

Manual



Train-the-Trainer

for Education & Career Support



Educational & vocational situation that suits abilities, personality, passion and future plans



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Why Education and Career Support?

Childhood, Adolescent and Young Adult (CAYA) cancer has a disruptive impact on education and career pathways, both during and after treatment (e.g. Vetsch et al, 2018; Nicklin et al, 2021; Foster et al., 2021). Cancer treatment leads to more frequent involuntary absences from school (from primary school to university, depending on age) or the workplace. At the same time, schools and workplaces are often unaware of the needs associated with the disease and treatment. Furthermore, there is usually a lack of knowledge about what additional support can be offered. Survivors are more likely to be unemployed than comparative populations (Devine et al., 2022).

After treatment, returning to school, training or work or, depending on age, even starting school or work can be a major challenge. On the one hand, it can be socially and emotionally exhausting to reconnect after a long absence. Sometimes this can even lead to discrimination at school or in the workplace due to the difference between survivors and their peers who do not have the disease. On the other hand, the long-term effects of the disease or treatment can make it difficult to regain previous levels of ability, performance and stress tolerance.



To minimise this disruptive impact on education and career pathways, a *Train-the-Trainer* concept for HCPs on education and career support has been developed following a systematic review of the literature and desktop search of existing materials, as well as the results of two focus groups on the topic. In addition to the actual intention to develop the concept for health care professionals (HCPs), it was decided in the course of the development process to expand the target group of the concept. It should also be accessible to people who want to set up education or career support in their institutions or organisations or who want to create awareness in their area.

The *EU-CAYAS-NET Train-the-Trainer* concept is tailored to the needs of CAYA cancer survivors and aims to equip participants with the necessary knowledge, attitude and skills to deepen their knowledge and be able to disseminate knowledge or build educational and career support in their national/local structures.



Framework

For good planning of the training, consider the accessibility of the location, any special needs of the participants and a sensible and sufficient break organisation

Prerequisite for leading the training:

- Co-lead patient advocate & healthcare professional (desirable: from psychology or social work background)
- All those who have taken part in the *Train-the-Trainer* programme as trainees (desirable: participation in online follow-up group)

Trainees:

- People already working in the field of education & career support
- Anyone who wants to set up something in this field
- Anyone who is interested and wants to work with us to increase awareness in this field

Recommended duration:

- 1,5 days face-to-face training
- Online follow-up sessions and supervision

Methodology:

- Active learning approach
 - In addition to imparting knowledge, skills and materials, the training provides space for self-reflection to better understand possible fields of action and problems through self-awareness.
 - Sufficient time is planned during the training for an exchange of experience (e.g. for trainees to learn from each other).

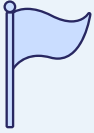


Training content and modules

Modules and content:

Module 1	Welcome: Teambuilding and introduction to the training
Module 2	Impact of CAYA Cancer on education and work: challenges & protective factors
Module 3	Personal factors: Reflection on education- and work-related strengths and weaknesses
Module 4	Environmental factors: Analysis of school and workplace conditions & social network
Module 5	Environmental factors: Finances and legal framework
Module 6	Specific support options
Module 7	EU-CAYAS-NET recommendations for career support
Module 8	Guidance aspects - Communication & attitude
Module 9	Closing summery, follow-up sessions, evaluation

Welcome: Teambuilding and introduction to the training



Goal

- Getting to know each other, building trust within the group; assessing the level of expertise and experience in the group; clarifying expectations
- Overview of the training programme, presentation of the methodology





Method

- Group work
- Theoretical input



Materials

- Flipchart
- Sticky notes
- Exemplary materials for group work ( pages 7-8)
- Background to EU-CAYAS-NET *Train-the-Trainer* ( page 9)

Inspiration for group work – Exemplary materials

Task: The participants have to stand next to previously placed posters with different colours/symbols that correspond to their role.

Who is who?

What role are you in here?

- (1) You are a patient advocate/ambassador
- (2) You are a representative from a patient organisation
- (3) You are a health care professional/researcher (please indicate your profession)
- (4) You are somebody else 😊

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Task: The participants mark their home country with a sticker or pen on a map of Europe or the world.

Who is who?

What country are you from?



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Task: The participants mark their previous experiences in the field on a previously placed poster.

Who is who?

How would you rate your own experience in the field of education/career support in CAYA Cancer?

	1	2	3	4	5	6	7	8	9	10	
beginner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	expert

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Task: The participants have to stand by the previously placed posters (in different colours or symbols) that correspond to their motivation for taking part in the training.

Who is who?

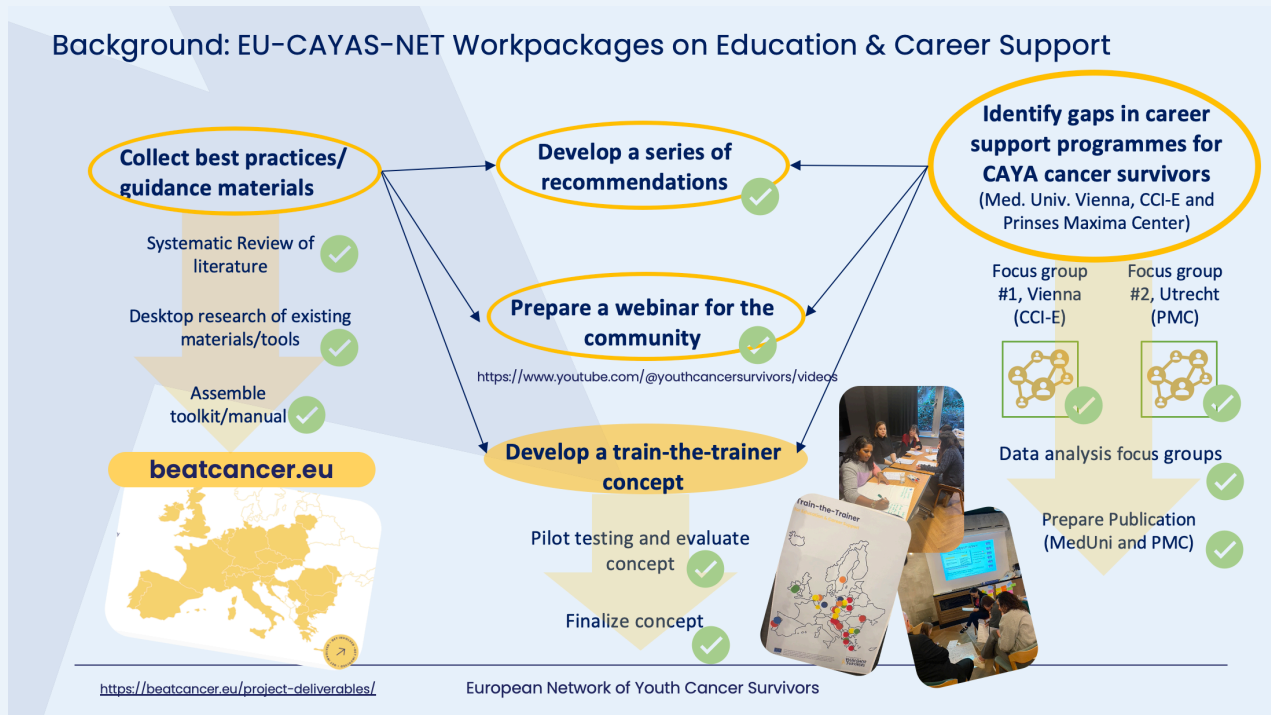
Why are you here?

- (1) You are a trainer/coach for career support in the field of CAYA Cancer
- (2) You offer education/career support in your institution/organisation
- (3) You want to build up education/career support in your country
- (4) You are interested in this topic and decide later
- (5) You are here for a completely different reason

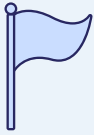
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Theoretical input – Background to EU-CAYAS-NET *Train-the-Trainer*

Overview of all tasks on education and career support that have been carried out within the EU-CAYAS-NET project and have been incorporated into the development of this manual.



Background: Impact of CAYA Cancer on education and work: challenges & protective factors



Goal

- Broaden background knowledge to...
 - enable differentiated, individualized and effective support,
 - avoid underestimation or overestimation,
 - avoid insecurity and fear of the topic.







Method

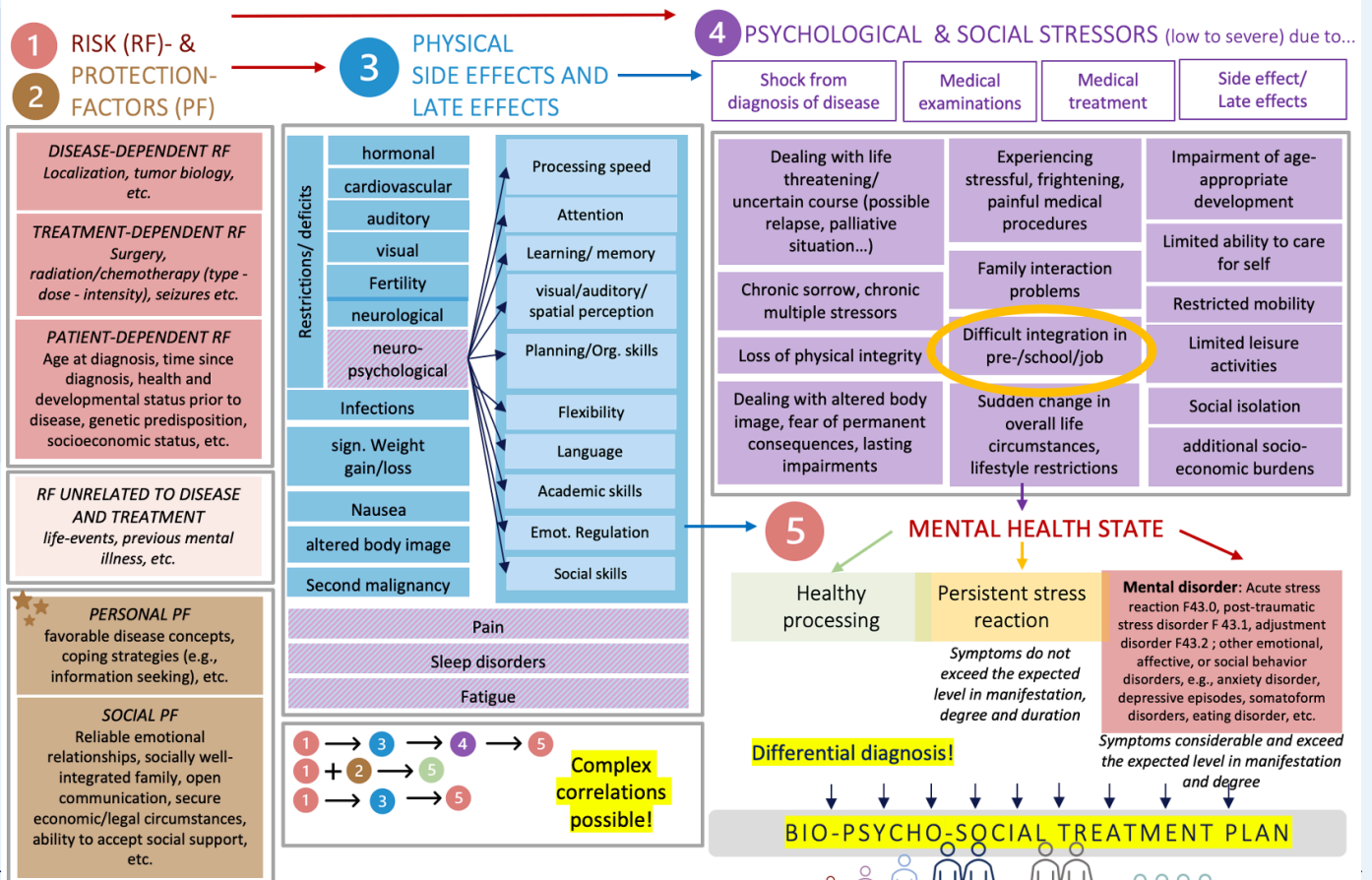
- Theoretical input



Materials/ content

- Disease- or treatment-related physical, psychological and social **late effects; protective factors** ( figure “What factors impact Mental Health in CAYA Cancer Survivors”, page 10)
- Normative and non-normative **developmental tasks** for children, adolescents and young adults ( pages 11-12)
- **Contextual factors** that influence participation in education and employment ( e.g. Davis et al., 2022 and pages 13-14)
- **Key points for education and career support** ( pages 15-16 and download on <https://beatcancer.eu/project-deliverables/>)

What factors impact Mental Health in CAYA Cancer Survivors?



Sources: Schröder, 2019; Cheung, 2018; Kahallery, 2020; Krull, 2018; Wiener, 2015.

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Developmental milestones – physical & psychological developmental steps

Goal: Achievement of autonomous living situation = emotional-social independence from adults and authority figures, economic independence

15-18 years

Physiological:

- puberty,
- mood changes,
- frontal brain development



dependence on doctors, medications, parents

lack of participation in usual activities

Parents often find "letting go" more difficult than with healthy children

Psychological:

- identity development
- desire for „normality“ – being like the others
- exploring sexuality
- importance of body image
- importance of peer relationships
- create educational and vocational foundation
- starting process to become emotional-social independent
- legal milestones



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Developmental milestones – selected physical & psychological developmental steps

18-25 years

Physiological: frontal brain development completed, advanced executive function emerges, impulsiveness declines

Psychological:

- experimenting with social norms, belief systems, relationships
- creating educational and vocational foundations
- starting processes to become financially independent

25-39 years

- establish identity
- consolidating educational/vocational goals
- reaching financial independence
- formalizing romantic relationships
- starting families

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Non-normative developmental tasks

- accepting physiological changes, limitations (e.g. hair loss ...)
- dealing with a limited future perspective (e.g. regarding career choice...)
- enduring uncertainty about the future development of the disease
- and more...



Lack of role models for coping with non-normative developmental tasks in this age group!



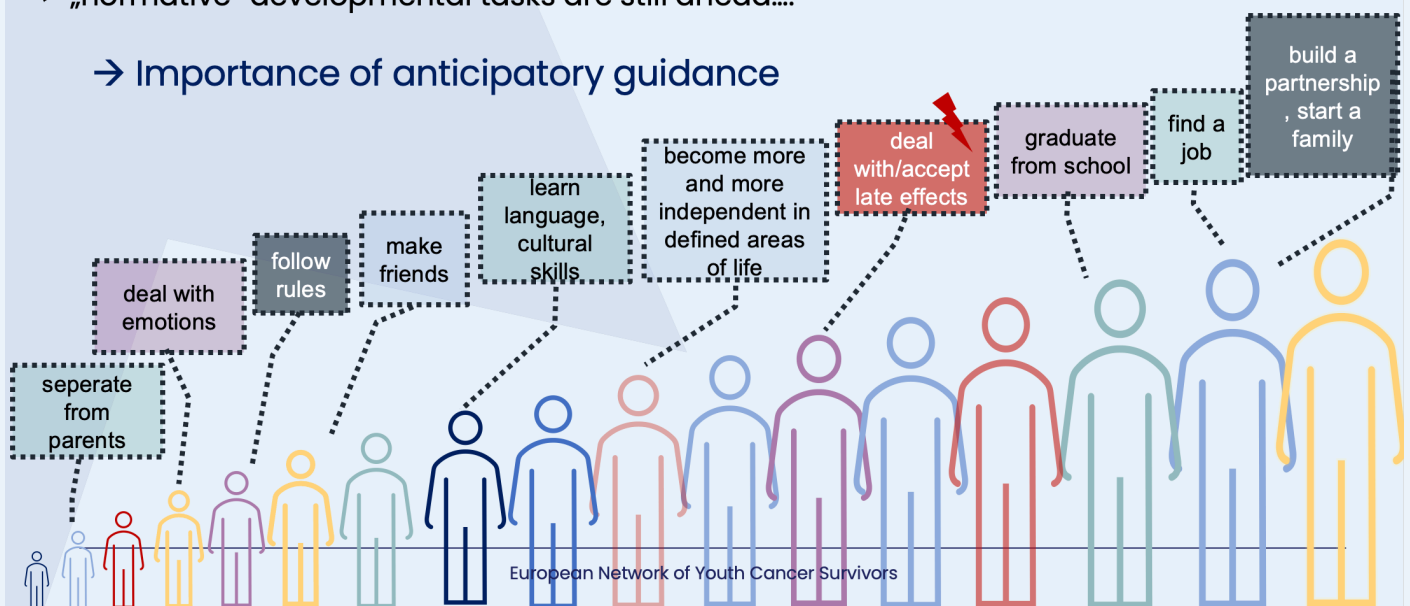
Importance of Mentoring Programs

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Normative and non-normative developmental tasks

- ✓ Children/AYAs have more „post-cancer years“ than adults
- ✓ „normative“ developmental tasks are still ahead....

→ Importance of anticipatory guidance



Article

Using Intervention Mapping to Develop an Education and Career Support Service for Adolescents and Young Adults Diagnosed with Cancer: Identification of the Contextual Factors That Influence Participation in Education and Employment

Esther L. Davis ¹, Kristina S. Clarke ¹, Pandora Patterson ^{1,2,*} and Jennifer Cohen ^{1,3}

Disrupted educational attainment

- For AYAs of school-age, cancer and its treatment disrupt school attendance up to three years post-diagnosis.
- Disrupted educational attendance is associated with reduced educational attainment, impacting employment outcomes and career development.
- Young adult cancer survivors are more likely to be unemployed or underemployed than their same-age peers and up to 50% of AYAs identified ongoing difficulties with attaining their prior education or employment goals two years post-diagnosis.

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Impact on future health and wellbeing

- As education and employment are social determinants of health disruptions to participation and engagement can have a significant impact on the future health and wellbeing of AYAs.
- Being under- or unemployed is associated with reduced economic productivity, social participation, and financial insecurity, as well as poor physical and psychological health and quality of life.

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Esther L. Davis¹, Kristina S. Clarke¹, Pandora Patterson^{1,2,*} and Jennifer Cohen^{1,3}

Unmet need for support

- Many AYAs with cancer report an unmet need for support with **acquiring and maintaining** education and employment.
- Young people with a cancer diagnosis report not feeling supported to cope with the **changes** to their education and/or employment during treatment and difficulty **accessing** an education and career advisor.
- AYAs with cancer describe **specific education and career support needs**, including a need for information about the effects of cancer and its treatment on participation in education and employment, personal consultation on career development, and job readiness and work skills training.

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Article

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Esther L. Davis¹, Kristina S. Clarke¹, Pandora Patterson^{1,2,*} and Jennifer Cohen^{1,3}

Unmet need for support

- Although support from peers and parents plays an important role in educational or career attainment, AYAs described feeling better supported when they received **formal support** from education and career professionals, rather than informal support from parents or friends.
- Despite the evidence for the efficacy of formal education and career support, many young people report being **unable to access** this type of specialised professional support.
- **Few evidence-based interventions** developed to meet the specific needs of AYAs diagnosed with cancer

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The Pocket Cards on education and career support were developed under Task 3.2.1 in a working group consisting of healthcare professionals and patient advocates, and then agreed via a Delphi survey and several consensus meetings.

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 

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6 Steps to improve educational support

#1 Get clear overview of personal **STRENGTHS and DIFFICULTIES.** *Cope with limitations - benefit from strenghts* 

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.

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

Go for it!

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.

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

- ! 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

i Find keypoints for career support on the back

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



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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.

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 strenghts

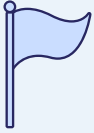
#2 Analyse **WORKING CONDITIONS** to identify where adaptations can be made.

#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.**

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

Personal factors: Reflection on education- and work related strengths and weaknesses



Goal

- Self-reflection and analysis of one's own education- or job-related strengths and weaknesses.
- Acknowledging the importance of knowing one's own strengths and weaknesses to find a suitable education or job, particularly in the case of late effects.
- Realising what can be a relevant strength in the context of education or work.



Method

- Self-Reflection/ Partner work



Materials/ content

- Exemplary material for Self-Reflection ( page 19)

Partner-Interview – Self-Reflection

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Which strengths are helpful in your training/job? Which strengths can you make use of?

Are there strengths that you cannot realise in your job/training? That nobody knows about?



general, disease-related or unrelated

Processing speed
 Hearing
 Load capacity
 Endurance
 Logical thinking
 Communication
 Organisation
 Vision
 Mathematical skills
 Accuracy
 Stress resistance
 Enthusiasm
 Empathy
 Loyalty
 Team spirit
 Flexibility
 Organisation
 ...and many more...
 Creativity
 Memory
 Problem solving
 Language
 Attention
 Multi-tasking
 Forward-thinking
 manual skills

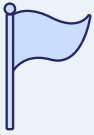
What weaknesses do you have, that sometimes make your job/training difficult?

What exactly happens?
How do you deal with the situation?

Do your colleagues know your strengths or weaknesses better?



Environmental factors: Analysis of school and workplace conditions & social network



Goal

- Analysing education & working conditions: facilitators and hindering factors.
- Raising awareness that environmental factors have a major influence on school/job performance and consequently must be analysed in detail and very often adapted.




Method

- Group work: *What can be hindering factors in the school or work context?*



Materials/ content

- Exemplary material for group work ( page 21)
- Flipchart
- Sticky notes

Inspiration for group work

Task: In groups of 3-4 people, hindering factors in school or at work are discussed and collected on a poster. The results are then briefly presented and discussed in the whole group.

Environmental factors:

School- and Workplace conditions & social network

- School-/workplace condition
- Teacher/employer
- Family/friends/peers/colleagues
- HCPs and other professionals



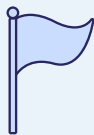
Where might barriers be hidden?

- (1) School
- (2) Job



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Environmental factors: Finances and legal framework



Goal

- Broaden knowledge about legal and financial regulations and challenges in the educational- or work-context.



Method

- Theoretical input
- Group discussion
- Collection of national best practice models

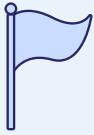


Materials/ content

- Flipchart
- Sticky notes
- In autumn 2024, a publication with specific information on financial and legal topics will be published on our website *beatcancer.eu*. Visit it regularly to stay up to date.



Specific support options



Goal

- Learn about and discuss specific support measures and best practice models.




Method

- Theoretical input
- Group work: *“Specific support options in working life”*



Materials/ content

- **Worksheets** ( pages 24-30, that deal with various possible limitations/impairments in school life, e.g. chronic fatigue or memory deficits and how to deal with them. How can the respective limitation/impairment be recognised? How can targeted support be provided?)
- **Task:** Based on the lists in the school context, create suitable checklists for working life.

Reduced resilience/chronic fatigue

How do I recognize it?



- Difficulty getting to school on time
- Severe tiredness and exhaustion, which increases as the school day goes on
- Lack of motivation
- Increased irritability
- Impaired concentration or memory difficulties
- Frequent confusion
- Slower working style
- Less interaction with classmates
- Decreased appetite

What can I do?



- Gradual integration: Initially, the pupil returns to school for a reduced number of hours, which is gradually increased (with regeneration); preferred attendance of main subjects and favorite subjects; alternation of strenuous/less strenuous lessons; e.g. starting school only at the second or third lesson
- If necessary, maintain the reduction in lessons in the event of persistently reduced resilience
- Individual form of task setting/performance review/assessment
- Individual organization of breaks
- Allow eating and drinking in the event of a severe "drop in energy" (by prior arrangement), e.g. chewing gum has been shown to increase alertness in the short term
- Enabling movement units and other activating measures



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Limitation of the processing speed/drive

How do I recognize it?



- The pupil shows a slower working pace (generally or only for specific tasks)
- The pupil appears "lazy", unmotivated, inattentive, distracted, "obtuse", slow, sluggish, withdrawn and/or depressed
- The pupil is lacking drive and/or lacks ideas, especially during free time

What can I do?



- Variation of working times for exams/schoolwork
- Assessment and positive feedback on completed tasks instead of emphasizing what is missing
- Avoiding time pressure whenever possible, as otherwise the pupil will quickly come under pressure, "lose their nerve" etc.
- Additional signal at the beginning of tasks that it's time to get started
- Providing a structure (of the day, of tasks, etc.)
- Providing a basic structure for free work/in freely organized time or for choices, as the pupil lacks their own initiative or ideas (drive) due to illness



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Limitation of attention & concentration

How do I recognize it?



- Daydreaming, digression
- Increased distractibility
- Difficulty holding back reactions (e.g. calling out answers without being called on by the teacher)
- Short attention span
- Strong fluctuations in attention during the day
- Significant decrease in ability to concentrate in the second half of the day, without regeneration/recovery after a break
- Overstrain with too many or several tasks to be completed simultaneously
- Significantly increased susceptibility to errors with increased time pressure

What can I do?



- Giving hints to make it easier for the pupil to "stay on task" (e.g. briefly addressing them, small hints, often making eye contact, asking them to change their sitting position or sit on the front edge of the chair)
- Sit at the front of the class
- Create a "low-stimulus" environment (e.g. at the seat) to reduce distraction
- Establish clearly structured reinforcement/reward systems when prolonged attention or restraint of impulses is required
- Allowing the pupil to concentrate on one task at a time
- Individually designed breaks and variation of working times



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Limitation of learning & memory capacity

How do I recognize it?

- Difficulty remembering things when they are needed
- Forgetting repeatedly learned information (e.g. also routine procedures)
- Difficulty following complex and multi-step instructions
- Fluctuating memory performance - even for similar tasks
- Frequent follow-up questions
- Confabulating in the case of memory gaps (i.e. more information is recalled from memory than is stored; often unconsciously, also to hide unpleasant memory gaps); the content may appear constructed or it may appear that the pupil is making things up
- Telling the same information several times without the pupil realizing it; also no noticeable gain in content when asked

What can I do?

- Use simple, clear instructions
- Asking whether the student has understood and memorized the instruction
- Portioning and structuring learning content; if necessary, reducing it accordingly
- Incorporating learning and memorization strategies into the lesson, e.g. mnemonic devices, mnemonic sentences, mind maps, effective note-taking, underlining/marking core content, omitting unimportant content, etc.
- Use different materials to support the memorization process ("for all senses"), e.g. with pictures, written learning materials, highlighters, sounds, shaped letters, etc., so that functioning memory structures (e.g. visual memory) can be used making things up
- In the case of confabulation: do not make assessments of recurring content, i.e. do not correct statements each time, but leave them as they are to avoid conflicts; do not expose the pupil and seek a way of dealing with this (also with classmates and parents)



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Limitation of learning & memory capacity

How do I recognize it?

- Giving the impression that there is no learning gain (e.g. with vocabulary, when applying arithmetic operations or subject-specific knowledge)
- Recognition works better than free recall of content (e.g. the student cannot answer the open question about what was covered in yesterday's lesson, but recognizes the content in the textbook)

What can I do?

- Plan deliberate breaks between memorization, especially if the content is similar (e.g. a break between learning vocabulary in two foreign languages); ideally, alternate as many different memorization contents as possible [e.g. first memorize vocabulary of a foreign language (= verbal memory), then flags of different countries (= visual memory)]
- Providing assistance, e.g. written instructions, homework diary, checklists, clocks, memo cards, signal cards, dictaphones, calculators, etc.
- Developing routines
- Offering regular repetitions
- Reminding students of regularly occurring procedures
- Carrying out tests in multiple-choice answer format, as recognition is easier than freely reproducing memory content
- Connecting new learning content with what has already been memorized



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European Network of
**YOUTH CANCER
SURVIVORS**

Limitation of executive functions (e.g. ability to organize, plan and act)

How do I recognize it?



- Unstructured, chaotic and aimless way of working
- Having the impression that the pupil does not understand the task
- Difficulties:
 - making a plan (for the school day, a project or other activities)
 - thinking ahead
 - making decisions (e.g. when there are several possible solutions)
 - creating concepts
 - dividing a task into sub-problem and solving them step by step (e.g. the pupil cannot find a start; forgets the sub-problems and/or confuses the steps)
 - distinguishing relevant from irrelevant information (often insisting on unimportant details)
 - flexibly adapting solutions/behavior/rules to new situations (new situations or exceptions cause stress)
 - recognizing and correcting mistakes
 - assessing the consequences of actions

What can I do?



- If possible, provide clearly structured plans (e.g. timetables, daily plans and work plans that the pupil only has to "tick off")
- Use of planning aids (e.g. visual illustration on a large poster: noting down action steps, goals or alternative solutions)
- Structuring and portioning tasks so that partial successes are possible
- Support in the definition of (partial) goals - (written or verbal) highlighting of relevant information in tasks (especially for tests/exams)
- Conscious preparation for new situations
- Discussing cause-consequence relationships
- Prompting to check for errors



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Insecure social skills

How do I recognize it?



- Socially insecure to inappropriate behavior (e.g. lack of distance)
- Lack of "perspective taking": Inability to put themselves in the shoes of others
- Good interaction with adults, but difficulties with peers (behavior seems "different"; not age-appropriate "childlike" or "pubertal", but too adult; no common topics with peers)
- Rigid or inflexible behavior
- Difficulties:
 - to correctly interpret non-verbal communication/clues
 - making new friends and keeping old friends
 - understanding abstract language (e.g. jokes, metaphors)

What can I do?



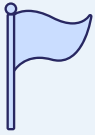
- Informing parents and (jointly) organizing support from a guidance teacher, school psychologist, school doctor, care clinic or aftercare facility
- Encouraging participation in school excursions, class trips, project weeks and other school activities
- Use of a pupil sponsor, mentor or buddy system
- Involvement of classmates, discussion with the class



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EU-CAYAS-NET recommendations for career support



Goal

- Learn about EU-CAYAS-NET recommendations for career support.




Method

- Theoretical input
- Group discussion

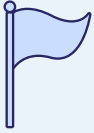


Materials/ content

- Pocket Cards on education and career support ( pages 16-17 and download materials on <https://beatcancer.eu/project-deliverables/>)
- In autumn 2024, a publication will be published providing comprehensive information and recommendations for career support. Currently, intensive work is being done to compile all the important details. It is therefore worth visiting our website *beatcancer.eu* regularly to stay up to date and not miss any important information.



Guidance aspects – Communication & attitude



Goal

- Learn about the basic principles of communication with young people with or beyond cancer.
- Developing communication skills and an appropriate attitude through self-reflection.



Method

- Theoretical input
- Role play “*Respect feelings*”
- Group discussion



Materials/ content

- Pocket Cards on communication ( pages 33-34 and download materials on <https://beatcancer.eu/project-deliverables/>)
- Available guidelines on communication about serious matters

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](https://www.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 person's 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'T'S

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"

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



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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.

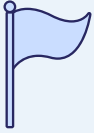
#12 PLAN & ACT

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.

Closing summary, follow up sessions, evaluation



Goal

- Evaluation of training
- Discuss open questions
- Collect and make the content available, that was generated in the training.
- Ensure possibility of future collaboration/networking of the group (for all who want to join).
- Plan focus of next online follow-up sessions (e.g. supervision, open questions, exchange of best practice models, etc.).



Method

- Group discussion



Materials/ content

- Flipchart
- Sticky notes

Space for
thoughts



Further reading

Braun, I., Friedrich, M., Morgenstern, L., Sender, A., Geue, K., Mehnert-Theuerkauf, A., & Leuteritz, K. (2023). Changes, challenges and support in work, education and finances of adolescent and young adult (AYA) cancer survivors: A qualitative study. *European journal of oncology nursing : the official journal of European Oncology Nursing Society*, 64, 102329. <https://doi.org/10.1016/j.ejon.2023.102329>

Davis, E. L., Clarke, K. S., Patterson, P. & Cohen, J. (2022). Using Intervention Mapping to Develop an Education and Career Support Service for Adolescents and Young Adults Diagnosed with Cancer: Identification of the Contextual Factors That Influence Participation in Education and Employment. *Cancers*, 14(19), 4590. <https://doi.org/10.3390/cancers14194590>

Dax, V., Edwards, N., Doidge, O., Morkunas, B., Thompson, K., & Lewin, J. (2021). Evaluation of an Educational and Vocational Service for Adolescent and Young Adults with Cancer: A Retrospective Review. *Journal of adolescent and young adult oncology*, 10(1), 56–65. <https://doi.org/10.1089/jayao.2020.0009>

Devine Christen S, Mulder RL, Brown MC, Ingerski LM, Mader L, Potter EJ, Sleurs C, Viola AS, Waern S, Constine LS, Hudson MM, Kremer LCM, Skinner R, Michel G, Gilleland Marchak J, Schulte F. Recommendations for the surveillance of education and employment outcomes in survivors of childhood, adolescent, and young adult cancer: A report from the International Late Effects of Childhood Cancer Guideline Harmonization Group. *Cancer*. 2022. <https://doi.org/10.1002/cncr.34215>

Foster, R.H., Hayashi, R.J., Wang, M., Liu, W., Mohrmann, C., Howell, R.M., Smith, S.A., Gibson, T.M., Srivastava, D., Green, D.M., Oeffinger, K.C., Leisenring, W.M., Robison, L.L., Armstrong, G.T., Krull, K.R. and Hardy, K.K. (2021). Psychological, educational, and social late effects in adolescent survivors of Wilms tumor: A report from the Childhood Cancer Survivor Study. *Psycho-Oncology*, 30: 349–360. <https://doi.org/10.1002/pon.5584>

Nicklin, E., Pointon, L., Glaser, A. et al. (2021). Unmet support needs in teenage and young adult childhood brain tumour survivors and their caregivers: “it’s all the aftermath, and then you’re forgotten about”. *Support Care Cancer* 29, 6315–6324. <https://doi.org/10.1007/s00520-021-06193-x>

Thompson, A. L., Christiansen, H. L., Elam, M., Hoag, J., Irwin, M. K., Pao, M., ... Kelly, K. P. (2015). Academic continuity and school reentry support as a standard of care in pediatric oncology. *Pediatric Blood and Cancer*, 62(Suppl 5), S. 805–817. [doi:10.1002/pbc.25760](https://doi.org/10.1002/pbc.25760)
Vetsch, J., Wakefield, C.E., McGill, B.C., Cohn, R.J., Ellis, S.J., Stefanic, N., Sawyer S.M., Zebrack, B., Sansom-Daly, U.M (2018). Educational and vocational goal disruption in adolescent and young adult cancer survivors. *Psycho-Oncology*, 27: 532–538. <https://doi.org/10.1002/pon.4525>

<https://beatcancer.eu/resources/>

<https://beatcancer.eu/resources/mental-health/article/bridging-the-gap-researching-together/>

<https://beatcancer.eu/resources/mental-health/article/lab-book-research-together-in-junior-research-academy/>

After the workshop



- Participate in our follow-up sessions
 - to collect more best practice models for education and career support,
 - to discuss concrete options for implementation of support options,
 - to reflect together on particular challenges and
 - to continue to learn from each other.
- Spread the word about the *Train-the-Trainer* opportunity or plan/organise your own training as a trainer in your region, institution or organisation.
- Participate in discussions and initiatives in the health and education system that could improve education and career support options.

Interested persons can also contact the Medical University of Vienna (eucayasnet@meduniwien) or CCI Europe (office@ccieurope.eu)

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