained low mood
- Lack of motivation & energy

ALTHOUGH NOT EVERYONE WILL DEVELOP DEPRESSIVE SYMPTOMS, BEING AWARE OF THE POSSIBILITY IS CRUCIAL. CONSIDER THAT DEPRESSION CAN HAVE VARIOUS UNDERLYING FACTORS.

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SEEK PROFESSIONAL HELP

if the following persists for at least 2 weeks:

- You feel stuck in your process of dealing with your cancer history.
- You notice a big gap between how you think about your life and how you feel about it.
- You feel a pressure to appear happy and thankful, but on the inside you feel sad and empty.
- "I would not mind not to wake up tomorrow" is a thought that comes to your mind regularly.
- You struggle with sleep problems for a long time.
- You feel extremely tired without a clear phsysical reason.
- You feel like you've built a dam against sorrow and once you start crying, you will never be able to stop your tears.

POSSIBILITIES FOR SUPPORT

IT'S OK TO ASK FOR HELP!

SELF-HELP

- Storytelling
- Conversations
- Support groups
- Mentoring programmes
- Physical activity/sport
- Expressive arts
- Bibliotherapy

PROFESSIONAL THERAPY

- Psychoeducation
- Client centered therapy
- Cognitive behavioral therapy
- Systemic family therapy
- Clinical psychological therapy
- Neuropsychological therapy
- Group therapy
- EMDR (Eye Movement Desensitization & Reprocessing)
- ACT (Acceptance and Commitment Therapy)
- Other (e.g. Expressive therapies, Art therapy, Psychomotor therapy, Pharmaceutical therapy, etc.)

What's needed?

- Mental Health surveillance during treatment and in life-long followup care
- Easy access to psycho-social treatment

Find more information on: **beatcancer.eu**

MY RIGHT TO GRIEVE

Patients, survivors, carers, professionals – everyone is allowed to grieve

GRIEF

= natural response to loss, typically involving feelings of sadness, longing, anger, guilt, confusion and numbness. It is a complex and individualized process that varies greatly from person to person. Grief is necessary to process the loss you are experiencing.

Contact / Notes

Find helpful resources and book recommendations on: **beatcancer.eu**

MY RIGHT TO GRIEVE

Patients, survivors, carers, professionals – everyone is allowed to grieve

— I am allowed to cry, but I don't have to

— I am allowed to be angry and express my feelings

— I am allowed to be afraid

— I am allowed to laugh and be happy again

— I can have many different feelings at the same time

— I am allowed to forget for a while

— I am allowed to grieve as much as I want

— I shouldn't feel guilty

— I am allowed to talk about the disease, if I want to

— I am allowed to talk about my grief, losses and fears

— I am allowed to talk about death and dying

— I can ask all the questions I want

— I am allowed to have some peace and quiet

— I am allowed to do things that comfort me and are good for me

— I am allowed to be weak

— I am allowed to take all the time I need

"SORROW THAT DOESN'T COME OUT, FESTERS. IT CAN MAKE YOU SICK. ONLY WHEN WE EXPRESS IT, IT WILL BECOME BEARABLE."
Dirk de Wachter, Psychiatrist

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HOW TO USE THESE POCKET CARDS

- Keep the pocket cards easily accessible – whether on your desk, in a display or in waiting areas in your institution.
- Use them as a reference guide when discussing mental health and psychosocial care with patients, survivors, families, carers, colleagues or teachers.
- Share the cards and information with others to raise awareness and start conversations about the importance of mental health support during and beyond childhood, adolescent and young adult cancer.
- Visit the website provided on the cards to access more resources and in-depth information on mental health and psychosocial care. Join our platform to connect with others.
- Use the spare space on the respective card to write down any notes or important contact details related to mental health services or support networks.

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THE POCKET CARDS ARE AVAILABLE IN MULTIPLE LANGUAGES

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Sources: Damm, L. et al., 2015; Stein, A. et al., 2019; Stivers, T., 2012; Skeen, J.E., & Webster, M.L., 2014

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My right to grieve:
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