

Employment Support for Cancer Patients

Overview

- A survey commissioned by the Ministry of Health, Labour, and Welfare in 2015 found patients' work cessation at 40% before treatment, following cancer diagnosis. The driving force was uncertainty about the unknown, coping with treatments, work capabilities diminishing and burdening colleagues; providing accurate information and consultation services starting at diagnosis is essential.
- Since 2013, employment consultants (labor and social security attorneys) are seconded to consultation and support centers. An initiative to
 improve work-treatment balance for cancer patients was rolled out 2018 2019, boosting job retention and workplace returns with more
 consultation services.
- Work-treatment balance coordinators are stationed at consultation and support centers from 2020, supporting patients liaising with primary
 physicians and employers. The service ensures seamless cancer patient support for work-treatment balance, with clear plans set for each
 patient covering treatment, daily lives, and work.

Diverse Consultation Needs

Employment (Job retention, return to work)

- Job retention support with early intervention, responding to individual needs
- Coordinating work conditions, e.g., shorter hours, accommodating treatments and managing daily lives
- Reduce anxiety, by providing information on treatments, work, and balancing lives
 - →Patient consultations, support for coordination between primary and occupational health physicians
- Support upon unfair or wrongful dismissal, mistreatment by employers
- Support with work leave and social security

Initiative for cancer patients work-treatment balance (2018-2019)

- Medical practitioners' awareness raised, more consultations/interventions

- Balance plan brochure – utilized in workplace relations - Seminars - patients better informed/prepared for employment



Support at Designated Cancer Care Hospitals

Employment Support for Cancer Patients (2013-)

The initiative supports either of the two:

- 1. Assign employment specialists (labor and social security attorneys) to cancer care hospitals, providing consultations, from 2013
- Provide consultation services for work-treatment balance improvement, by staff having completed designated courses, incorporating individual needs from diagnosis, supporting patients throughout their recovery, from 2020

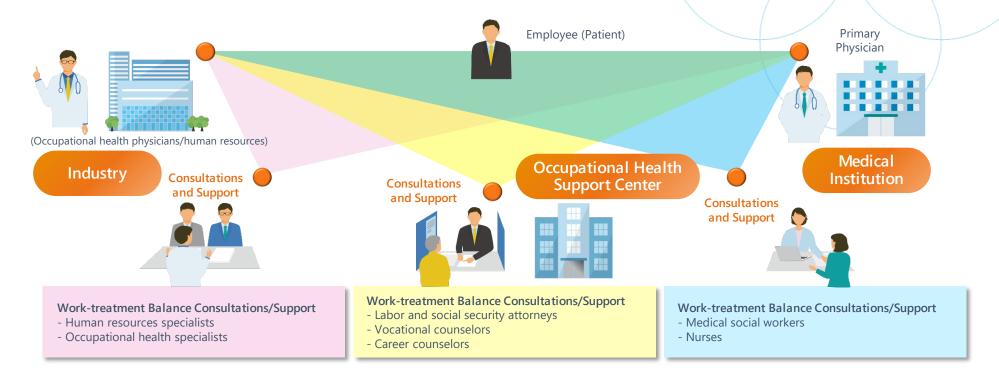


Work-treatment Balance Support for Cancer Patients

Treatments/Recovery Return to Work **Pre-Diagnosis** Diagnosis (Workplace) • Shared understanding developed through relative parties' discussions Work-treatment balance Raise Formulate plans for work-treatment balance support/return to work, support starts, upon awareness implement, and follow up request from employee (Individuals) Confidence eroded by side/late effects, anxiety over recurrence Upset with diagnosis, risk of leaving work Accommodation at workplace challenged Uncertainty over treatments, income, family (Leading to treatment interruptions, overwork aggravating disease) Distress over communicating to colleagues Doubts over re-entering workforce (Cancer Care Hospital) Assess Identify issues with treatments, Primary physician recommendation, formed from needs early daily activities, work conditions work information form Advice on communication with • Guidelines for work-treatment Balance Support workplace (Revised Mar 2021) Psychological support, alleviating anxiety, improving motivation Guidance on social welfare system Coordination with workplace, employment specialists, relative institutions 1. Support following individually tailored plans 2. Early intervention and continued support, provided from hospital team 3. Awareness activities for patients' families and medical practitioners (Initiatives) Comprehensive Support Initiative for Cancer Patients Employment (Part of Designated Cancer Care Hospitals Reinforcement Project) · Work/Treatment Balance Plan (1) Employment specialists (labor and social security attorneys) assigned for consultations from 2013 (Handy Notes for Balancing Work and Cancer Treatment) (2) Consultations and support by staff completing designated training courses from 2020

Occupational Health Support Project (Occupational Health Support Centers)

Work-treatment Balance Coordinators



Expertise: Human resources, occupational health, medical practice, social security

Function: Provide consultations and support patients throughout the passage to recovery

Role: Support patients with own expertise, coordinate involved parties

Advice on necessary adjustments incorporating treatment and work requirements and conditions, upon request

*coordinators provide advice to the patient while not representing service recipients at negotiations



Regional Consultation and Support Centers

One-stop cancer consultation services for patients and families, on psychological issues, treatments, daily activities, care issues. Established in 15 prefectures (Jul 2023)

Costs borne by: Prefectures (50% borne by central government)

Initiative: Recruiting/training specialists providing peer support/consultations,

analyzing consultations, improving access to peer networks

Regional Consultation and Support Centers

Prefectural Consultation and Support Centers



Set up one-stop cancer consultation centers, and train peer mentors

 Consultation training for nurses

National Cancer Center

 Distribute patient info brochures

Cancer information services

activities, care

Consult

Consult

Unhappy with current cancer care hospital, unsure of current treatment

Patient and families

Need one-stop consultations beyond medical, psychological, daily

Hospital referral upon relocation

Hospital ceased treatment offers; information on clinical trials and unapproved drugs needed

Information on cancer treatments

Second opinion physician referrals

Patient info brochure queries

Training programs for patient volunteer mentors providing consultations





Ministry of Health, Labour, and Welfare initiative for training Comprehensive Cancer Consultations

(Assigned to Japan Psycho-Oncology Society)

Training course material website: http://www.peer-spt.org/

©cancer care hospitals

Consultation and

National Cancer Center Japan

Comprehensive Cancer Consultations and Support - Capacity Building

*Peer support: support for cancer patients and families by cancer patients, former patients and their families sharing experiences and discussing issues.

Past / Current state

- Programs and literature to help train patient volunteer mentors, on hosting peer networks developed under an initiative (fy2011-fy2013).
- Patient mentor training/utilization advice offered to prefectural governments (fy2019-).

Peer support policies

- Ministry of Internal Affairs and Communications Cancer Control Administrative Assessment (Sep 2016)

 Peer support should be provided respecting the wishes of cancer patients and their families, however, over restraint from this regard can hamper attaining its original objectives. The Ministry of Health, Labour and Welfare (MHLW) should further encourage peer support activities by establishing and revising guidelines for patient volunteer mentor training program guidelines, consulting with patient groups and relevant academic societies.
- MHLW Conference on Future Direction of Cancer Care Provision (Oct 2016)
 Peer support activities/patient support groups to be expanded, further working with patients and former patients, by providing training on peer support.

Initiatives

Program guidelines to be updated, training offered to former and current cancer patients, Designated Cancer Care Hospitals medical staff and prefectural governments, in cooperation with patient advocacy groups /academic societies. (reference)

Training Initiative: http://www.peer-spt.org/ Workshop Info: http://www.peer-spt.org/annai/





Appearance Care

Definition:

Medical, cosmetic, and psychosocial care to address changes in appearance* to alleviate distress caused

* Changes in appearance caused by treatments do not necessarily require remedies. (Appearance support center - National Cancer Center Hospital website)

The Need

More cancer patients maintain social lives during treatment, thanks to advances in treatment. It is important to <u>provide support in medical settings</u> adjusting to changes in appearance.

Treatments	Typical changes in appearance
Chemotherapy	Loss of hair (scalp, eyelashes/brows), hand-and-foot syndrome, skin pigmentation, nails cracking/peeling/colors changing
Molecularly targeted therapy	Hand-and-foot syndrome, acne-like rash, dry skin, nail inflammation
Radiation therapy	Radiation dermatitis
Surgery	Surgical scars, loss of body parts, swelling

Study Projects

	Period	Research Topic
Comprehensive Research	2017-2019	Equity in cancer patient appearance care, and developing training programs for leaders
Initiative for Promoting Cancer	2020-2022	Implementing high-quality appearance care for cancer patients
Control - MHLW Health Labour Sciences Research Grant	2023-	Implementation of supportive care in clinics, factors impeding/encouraging its advancement
	2014-2016	Analysis of skin problems caused by cancer treatments, and establishing standard care
AMED	2017-2018	Establishment of standardized methods of care for acneiform dermatitis caused by molecular standard treatment drugs

Better consultations for living with cancer

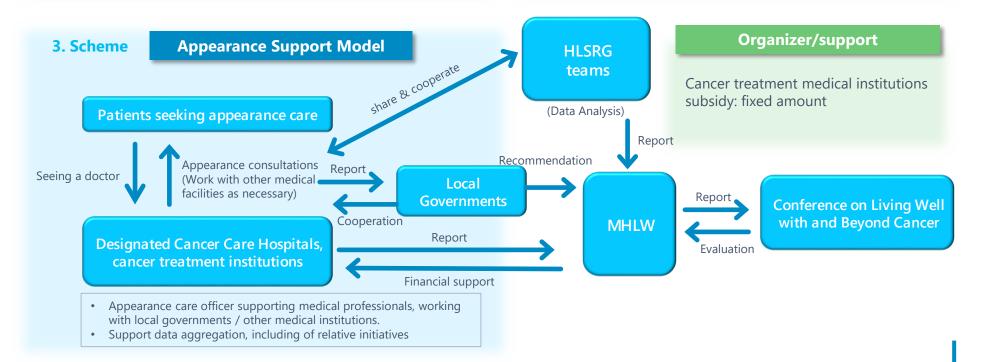
(Appearance Support Model Project)

1. Purpose

- Treatments can change one's appearance, affecting social life. Support at medical institutions to help patients cope is necessary.
- Support to be provided with medical institutions and local governments working together. Means tried and proven effective will be deployed throughout the nation.

2. Summary

- At Designated Cancer Care Hospitals and cancer treatment institutions, healthcare professionals will provide information and consultations to cancer patients requiring appearance care.
 The effect will be measured.
- MHLW Health Labour Sciences Research Grant (HLSRG) teams to be deployed in research and analysis.



Appearance Care Information Brochures

Leaflet for cancer patients

Advice on patients' interests
(hair, fingernails, skin, eyebrows/eyelashes)

Editors: Yokohama City/Yokohama medical practitioners/ National Cancer Center Hospital



https://www.city.yokohama.lg.jp/kurashi/kenko-iryo/iryo/gan/taisaku/appearance.html

Treatment guide for cancer care staff

Evidence on chemotherapy, molecular targeted therapy, radiotherapy, and routine cosmetics

Authors: specialists in medicine, nursing, pharmacology, cosmetic science, and psychology



"Guide to Appearance Care for Cancer Patients" 2021 edition Edited by: Japanese Association of Supportive Care in Cancer

Suicide Prevention

Designated Cancer Care Hospitals Guidelines

Designation requirements

- Utilization of a set guide to control suicide risks among cancer patients, spelling out specific responses and means of working with relative teams
- Information sharing schemes among relative specialists
- Services secured from local medical institutions if no in-house psychiatry / psychosomatic medicine

4th Basic Plan to Promote Cancer Control Programs

(Excerpt)

The Government of Japan is to deliberate on training, information provision and consultation support for healthcare staff to acquire accurate knowledge, towards preventing post-diagnosis suicide of cancer patients.

The government is also to comprehend suicide risks of cancer patients and its context, then to deliberate necessary action.

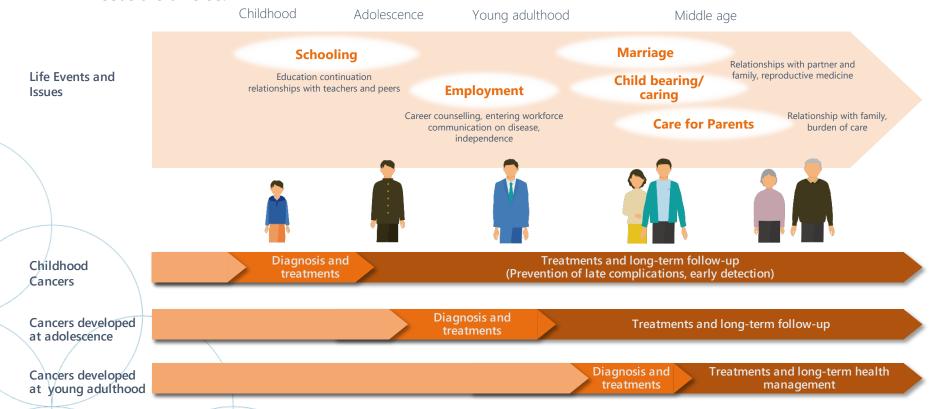


Accommodating major life events

Extract from submissions to Cancer Control Promotion Council – 3 Nov 2021

(Childhood and AYA)

- Involving wide range of life stages; developing early with possible complications much later, post treatment follow-up is required long-term.
- Schooling, employment, reproduction requirements vary by age group, psychosocial conditions differ; needs are diverse.



Childhood and AYA Generation Cancer Patients

and Families - Support Initiatives

Extract from submissions to Cancer Control Promotion Council – 3 Nov 2021

Needed initiatives		Major efforts	
(1)	Inpatient classes/accommodation	Improve Designated Hospitals for Childhood Cancers facilities	
(2)	Education support	 Bolster scheme for continued education of hospitalized senior high school students Improvement in long-term follow-up for children and AYA generation patients Coordinated support from hospitals specializing in childhood and adult cancers (Training counsellors, work with consultation and support units of liaison groups of cancer care hospitals) 	
(3)	Consultations and support for accommodating life events		
(4)	Employment Support	 Workforce entrance support for cancer patients (pilot model 2013-, national rollout 2016-) Comprehensive support for employment of cancer patients (2013-, modified 2020) 	
(5)	Palliative Care	Improvement of pediatric palliative care teams	

MHLW Health Labour Sciences Research Grant Projects

)	Period	Research Topic			
/_	2018-2020	Establishment of a comprehensive care provision system for cancer patients of adolescent and young adult (AYA) generation			
	2019-2020	Current state and future of at-home care for childhood cancer patients			
	2019-2021	Development/implementation of mental health care and high school education to AYA generation cancer patients			
	2020-2022	Establishment of long-term follow-up through collaboration between childhood cancer centers, and adult diagnosis and treatment departments			
	2020-2022	Equalizing psychological support for preserving fertility for childhood and AYA generation cancer patients and establishing a system for secure, long-term specimen storage: providing patient-centered cancer treatment			



Support for AYA Generation Cancer Patients and their Families - Information

Booklet for families of AYA generation cancer patients

AYA: Adolescent and Young Adult



About AYA generation/ AYA generation cancers/ AYA generation anxieties/ friends, partners, and family/ school/ work/ sex and reproduction/ financial uncertainties/ post-treatments/ families and siblings facing distress and concerns

2015-2017 MHLW Health Labour Sciences Research Grant (HLSRG) project "Research regarding the future shape of comprehensive cancer control for the adolescent and young adult (AYA) generation"

URL: https://ayateam.jp/wp-content/uploads/2019/04/AYA.pdf

 Fertility preservation therapy - information provision, consultation and support

To breast cancer patients who wish to have children in the future

To patients who are starting cancer and pregnancy consultations (for consultation staff)







2016 MHLW HLSRG project "Evidence regarding fertility in long-term survivors of childhood and youth cancer and research related to the creation of a fertility health network" URL: http://www.j-sfp.org/ped/index.html

Nationwide network - AYA cancer support team

Establishing coordination between multidisciplinary support teams in designated cancer care hospitals and regional networks



2018-2020 MHLW HLSRG project "Research regarding the establishment of a comprehensive care provision system for cancer patients in the adolescent and young adult (AYA) generation" URL: https://ayateam.jp/

Decision-making Support

Partially revised from documents submitted to the Conference on Living Well with and Beyond Cancer (23 Dec 2021)

- Convention on the Rights of Persons with Disabilities
- Act Promoting Adult Guardianship Use
- Basic Plan for the Promotion of Adult Guardianship Use (Cabinet Decision, Mar 2017)

Guideline Guideline Guideline Guideline Guideline Hospitalization of **Decision** making **Medical care Decision** making patients without support for Guardianship with decision making support on daily family support, and provision of decision making and social lives for process in final with medical care welfare services support stages of life patients with decision making for the disabled (revised) dementia difficulties

Source: Health Labour Sciences Research Grant (MHLW Scientific Research)
Excerpts from " Research on developing simple and effective decision-making support initiative, to improve the Geriatric Cancer Care Quality" group.

Decision support guide for geriatric patient care

Partially revised from documents submitted to Conference on Living Well with and Beyond Cancer (23 Dec 2021)

- Invite patients to decide on every major issue, including dementia patients
- Garner support from comedicals when facing difficulty making decisions
- Respect individual values
- Explain in relaxed spaces, in the presence of friends and family
- Lay out options in plain language, encouraging responses
- Take cues from nods, hand gestures, and smiles
- Invite patient to explain their understanding
- Check multiple times, with ample intervals, from multiple staff

意思決定6つの基本姿勢 行う。周囲の支援者の価値観を押しつけ 意思決定できるように可能な限り本人の 能力を向上させるための支援を行う。 意思決定支援の手引き ナをもって、意思決定能力を

(https://www.ncc.go.jp/jp/epoc/division/psycho_oncology/kashiwa/research_summary/050/020/index.html)

Source: Health Labour Sciences Research Grant (Comprehensive Research Initiative for Promoting Cancer Control - MHLW Scientific Research) Research on the development of a simple and effective decision support program to improve the quality of cancer care for geriatric cancers.