



# Career support for young people living with and beyond cancer

A report from the European Network of Youth Cancer Survivors

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## The issue

Choosing and completing a suitable course of vocational training is an important milestone in the development of adolescents and young adults (AYAs), as is finding a job that matches their abilities, opportunities and aspirations. The way in which a person is ultimately able to participate in working life subsequently influences their physical, mental and social health.

Findings from clinical practice and research to date indicate that adolescents and young adults are often unable to participate satisfactorily in the labour market after a cancer diagnosis. There are many reasons for this: in addition to disease- and treatment-related factors, environmental factors (e.g. arrangement of workplace, lack of suitable work equipment), aspects of one's own behaviour (e.g. way of communicating about the disease, readiness to accept support) or political and social factors (e.g legislation, access to insurance) play a role. At the same time, there is a significant gap in the provision of appropriate support services.



## A call for action

In order to improve this situation, one of the EU-CAYAS-NET work packages was dedicated to the topic of career support. Among other tasks, a literature search\* was carried out to get an overview of existing, effective support options. This report summarises the results and provides a brief outlook on the other project outcomes related to career support (page 11 & 12).

#### **Acknowledgments:**

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### Led by:





### Contributing Consortium partners:

















<sup>\*</sup>Search date: 11/2023; Search period: 25.09.2023-19.11.2023; Database: Pubmed; Search terms: interventions for 1) AYAs with 2) cancer in 3) working life, grey literature was included

## There is still far too little knowledge!

Research has shown that there are hardly any intervention studies for young people with and beyond cancer to improve participation in working life. Two reviews with similar research questions and search criteria were recently conducted (Davis et al., 2022; Devine et al., 2022).

Until 2021, no study could that identified examined interventions to improve employment outcomes in survivors of cancer in childhood, adolescence and young adulthood (Devine et al., 2022). However, Devine and colleagues developed clear recommendations for regular follow-ups of educational occupational status in their report to the International Late Effects of Childhood Cancer Guideline Harmonization Group (IGHG).

Devine, K. A., Christen, S., Mulder, R. L., Brown, M. C., Ingerski, L. M., Mader, L., ...& International Guidelines Harmonization Group Psychological Late Effects Group (2022). 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, 128(13), 2405–2419. https://doi.org/10.1002/cncr.34215

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Davis et al. (2022) created a clear model that includes risk factors for limited participation in working life, where possible interventions can be applied.

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



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## Acronyms & Abbreviations

AYA - Adolescents and young adults

CAYA - Children, adolescents and young adults

EU-CAYAS-NET - European Network of Youth Cancer Survivors

IGHG - International Late Effects of Childhood Cancer Guideline Harmonization Group

Our search also covered the period after 2021. Since then, two relevant studies have been published. Furthermore, an additional study from 2010 was found.

Intervention aimed at people aged
13-26 years

The following interventions were described as helpful:

- Individually tailored advice, specific recommendations
- 2 Education about the impact of the disease & its treatment on the person's vocational performance
- Counselling for survivors & institutions/workplace

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# Counselling for CAYA cancer survivors and institutions/workplaces

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

### Australia

This retrospective cohort study included a sample of 219 individuals aged 13 to 26 years (average: 19.6 years). The study examined the long-term impact of individually tailored counselling provided by the Education and Vocational Support Program (EVSP) on educational and employment outcomes. The counselling was provided to both survivors of cancer adolescence or young in childhood, adulthood educational and to institutions/workplaces and included: (1) education about the impact of cancer on academic/vocational performance and (2) specific recommendations regarding support options to improve academic/ vocational performance. Overall, more than 90% of the referred adolescents and adults (AYAs) attended program. 79% of them were successfully integrated into school/work

Intervention aimed at people aged 24-44 years

- 1 Assistive technology
- 2 Ergonomic adjustments
- Support in applying disadvantage compensation
- Vocational retraining or further education
- 5 Psychosocial support
- 6 Financial support from carers
- Financial support from public services or patient organisations

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## Support on multiple levels

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

## Germany

The authors conducted semi-structured interviews with 11 AYAs (between 24 and 44 years old, average: 31.5 years). The respondents identified the following interventions as beneficial for vocational participation:

- Support through assistive technology devices or ergonomic adjustments
- Additional training opportunities
- Support in applying disease- or lateeffect-related disadvantage compensation (e.g. barrier-free examination procedure or accessible workplace)
- Conversations with family, partners and friends
- Psychological support during rehabilitation and aftercare
- Financial support from families, parents and spouses
- Financial support from public social services or patient/survivors organisations

Intervention aimed at people aged 18-25 years

- Job search assistance
- Workplace support

## Support that is easily accessible

Strauser, D., Feuerstein, M., Chan, F., Arango, J., da Silva Cardoso, E., & Chiu, C. Y. (2010). Vocational services associated with competitive employment in 18–25 year old cancer survivors. Journal of cancer survivorship: research and practice, 4(2), 179–186. https://doi.org/10.1007/s11764-010-0119-9

#### **USA**

A retrospective search of the Rehabilitation Services Administration (RSA) database was conducted to determine whether the use of any type of vocational support was associated with employment among AYAs.

The Survivors made use of the following vocational support services: Assessment of individual situation (e.g. eligibility), diagnosis and treatment of medical conditions, vocational rehabilitation, counselling, job skill training, tutoring or literacy classes, job search assistance, workplace support, transportation services, reading (aloud) services, interpretation services, personal care services, technical assistance services, information services, assistance with referral to other agencies, and other services.

A total of 368 AYAs aged 18 to 25 (average: 21.5 years) were registered in the database. They accounted for only 0.4% of all people receiving vocational support under the RSA. Of the unemployed survivors receiving support, 51.6% (n=190) found successful employment. In particular, those individuals who received support with job search assistance or at work itself had an increased chance of being employed. The provision of financial or medical services was associated with a lower likelihood of being employed.



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## A glimpse at career support for adults

Due to the small number of studies specifically targeting AYAs, our search was extended to include the entire working-age population (meaning people up to the age of 65).

With this broader focus, it was possible to identify more studies that examined career support interventions during or after cancer.

To highlight possible approaches, three exemplary studies are presented below that can serve as inspiration for interventions and their practical implementation.

Self-reflection

Planing and achieving realistic goals

> Personalised support

Practical counseling

> Online adive and support

Dealing with symotoms and long-term effects

> **Psychological** support

Identifying barriers in the work environment

Intervention aimed at people aged 25-65 years

- Self-reflection
- Planning and achieving realistic goals
- Identifiying barriers in the work environment

#### **Great Britain**

randomised controlled trial examined how a guided workbook help survivors achieve professional goals after treatment. The intervention consisted of a workbook that was individually guided by a counsellor and aimed to support survivors in setting, planning and implementing career steps. The focus was on promoting self-reflection, planning realistic goals and identifying barriers in the work environment.

## Supporting selfreflection and planning

Grunfeld, E. A., Schuhmacher, L., Armaou, M., Wood, P. L., Rolf, P., Sutton, A. J., Zarkar, A., & Sadhra, S. S. (2019). Feasibility randomised controlled trial of a guided workbook intervention to support work-related goals among cancer Survivors in the UK. BMJ Open, 9(1), e022746. https://doi.org/10.1136/bmjopen-2018-022746

A total of 35 survivors of working age (average: 50 years) participated in the study, divided into two groups: (1) a control group that received standard care, (2) an intervention group that additionally received the workbook. After six months, it was found that 30% of the control group had returned to work full (including part time gradual or resumption of work). In contrast, the rate in the intervention group was 43%. After one year, 47% in the control group and 68% in the intervention group had returned to work. The results showed that most participants were able to use the workbook to better pursue their professional goals and overcome challenges in the work environment.



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Intervention aimed at people aged 18-65 years

# Digital coaching programme for the return to work

Lo, J., Ballurkar, K., Fox, S., Tynan, K., Luu, N., Boyer, M., & Murali-Ganesh, R. (2021). A digital coaching intervention for cancer survivors with job loss: Retrospective study. JMIR Cancer, 7(4), e31966. https://doi.org/10.2196/31966

- Management of symptoms and late-effects
- 2 Setting realistic goals
- Nutrition, exercise and sleep routines

#### Australia

The retrospective study examined a digital coaching programme for survivors who had been unemployed for at least three months due to their cancer and examined 250 treatment. It survivors of working age (18-65 years) who were divided into two groups: those who used the digital programme (n = 125) and those who did not use it (n = 125).



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The programme consisted of an app and three telephone consultations with health professionals over a period of 12 weeks. The programme was aimed at managing symptoms and adverse side effects during and after treatment to facilitate the return to work. This included, e.g., setting realistic goals and setting new goals as soon as they were achieved, as well as improved nutrition, exercise and sleep routines.

The study showed that survivors who used the coaching programme returned to the labour market more likely and faster. Of the survivors who used the coaching programme, 39.4% returned to the labour market within 18 months of the programme, compared to 17.6% of the survivors who did not use the coaching programme. Survivors with the coaching programme returned to work after an average of 70.6 weeks, compared to 87.1 weeks for survivors without the coaching programme. Overall, the programme helped survivors to be better prepared for re-entering the job market. They felt emotionally stronger, were more optimistic selfand showed confidence in looking for new jobs.

Intervention aimed at people aged 18–68 years

#### **Netherlands**

This randomised controlled trial examined whether a tailored return to work programme for cancer survivors could help them find a job faster. The study included 171 survivors between the ages of 18 and 68 years (average: 48.4 years) who were unemployed after their diagnosis. They were randomly assigned to two groups: (1) intervention group that received the (2)tailored programme, control group that received standard care without any special support.

- Tailored support from a trained person
- 2 Setting individual goals
- Psychological and practical support



# Tailored programme reduces anxiety and depression

Van Egmond, M. P., Duijts, S. F. A., Jonker, M. A., Van der Beek, A. J., & Anema, J. R. (2016). Effectiveness of a tailored return to work program for cancer survivors with job loss: Results of a randomized controlled trial. Acta Oncologica, 55(9-10). 1210-1219. https://doi.org/10.1080/0284186x.1213417

The intervention consisted of individually tailored support from a trained person, who worked with the participants to set individual goals, supported them in their iob search and applied targeted strategies for professional reintegration. support included psychological and practical counselling, help finding new e.q. managing opportunities or in physical and psychological effects of cancer and its treatment. The results showed that the programme had no significant impact on the return to work: both groups showed similar rates of return to work. However, participants in the intervention group reported a better quality of life and less anxiety and depression compared to the control group. Although the programme did not accelerate the return to work, it had a positive impact on the survivors' wellbeing.

## **Conclusion**

#### Any questions or comments?

Contact the Medical University of Vienna (eucayasnet@meduniwien.ac.at) or CCI Europe (office@ccieurope.eu)

This report indicates that there is a paucity of studies examining career support interventions. However, there are some promising approaches, including individual counselling, return-to-work support, and digital coaching programmes. These interventions promote self-reflection, realistic goal setting, and the management of long-term effects.

The results emphasize the importance of targeted interventions to facilitate vocational opportunities and enhance the quality of life and social participation of young cancer survivors.

To meet the challenges of young cancer survivors, various practice-oriented materials have been developed in addition to this report. These materials have been developed to empower cancer survivors in their professional and personal development and provide a solid foundation for long-term support.

#### **Pocket Cards**

These cards cover important topics such as educational and career support during and after cancer, talking with young people about serious matters and the difference between grief and depression.

#### **Educational video**

This video sheds light on the unique challenges faced by survivors, while also highlighting their capabilities and potential opportunities for education and career advancement.

### **Train-the-Trainer Manual**

This manual was developed to support interested parties in developing educational and career support for young survivors. It offers nine modules that promote self-reflection and help to develop and pass on individual education and work strategies.

## Visit our website beatcancer.eu

...to find more materials on education and career support!











Train-the-Trainer concept & manual







Educational video on education & career support







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