

European Network of



Let's talk about

Mental Health and Psychosocial Care

during and beyond childhood,
adolescent and young
adult cancer

A set of EU-CAYAS-NET
pocket cards for
guidance and awareness



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Let's talk about...



10 Keypoints on
Mental Health



Career support



Talking about serious
matters



Neuropsychology
(in preparation)



Do's and Don'ts in
communication



Fear and hope



Social dimension



Grief and depression



Education support



My right to grieve

10 Keypoints to take care of your Mental Health

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.

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.



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.



Find a support system



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



Educate yourself



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



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Stay connected

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



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.



Relaxation exercises

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



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 think positively. Despair and hope can alternate and that's okay!



Involve healthcare professionals

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



See pocket card
"The balancing act
between fear and hope"

Contact/Notes



Find more information
on: [beatcancer.eu](https://www.beatcancer.eu)



Recommendations
for anyone involved
in a conversation

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 persons 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.

#5 ADAPT LANGUAGE

Use gentle & careful language oriented to the DEVELOPMENTAL STAGE of the young person. Consider both verbal & nonverbal communication.



e.g. eye contact, personal space

#6 RESPECT EMOTIONS

Take emotions seriously. Name emotions, respect them, don't minimize.



Find more information on: beatcancer.eu



Contact/Notes



Talking with young people about serious matters

#7 BE SINCERE

Young people expect honest answers to honest questions in order to build trust.

#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.

*e.g. What do you already know?
What and how much do you want to know?
What exactly are you worried about?*

#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 underchallenge.

It is okay to be overwhelmed and look for help when communicating.

#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 understanding 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

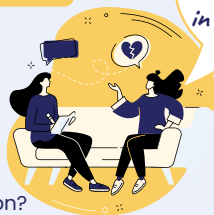
Open communication has proven to be a protective factor for everybody involved. A trusted person can be a valuable source of support during difficult conversations.



Do's and Don'ts in communication

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?



*Recommendations
for anyone involved
in a conversation*

Contact/Notes



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



Key Takeaways

- Be curious
- Be patient
- 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 persons experience, not what you think it is
- Try to be comfortable with silence, non-verbal communication can also be effective and comforting



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 empathic, 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"

The social dimension

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

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



Social relationships

- **Interpersonal relationships**
- **Social networks**
- **Social support**



Socio-ecological factors

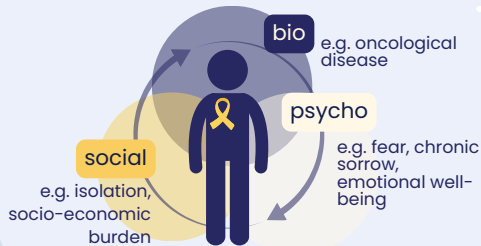
- **Environmental factors**
(e.g. urban vs. rural, climatic conditions, air quality)
- **Mobility**
(e.g. availability of transport, accessibility of workplaces, schools, healthcare facilities)



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.



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**



Contact/Notes



Hey!

Education Support

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

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 options

! Dedicated professionals in follow-up care with the necessary **knowledge, skills and time** to coordinate communication between young person/family, school and healthcare team



i Find keypoints for education support on the back

i Find support material in different languages on: beatcancer.eu



NORMALITY wherever possible
- **SUPPORT** wherever needed

Our goal: education that suits abilities, personality and future plans

Contact/Notes



6

Steps to improve educational support

#1

Get clear overview of personal **STRENGTHS and DIFFICULTIES**.

*Cope with limitations
- benefit from
strengths*



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.

#6

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

Go for it!

DISADVANTAGE COMPENSATION

=compensation for disease-related disadvantages to ensure equal opportunities

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

*No favouritism,
but reduction of
disadvantages*

Hey!

Let's make Career Support a priority



What's needed?

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

! Continuous surveillance and **long-term** support in follow-up care...

... for young people living with and beyond cancer, their caregivers & 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** resources to coordinate communication

... between young person/family, workplace, healthcare team and career support providers

! **Peer-support** programmes

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

i Find keypoints for career support on the back

i Find support material in different languages on: **beatcancer.eu**



Contact/Notes



Key points on vocational support

TRANSPARENT: plan and discuss support options **TOGETHER.** Communicate with all parties involved.

(young person, carers, employers, colleagues, career support providers)

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. Prevent bullying.

Goal

Vocational situation that suits abilities, personality, passion and future plans

NORMALITY wherever possible
- **SUPPORT** wherever needed

Get clear overview of work-related **STRENGTHS & DIFFICULTIES.**

e.g. through neuropsychology or occupational medicine



#1

Cope with limitations - benefit from strengths

#4

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

#3

PERSON-CENTERED support: tailored measures & adaptations to individual needs. Consider bio-psycho-social background and **PLAN AHEAD.**

#2

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

- ✓ Adjustment of working hours
- ✓ Framework conditions or type of activity
- ✓ Provision and use of appropriate tools & aids
- ✓ Room for rest & more...

The balancing act between fear and hope

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



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

- 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.

- 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.

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 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

Right is what feels right for you!



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

What’s needed?

! Continuous **Mental Health surveillance** during treatment and in life-long follow-up 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

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

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.



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

Depression

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

- Sadness
- Loss of interest in activities & social life
- Fatigue
- Appetite \updownarrow
- Sleep \updownarrow

Although not everyone will develop depressive symptoms, being aware of the possibility is crucial. Consider that depression can have various underlying factors.



Find more information on:
beatcancer.eu



Contact/Notes

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 physical 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.



Self-help

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

Possibilities
for support



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 Expressive therapies, Art therapy, Psychomotor therapy, Pharmaceutical therapy etc.



What's
needed?



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

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.



Despite the freedom to grieve in one's own way, the lack of societal acceptance and understanding of diverse grieving processes can lead to stigmatization and isolation for those mourning.

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



Contact/Notes



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My right to grieve



Patients, survivors, carers, professionals - everyone is allowed to grieve in their own way

- 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

How to...



#1 Keep the pocket cards easily accessible – whether on your desk, in a display or in waiting areas in your institution.

#2 Use them as a reference guide when discussing mental health and psychosocial care with patients, survivors, families, carers, colleagues or teachers.

#3 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.

#4 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.

#5 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.

beatcancer.eu



Imprint



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10 Keypoints on Mental Health:

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Talking about serious matters:

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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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