HOSPITAL COMPLEX

Supportive care

IN PARIS AND SAINT-CLOUD





"Every patient must be able to benefit from supportive care."

Cancer patients cannot be cared for without support care at the Institut Curie.

Professionals don't stop at just treating the disease. Very early on in the patient's care pathway, supportive care needs are identified to provide help and support during treatment.

The Institut Curie has a DISSPO Département Interdisciplinaire en Soins de
Support Pour l'Oncologie (Interdisciplinary Department of Oncology
Support Care), which brings together these
skills and leads the entire oncology support

professionals to be there for patients and their families, throughout their care.

team.

With this booklet, DISSPO informs patients about the support care services available to them, as well as the various assessment tools and coordination procedures for patients treated at the Institut Curie.

The advice, recommendations and information provided in this booklet are intended to help you live better with and educate patients. These data are reliable, recognized by learned societies, scientifically proven and validated by expert committees

Whether these services are provided inhouse or outside the Institut Curie, the aim of these referral centers is to facilitate access to supportive care and provide help and support close to home.

From now on, this booklet will serve as a reference for patients and their families seeking information and will be a support for professionals.

Patients, families and loved ones can assess the usefulness and relevance of this long-awaited document.

Thanks to the editorial teams

Sylvie Arnaud,

Director of Care at the Institut Curie



The patient is at the heart of the Institut Curie's medical project, which has been developed and designed in collaboration with all teams with the aim of

continuously improve the quality of care. The human dimension is paramount, combined of course with the availability of ever more innovative techniques. This medical project is structured around 6 axes, one of which, "Moving from targeted to integrated care", is led by our Interdisciplinary Department of Oncology Support Care (DISSPO).

We believe that each patient has a unique history. The hospital as a whole must take care of the sick person as a whole, with the other dimensions of his or her health and personal, family, social and professional life.

Professor Pierre Fumoleau,

General Manager, Ensemble Hospitalier of the Institut Curie



We are committed to providing individualized care for each patient:

- 1 Personalize care paths to ensure patients' physical and mental well-being
- 2 Constantly monitoring support care needs
- **3** Strengthening pain management with hypnosis and cutting-edge techniques
- **4** Creating a therapeutic education platform
- **5** Developing complementary approaches integrated into a care pathway
- **6** Ensuring care tailored to the profile of each elderly patient with cancer(s)
- **7** Enabling early access to care integrated palliative care
- 8 Fighting undernutrition
- **9** Better coordination of city-hospital relations
- **10** Helping patients return to work
- 11 Promoting prevention through appropriate physical activity and healthy eating
- 12 Innovating and improving care through the creation of a human and social sciences research center

/ support care

(i) Introduction

Supportive care refers to all the care and support that can be offered to a person suffering from cancer, in association with anti-tumor treatments such as chemotherapy, radiotherapy or surgery. It concerns all cancer patients localized or metastatic, receiving curative treatment or in chronic disease

The essential aim of supportive care is to improve patients' quality of life, by responding to the needs they express, particularly in the following areas: nutrition, symptoms, etc. including pain management, stress management, social support, psychological support, promotion of physical activity and health. They aim to optimize symptom relief, psycho-social support and accompaniment, as well as promoting well-being and preventive behaviors to improve health. Supportive care also aims to encourage patients' active participation in their care project, in the medical decision-making process and in the management of day-today treatments.

Support care professionals have different specialties (dietician, physiotherapist, psychologist, social worker, palliative care doctor and nurse, etc.). They have a multidisciplinary approach: their skills

These complementary services provide a comprehensive approach to patients and their families. When necessary, support care teams hold multi-professional meetings to coordinate care, in close collaboration with the Institute's other departments, attending physicians and community caregivers.

For information on **Institut Curie's** supportive care services, visit curie.fr.

Don't forget to ask for access rights to the **myCurie** application, which can also provide you with useful information and help you with your care.



A few websites on the Internet will give you access to validated quality information on cancer and supportive care:

__ cancer-environnement.fr

Public information portal, published by the Centre Léon Bérard, on the risks of cancer associated with environmental, occupational or health-related exposures. individual behaviors. The information on this site is based on a synthesis of current scientific data.

__lecancer.fr

This site was created by the Montpellier Cancer Center. Its aim is to provide comprehensive information for cancer patients and their families. It also provides a forum for discussion, exchange and support.

__ rosemagazine.fr

Rose Magazine is the leading women's magazine for women affected by cancer. Distributed free of charge in cancer centers, it also exists in a web version. Rose Magazine features surveys and portraits,

practical guides, as well as financial, legal and psychological help. It also gives advice on how to remain a woman during this ordeal, how to apply make-up, how to dress, how to take care of yourself, how to travel, how to eat well, how to dream, how to read... Last but not least, it's a place for patients and their loved ones to share their experiences, via the forum or the "petite flamme" section.

AFSOS: Association Francophone de Soins Oncologiques de Support

www.afsos.org/les-soins-de-support/discover-all-support-care

AFOS's mission is to promote supportive care and support reflection on the organization of care and the expertise of professionals. AFSOS piloted the drafting of of over 100 reference systems, and organizes an annual conference.

With the above link you will find a lot of information and advice.

__ NACRe - National Food Cancer Research Network

www6.inra.fr/nacre/Le-reseau-NACRe/ Outils-tous-publics

This network brings together teams from

and experts working in the field of "nutrition and cancer". Its primary mission is to contribute to the development of research in the field of nutrition and cancer by promoting scientific exchanges and the setting up of multidisciplinary projects. Its second

mission is to pass on knowledge to the general public.

With the above link you will find lots of information and advice.

__LCC: Ligue contre le cancer (League against cancer) lique-cancer.net

La Ligue contre le cancer is a nongovernmental organization founded in 1918 and recognized as being in the public interest. Its mission is to prevent and promote cancer screening, support sufferers and their families, and provide financial support for public research in all areas of cancerology.

You'll find a wealth of information on cancer and supportive care, as well as contact details for the Ligue spaces active in each département.

will give you access to a range of supportive care services. You can also join the site's community of patients who wish to express their opinions, feelings and ideas.

__INCa: French National Cancer Institute e-cancer.net

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PREVENTION THROUGH A HEALTHY LIFESTYLE

A balanced diet and physical activity adapted to your medical situation are essential for your health.

Daily nutrition Adapted physical

_activity

National recommendations Partner

associations

2

INFORM, RAISE AWARENESS, EDUCATE

Throughout your healthcare journey, we'll support you in your quest for information to help you become more independent.

Welcome and information structures

In Paris: ERI, Espace Rencontre et Information

In Saint-Cloud: the Maison des Patients et des Proches (Home for Patients and Relatives)

— Patient health education

3

CARE: SUPPORT CARE UNITS

Throughout your care journey, your medical team can refer you to various supportive care professionals.

_ Dietetics and nutrition team__

Psycho-oncology team__ Functional rehabilitation team__ Social services

team

Pain team— Palliative

care team... Onco-geriatrics

team

__ Addictology consultation - Paris__

Wound and healing research unit___

Stoma therapy nursing team__ Non-

medicinal techniques

such as hypnosis or sophrology_

Socio-aesthetic treatments

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COORDINATING CARE PATHS

In certain situations, we coordinate care with out-of-hospital care providers.

Focus on a few steps in the care process:

- __ The announcement system
- __ The unscheduled reception unit__

The coordination unit__ The surveillance unit

Focus on a few steps in the care process:

__ Accueils Cancer de la Ville de

Paris_ Partner establishments_

Care networks__ Hospitalisation à

domicile (HAD)

- __ Home nursing services (SSIAD)
- Home service providers

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PROMOTING PATIENT RIGHTS

We support the promotion of patients' rights Health democracy:

Patient associations

Patient rights The

trusted support person

Advance directives

The right to deep and continuous sedation until death

__ The rights of relatives__

Places of worship

__ The Ensemble Hospitalier Ethics Commission



Prevention through a healthy lifestyle

EVERYDAY NUTRITION

It is advisable to follow the recommendations for the nutritional prevention of cancers (see table below of Santé Publique France 2019 recommendations).



Recommendations	Comments
Fruits and vegetables	At least 5 portions (80 to 100 g) of fruit and vegetables a day in any form: fresh, frozen or canned. For example, 3 portions of vegetables and 2 fruits. As far as fruit juices are concerned, only one glass a day can make up for one portion of fruit and vegetables, with freshly squeezed fruit the preferred choice.
Pulses (lentils, beans, chickpeas, etc.)	At least 2 times a week as they are naturally rich in fiber
Nuts (walnuts, hazelnuts, unsalted almonds and pistachios, etc.)	A small handful a day, as they are rich in omega-3s
Home-made	
Wholegrain or cereal bread, wholegrain pasta and rice, wholegrain semolina	At least 1 whole-grain starch a day because they are naturally rich in fiber.
Alternate consumption of fatty and lean fish	2 times a week, including 1 oily fish (sardines, mackerel, herring, salmon)

	Rapeseed, walnut and olive oil	Added fats (oil, margarine) can be consumed every da in small quantities. Choose rapeseed or walnut oil. and olive oil.
2	Sufficient but limited consumption of dairy products	2 dairy products (butter, milk, yoghurt, cheese, cottage cheese, petits suisses) a day. 1 portion = 150 ml milk or 125 g yoghurt or 30 g cheese.
GO TO	Seasonal and locally produced foods Organic food	Favoring the use of raw products rather than processed ones, seasonal foods, short supply chains, and variety by diversifying the places and methods of supply.
	Alcohol	Maximum 2 glasses a day, not every day. One glass = 10 cl of wine or 25 ml of beer or 3 cl of whisky, i.e. 10 g of alcohol.
	The products and sweetened beverages	We recommend limiting sugary drinks and fatty, sugary, salty and ultra-processed foods.
REDUCE	Salt and salty products	It's advisable to reduce your salt intake: avoid eating salty foods and table salt all daylong.
œ	Cold meats	Limit deli meats to a maximum of 150g per week.
	Meat (pork, beef, veal, mutton, lamb, offal, horse, game)	Favour poultry and limit other meats to aim for around 500 g a week.

Among the risky behaviours, we obviously find smoking, alcohol consumption, exposure to ultraviolet light, unbalanced diet and sedentary lifestyle.

A few tips to follow:

_Avoid excessive portions and consumption, snacking, regular consumption of grilled or heavily browned products, restrictive diets (ketogenic, slimming, therapeutic fasting, acid-base fasting, etc.).

Source

invs.santepubliquefrance.fr/Publications-et-outils/Rapports-et-syntheses/Maladies-chroniques-et-traumatismes /2019/Recommendations-relating-to-food-physicalactivity-and-sedentariness-for-adults)

__The consumption of food supplements in excess of the recommended dietary allowance is not recommended on the basis of currently available scientific data.

Finally, take enough time to eat and enjoy your meals.

Restrictive diets and fasting

Therapeutic fasting and restrictive diets (ketogenic, low-carb):

No beneficial effect has been demonstrated, either on the disease or on the effects of treatment. Some studies have even

reported deleterious effects of these diets, such as reduced efficacy of anti-cancer treatments, and a risk of worsening undernutrition. They are therefore not currently recommended. However, if you still wish to fast or follow a restrictive diet, it is important to inform your GP and referring oncologist.

Food and drug interactions

Grapefruit juice: avoid as it contains substances that inhibit cytochrome P3A4 (CYP3A4). This increases the toxicity of certain chemotherapies (e.g. Taxol®, Taxotère®, Holoxan®, Navelbine®, Tarceva®, Iressa®...), leading to the risk of overdosing.

St. John's wort: on the other hand, is a CYP3A4 inducer and reduces treatment efficacy.

Green tea: there is no known benefit associated with green tea consumption during cancer treatment. On the contrary, green tea is known to increase chemotherapy toxicity and reduce the effectiveness of chemotherapy or radiotherapy. It is therefore prudent to avoid drinking green tea on the day of treatment, as well as the two days before and after.

Food supplements and foods "anti-cancer": consumption of The use of dietary supplements or "miracle" foods (turmeric, spirulina, etc.) is not recommended. No beneficial effect has been demonstrated during the course of the disease, and some supplements may reduce the efficacy of anti-cancer treatments. Anti-cancer claims for certain food supplements are based on studies carried out only on cells and animals, and have never confirmed their anti-cancer benefits in humans

Soy and phytoestrogens:

A high intake of phytoestrogens (over 1 mg/kg/d) from soyfoods or dietary supplements is not recommended. For people who are used to consuming them, or who wish to do so, a moderate amount corresponds to 1 to 2 servings a day of soybased foods, such as tofu, soy milk, edamame beans and soybeans.

(one portion provides around 7 g of protein and 25 mg of phytoestrogens). Phytoestrogens are contained in a protein part of soy. Soy lecithin, soybean oil and soy sauce can therefore be consumed freely. In addition

mung beans do not contain phytoestrogens.

If your chemotherapy contains oxaliplatin: cold increases tingling sensations in the hands or feet, so avoid eating foods that are too cold or icy.

Find out more

The Institut Curie offers Nutrition-Cancer conferences to keep you informed during and after your treatment. Dates are available on curie fr

To register or for more information:

infosnut@curie.fr or 01 56 24 58 97

__ NACRe - Réseau National Alimentation Cancer Recherche www6.inra.fr/nacre

__ National Cancer Institute www.e-cancer.fr/Comprendre-prevenir-depister/ Reduce-cancer-risks

__ Cancer Environment | Official Cancer Risk Portal www.cancer-environnement.fr/

__ SNFCM news www.sfncm.org/

__ Eat Move: www.mangerbouger.fr

__Food and cancer - Ligue contre le cancer www.liguecancer.net/shared/brochures/alimentation-cancer.pdf

__ La Salle Beauvais cooking workshops vite-fait-bienfaits.fr/s/les-ateliers-1.php







PHYSICAL AND/OR SPORTING ACTIVITY DURING AND AFTER TREATMENT

The Institut Curie is mobilized and committed to promoting physical activity and/or sports as a non-therapeutic means of treatment.

by setting up a coordination system for drugrelated services

made available to you. The missions of this coordination are to enable you :

- access to knowledge and recommendations.
- benefit from tailored advice to your physical condition,
- access to programs tailored to your needs throughout your healthcare journey.
- __ to be directed near you to adopt an active lifestyle.

Throughout your treatment and after your illness, it's essential to maintain an active lifestyle, based on guidelines formulated by leading national and international scientific societies (Institut National du Cancer, National Comprehensive Cancer Network, American Cancer Society, American College of Sports Medicine) that are compatible with your physical condition.

We are at your disposal to help you in your approach, to advise you or guide you, in order to

to guarantee safe practice with

pleasure, in support of the partners who work at the Institut Curie and who are active in the field of sport and health near you.

In this booklet, we'd like to give you an insight into what we believe to be the essential role of physical activity and sport in the context of cancer, and hope that we can offer you the chance to try out and integrate a positive attitude to daily exercise into your daily life, for the sake of your overall quality of life and health.

What is physical activity?

Physical activity corresponds to "any bodily movement produced by skeletal muscle contraction resulting in an increase in energy expenditure relative to resting energy expenditure" (Caspersen 1985).

Physical activity is not limited to sports. Physical activity involves all the movements of everyday life and work, such as walking, gardening, housework, shopping, climbing stairs...

Recommendations concerning physical activity and sedentary lifestyles aim to encourage people to increase their physical activity and reduce their physical inactivity.

time spent sitting during the day. In fact, an individual can be both active, i.e. take part in sport or physical activity as recommended, and very sedentary, i.e. spend a lot of time sitting down, often for long periods of time.

Physical activity, adapted if necessary, or sport: many benefits

From the outset and during treatment, it is advisable to start or continue regular, appropriate physical activity on a daily basis.

The idea is to lead as active a life as possible, pursuing what you love to do.

This regular physical activity will contribute to a better overall quality of life during and after treatment, by relieving many symptoms such as fatigue, improving sleep, having a more positive outlook and fewer side effects. Physical and sporting activity also promotes better nutritional status and contributes to a better self-image.

It has been shown that sufficient, regular and prolonged physical activity (according to the criteria of intensity, duration and

frequency) can reduce the risk of recurrence and improve quality of life and life expectancy. This is known as "non-drug therapy" and can be prescribed by your doctor (oncologist or general practitioner); a certificate of non-indication to the practice, which may be accompanied by a prescription⁽¹⁾, is required to get started. A model

including the certificate of non indication is at your disposal.



Recommendations for physical activity during treatment

Doctors recommend regular physical activity, adapted to your state of health. While physical activity is essential, the conditions for practicing it vary according to your state of health, your treatments, and your individual wishes and possibilities. Precise guidelines for physical activity (duration - intensity - frequency) during treatment are determined by your individual state of health.

clinical condition and the possible occurrence of effects treatment.

The priority during treatment will be to prevent the onset of a sedentary lifestyle and reduced levels of physical activity from the outset of medical treatment.

To achieve this, we recommend:

- limit and break up (every 2 hours) sedentary periods (prolonged periods spent lying or sitting down, travelling in the car as a passenger, reading or writing while sitting down, sitting while looking at the TV, etc.). television, office work on the computer, etc.).
- interspersed with short phases of activity lasting a few minutes: getting up, moving around, etc.
- _ resume active behavior as soon as possible after surgery (unless medically contraindicated)
- __ start or maintain an active lifestyle during radiotherapy and medical treatment.

After a phase of immobilization, reconditioning or exercise training may be indicated, with a specialized functional re-education care (see Functional re-education unit).



A prescription⁽¹⁾ for adapted physical activity can be made by your oncologist in order to benefit from adapted physical activity classes given by professionals. and physical activity associations Institut Curie's sporting partners.

Find out more!

Practice recommendations physical activity after treatment

Recommendations for physical activity in the aftermath of treatment are in line with those for the general population. The aim is to adopt an active lifestyle incorporating the principles defined as optimal for the general population (ANSES, 2016), namely:

- _ reduce daily sedentary time spent sitting or lying down and break up prolonged sedentary periods
- _ at least 30 minutes* of cardiorespiratory exercise per day, at least 5 days a week, avoiding more than 2 consecutive days without exercise, of moderate to high intensity, with short periods of high intensity aerobics (see table)
- at least 2 sessions per week of moderate muscle strengthening of the lower and upper limbs and trunk, with 1 to 2 days of recovery time between two sessions: this corresponds, for example, to carrying groceries or going up and down stairs
- __ stretching and joint mobility practices 2 or 3 times a week: stretches held for 10 to 30 seconds and repeated 2 or 3 times (without discomfort or stiffness)
- Balance exercises at least 2 times a week can be incorporated into the daily or leisure activities of patients aged 65 and over.

Examples of physical activities requiring cardiorespiratory fitness, according to context and intensity

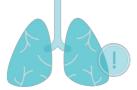
INTENSITY	Intensity markers	Activities of daily life	Recreational physical activity
MODERAT	Moderate shortness of breath Conversation possible Moderate sweating WHO severity scale: 5 to 6 out of 10 55% to 70% of FCmax	Walking at 5 - 6.5 km/hour Climbing stairs at slow speed	Swimming Bicycle at 15 km/hour
Þ	Marked shortness of breath Difficult conversation Profuse	Fast walking over 6.5 km/hour	Running 8 - 9 km/hour
ELEVA	sweating WHO distress scale: 7 to 8 out of 10 70% to 90% of FCmax	Climbing stairs at high speed	Cycling at 20 km/hour

Source Anses 2016

These benchmarks are medium- to longterm objectives. The notions of individualization and progressiveness are fundamental. It is recommended **to practice progressively**, both during a session and when resuming activity.

Warning: the appearance of signs such as persistent muscular pain, significant and/or unusual fatigue, reduced alertness, are warning signs of poor tolerance. physical activity. They require a temporary reduction in the program or spontaneous activities.

* or: 150 minutes of moderate-intensity endurance activity or at least 75 minutes of sustained-intensity endurance activity, or an equivalent combination of moderate- and sustained-intensity activity.



½ day of information and awarenessraising (1h30) from the Institut Curie on the benefits of physical activity

The Institut Curie puts at your disposal a ½ monthly awareness and orientation day to provide you with the information you need about physical activity at the start and throughout your journey, so that you can initiate or continue a safe practice and learn about the beneficial effects of this non-drug therapy.

The aim is to give you a better understanding of the importance of physical activity and sport in the management of your disease, and to encourage you to maintain or introduce it, by offering you appropriate advice and guidance.

Posters and flyers are available at the ERI, at the Maison des patients et des proches and in the waiting room. The annual ½-day program

The "My physical activity during and after my treatments: guidelines for my daily life" awareness campaign can be consulted at www.curie.fr

Register now for a date that suits you!

Institut Curie group physical activity and sports classes

Group classes are available for patients undergoing treatment, in partnership with the associations present at the Institut Curie. A number of slots are available, and adapted programs supervised by trained professionals are designed for you.

Your doctor (oncologist or general practitioner) may prescribe physical activity for you, depending on your functional limitations. If you wish to take part, you can do so on your own by contacting the contact below. A certificate of no contraindication to physical activity will be required prior to the start of classes.

Don't forget, the benefits are even greater when physical activity is started early.

Assessment with fitness tests

An assessment with fitness tests (muscular strength - flexibility - etc.) is available by appointment. This enables us to take stock of your physical condition. You will be given individual instructions on how to implement a physical activity adapted to your needs, as close as possible to the recommendations.

All group classes at the Institut Curie take your abilities into account and include exercises designed to help you initiate or maintain your fitness.

a sufficient level of autonomy and physical activity to reach benchmarks during and after treatment.

Our physical activity and sports partners may ask for a financial contribution. This should not be an obstacle to the implementation of this non-medicinal treatment.



Test your level of physical activity (self-assessment)

To find out more about your level of daily physical activity at the start of your treatment or during the course of your treatment, we suggest you fill in the selfquestionnaire provided in the appendix: this Ricci et Gagnon test can be taken on your own. It only takes a few minutes to complete. After completing Fill in the questionnaire, add up your points and discover your profile: are you active, inactive or very active? You can - if you wish - leave your questionnaire anonymously or complete it with your contact details (Institut Curie PIN) in the "Activité Physique" mailbox located at 25. rue d'Ulm 75005 Paris (opposite the elevator). If you wish to be contacted to initiate or maintain a physical activity program, please leave your contact details on the questionnaire, or let us know and we'll get in touch with you. Know that it's never too late to start and maintain a positive approach to your health!

Connected physical activity

In the near future, we hope to be able to bring you the latest technological advances in connected tools for the remote physical activity. For some of you, these technologies are applications that enable you to start, maintain or continue your daily activity(ies). These applications can offer different ways of putting this into practice in the form of group activities or

offer different ways of putting this into practice, in the form of group activities or individual classes following an assessment and physical tests, which can also be carried out with the support of certified connected applications. Patients, oncologists and physical activity professionals can thus better monitor their patients and their physical activity.

practical with personalized, accessible programs. These connected applications must be easy to use and reliable to guarantee the security of the programs and the data collected. **Stay tuned!**

Remember to create your DMP (Dossier Médical Partagé or health record) and to declare on www.dmp.fr that you are taking part in physical activity in line with health recommendations.

_ Contact us in Paris and Saint-Cloud :

activitesphysiques@curie.fr Tel: 01 44 32 40 98 www.curie.fr

Find out more

__ www.mangerbouger.fr/activite-physique

__ www.retouradomicile.fr/soins-de-support/ physical-activity-adapted/why-practice/

__www.e-cancer.fr/Professionnels-de-sante/ Risk-and-protection-factors/Physicalactivity/Physical-activity-and-cancertreatment

- __ www.sportetcancer.co
- __ m www.sielbleu.org
- __ www.sport-sante.fr



Inform, ? raise awareness,

RECEPTION AND INFORMATION AREAS FOR PATIENTS AND THEIR FAMILIES

Two resource centers are available to you during and after treatment: the Espace de Rencontres et d'Information (ERI) in Paris and the Maison des Patients et des Proches in Saint-Cloud

At each site, a health coach and volunteers form a team ready to listen to your needs for information, guidance and discussion.

Their missions are as follows:

- Listening to your questions.
- Provide validated brochures on cancer and its treatment.
- _ Helping you to take charge of your care.
- __ Inform you and refer you to support care professionals or the patient health education unit (see specific paragraph below).
- Direct you to resources close to home.

We organize themed conferences on the most important topics of concern, such as managing the side-effects of hormone therapy, nutrition, adapted physical activity and so on.

Information on the organization of these conferences are available:

- _ On the Institut Curie website or the mycurie.fr application
- _ On flyers available at the hospital day chemotherapy sessions and by posters in the hospital (entrance hall or waiting room)

We offer you a path to well-being by taking part in group workshops art therapy, yoga, qi gong, sophrology, meditation, Nordic walking and more.

To meet us or contact us in Paris:

Meeting and Information Area (ERI) 25 rue d'Ulm. Paris 01 44 32 40 81 messagerie.eri@curie.fr

To meet us or contact us in Saint-Cloud

Maison des Patients et des Proches 20 rue de la Libération, Saint-Cloud 01 47 11 23 40 sc.maison-des-patients@curie.fr



PATIENT EDUCATION

Therapeutic patient education (TPE) is a set of practices that consists of including pedagogy in care, with the aim of enabling sick people to develop, deploy and acquire skills that will enable them to improve their state of health.

The objectives are to develop medical knowledge and skills, and to adopt behaviors that help improve their health and quality of life.

It is offered at the hospital in the form of individual sessions, group workshops and conferences for patients and their caregivers. Sessions and workshops are led by Institut caregivers and patient partners.

Topics include the port-a-cath (implantable chamber), treatment side effects. interpretation of blood tests, dietetics, understanding the physiology of the disease and treatments, the benefits of physical activity, and how to keep fit. resuming work, pain, adapting to change, communicating with family and friends, preparing for medical/paramedical consultations, hormone therapy, sexuality, etc.



Who refers you to us?

You can register by phone, e-mail or at the Paris site reception desk at the top of the bridge.

The doctors, surgeons and caregivers you have met may suggest that you take part in an education program. You'll need to sign up directly, as this will ensure your personal motivation, which is a prerequisite for the success of the program.

To meet us and contact us. for all site patients Paris or Saint Cloud:

Reception desk - hall 26 rue d'Ulm 01 56 24 58 97 utep@curie.fr





Care: support care units

THE DIETETICS-NUTRITION TEAM

At the Institut Curie, nutrition is seen as an integral part of patient care.

Our dieticians are responsible for ensuring that patients are in good nutritional condition. Our priority is to prevent and combat any problems of undernutrition linked to treatment or the disease, and to adapt diet to the side effects of treatment, thereby contributing to your well-being and quality of life.

Our missions

- Information through nutritional awareness conferences and therapeutic education workshops.
- Prevention and management of undernutrition.
- _ Dietary advice and prescriptions: treatment side effects, loss of appetite and weight loss, swallowing difficulties, transit disorders.
- Prescriptions for oral nutritional supplements.
- Artificial nutrition (gastric tube or intravenous) on prescription from the medical team.

— Systematic follow-up from the start of treatment in some situations (patients undergoing treatment for ENT or digestive tumors, patients in sheltered accommodation, teenagers/young adults).

For patients who so wish, dietetic care can be organized in town, at a preferential rate, by the dieticians of the Oncodiet network (consultations by specialized liberal dieticians) upon presentation of the flyer validated by an Institut Curie doctor

Who refers you to us?

Doctors, surgeons, caregivers you've met.

Where can you meet our team?

In consultation, day hospitalization or conventional hospitalization.

_To contact us in Paris :

01 44 32 44 97

To contact us in Saint-Cloud :

01 47 11 15 24

PSYCHO-ONCOLOGY TEAM (UPO)

The Adult Psycho-Oncology Unit brings together psychologists and psychiatrists who work with cancer patients undergoing treatment at the Institut Curie, whether they are

during treatment, upstream for people at genetic risk, or downstream during the first few months following the end of specific cancer treatments.

Our missions:

Our role is to evaluate.

support and manage psychological reactions or psychological or psychiatric disorders that may arise in the context of cancer diagnosis and treatment, and generate psychological distress.

We offer:

_ interviews with patients, which can take place individually, as a couple, or sometimes as a family, and last an average of 45 minutes.

They take place in the consultation room for outpatients, or at the patient's bedside in conventional or day hospitalization.

A summary report is included in your medical file to ensure better coordination with other Institut Curie professionals involved in your care.

The length of the follow-up varies greatly, from a single meeting to several months or years, depending on your needs.

- _ interviews for patients' loved ones (spouse, child, parent, other relative), at any point in the care process.
- _ relaxation groups are offered during and after the treatment period (up to 2 years after treatment).

the end of the final radiotherapy treatment) for patients who wish to

learn to better control their emotions or certain symptoms that are bothering them.

These groups are closed and operate on the basis of 6 consecutive 1.5-hour sessions held in the late morning on Tuesdays or Thursdays. They are always preceded by a meeting with the psychologist in charge of the group.



Who refers you to us?

Any patient can ask to meet a member of the Unit at any point in their care, if they are feeling distressed or simply need to talk about their experience of illness and treatment.

The caregivers you meet during your treatment will systematically suggest that you be treated by a psycho-oncologist:

- if you have a psychological disorder prior to the onset of cancer (e.g. anxiety or depressive disorder, psychotic disorder, addictive behavior);
- _ if you have a depressive state with dark thoughts or a behavioural disorder;
- _ if you find it difficult to follow the recommended treatment.

— and in a few other special situations requiring a psycho-oncological assessment, at least on an ad hoc basis (if you are an adolescent or young adult, undergoing oncogenetic treatment or being treated for chronic pain, etc.).

Where can you meet our team?
In-patient or out-patient
day or conventional

To contact us in Paris : 01 44 32 40 33

_ To contact us in Saint-Cloud : 01 47 11 23 80

How long is the follow-up period?

In the event of persistent difficulties over time, or when the problems identified are not directly related to to the illness situation, the psycho-oncology team will discuss with you the possibility of referring you to another mental health professional. Our role is to help you find a relay or another place for psychological care outside the hospital.

Institut Curie, such as:

the team at your local medicalpsychological center;

_a psychologist from the Accueils Cancer de la Ville de Paris, or from the Ligue contre le Cancer committee in your département, or from a cancer network;

a city psychologist, psychiatrist or psychotherapist.



FUNCTIONAL REHABILITATION UNIT

The Functional Re-education Unit is staffed by a team of masseur-physiotherapists empowered to support you throughout your treatment, using manual or instrumental techniques to strengthen, restore or compensate for impaired function.

Their expertise and the variety of tools at their disposal enable them to intervene in preventive and rehabilitative actions adapted to the diversity of our customers' needs.

pathologies and care. Rehabilitation aims to improve your quality of life and independence by helping you to regain ease of movement in everyday life, and to become more aware of your body and breathing.

In this context, learning mind-body techniques such as relaxation or hypnoanalgesia can help you to

to help you manage your symptoms and improve your well-being.

During your follow-up, exercises will be suggested and explained to you so that you can actively and independently pursue your rehabilitation.

The masseur-physiotherapist can advise you on the choice oftechnical aids or devices likely to contribute to your well-being and independence on a daily basis.

Fatigue is a frequent symptom during treatment. Fatigue is multifactorial and can be managed by a multidisciplinary team, including physiotherapists.

Who refers you to us?

The rehabilitation team works on doctor's orders throughout your treatment, mainly on an inpatient basis. At the end of your hospital stay, a link with the professionals is ensured in order to to ensure the continuity of your care.

To contact us in Paris : 01 44 32 42 22

To contact us in Saint-Cloud :

Find out more

__ List of physiotherapists for manual lymphatic drainage: www.aktl.org

Association vivre mieux lymphedema (avml): www.avml.fr

SOCIAL SERVICES

When illness strikes, it can disrupt or weaken a person's life, family organization and professional situation. Anticipating potential difficulties as early as possible facilitates support in the care process.

The hospital social service intervenes in a number of areas, from the moment illness accentuates or creates difficulties.

The social worker establishes a relationship of trust with people, based on welcoming them and listening to their needs. They help to improve living conditions in the social, health, family, economic and social fields. professional.

The hospital social services department works at They work as part of a multi-disciplinary team in the interests of the individual, and share certain information required for overall care. The social worker is nevertheless bound by professional secrecy.

The social service provides individualized support and group workshops. These two complementary modes of intervention provide insight and support for patients. It is also a free space for social and non-medical exchange.

Each situation will be the subject of an overall social assessment to best meet individual needs and propose an appropriate assistance plan, taking into account your resources. environment. It is essential for this support to be put in place, that the person is mobilized and involved in his or her project, whatever it may be.

The department's main missions are to:

- __ Advising, guiding and supporting patients and their families
- Ensuring access to patients' rights
- __ Supporting and accompanying people through administrative procedures
- Help organize discharge from hospital (possibly set up home help and coordinate with various partners)
- Providing information on issues related to maintaining and/or returning to employment

Who can contact the social services department?

Patients, their families and healthcare professionals.

Where can you meet our team?

For the first meeting, a social worker is on hand every day to make an initial assessment of your situation, and to guide you according to your needs, by telephone or during an interview.

The social workers then intervene in consultation, day hospitalization or conventional hospitalization.

_ To contact us in Paris :

Telephone answering service, daily from 9 a.m. to 5 p.m.

01 56 24 68 77

To contact us in Saint-Cloud:

Telephone answering service, Monday, Wednesday and Friday, 9 a.m. to 12.30 p.m.

01 47 11 15 17

THE PAIN TEAM

Pain is a frequent symptom in the cancer patient's journey, with many different origins: the tumour

The pain may be caused by the disease itself, by certain examinations such as punctures or biopsies, or by certain treatments (surgery, chemotherapy or radiotherapy). Pain can occur at any time during the course of the disease. disease, even in periods of remission.

It's important not to be left with pain you can't control. It can have repercussions on your personal, family, professional and social life. Don't hesitate to talk to your doctor or nursing staff about your pain.

Most types of pain can be treated by your general practitioner or a specialist. oncologist. But sometimes pain persists despite first-line treatment. In such cases, your oncologist may refer you for a consultation with

a pain specialist. His or her role will be to assess the pain syndrome, identify its causes and determine the most effective means of relieving it.

Our missions:

- _ Contribute our expertise in pain assessment and management.
- _ Assess, prevent and treat pain, in collaboration with inpatient and outpatient care teams.
- Assisting in the implementation of medicinal and non-medicinal means for the management of care-induced pain.
- _ Help manage patients with intrathecal analgesia.

Who refers you to us?

The doctors, surgeons and carers you have met.

You can also make a request directly or to your healthcare team.

Where can you meet our team?

In consultation, day hospitalization or conventional.

To contact us in Paris:

01 44 32 46 44

_To contact us in Saint-Cloud :

01 47 71 91 12

PALLIATIVE CARE TEAM

Palliative care is an integral part of oncology care, whenever justified by the complexity of the situation. Contrary to popular belief, palliative care is not reserved exclusively for patients at the end of life.

Palliative care is personalized, active care delivered as part of a holistic approach to people with advanced cancer. The aim is to promote quality of life on a daily basis by alleviating symptoms, in particular pain, psychological suffering, anxiety and depression.

family and social difficulties, or existential and spiritual distress. We also offer support for loved ones.

The palliative care team is made up of doctors, nurses and medical assistants.

Our missions:

_ Relieve symptoms_

Promote autonomy,__

Support loved ones,__

Preserve quality of life,

- Define personalized care plans in consultation with the various healthcare professionals,
- _ Coordinate continuity of care with community caregivers, attending physicians, palliative care networks, HAD (hospitalization at home), private nurses and service providers.
- ** End-of-life: The palliative care team supports patients and their families at the end of life. They visit the various hospitalization units, including

are LISP (lits identifiés de soins palliatifs). As there is no palliative care unit at the Institut Curie, we work in partnership with palliative care units (USP) close to patients' homes. For patients in We work with homecare networks.

Who refers you to us?

We usually intervene

at the request of oncology teams.

You can also make a request directly, or to the health-care team in charge of your care. The 1999 law gives patients the right of access to palliative care teams.

Where to meet our team:

In a consultation or day-care hospital support/palliative care.

The day hospital provides a half-day opportunity for joint, concerted assessment by a number of players: oncologist, psychologist or psychiatrist, dietician, social workers, etc.

Conventional hospitalization in oncology or surgery.

Volunteers from the founding ASP: Association pour l'accompagnement et le développement des soins palliatifs (Association for the support and development of palliative care)

At the Paris site, a team of volunteers from the founding ASP are trained in listening and support. and their families is attached to the palliative care unit.

_ To contact us in Paris :

01 44 32 46 40 or 01 44 32 41 38

Find out more

- __ ASP founder www.aspfondatrice.org
- __ Société Française d'accompagnement et de soins palliatifs: www.sfap.org
- __ Listening and support service www.sosfindevie.org
- __ National Center for Palliative Care and the end of life: www.spfv.fr





ADDICTOLOGY CONSULTATION

Why addictology?

Tobacco

"I smoke and I can't stop."
For more effective care (improved healing, more effective treatment, reduced per- and post-operative risks), we offer professional help with weaning.

Alcohol

"I regularly drink 2 or more glasses of alcoholic beverage (wine, beer, hard liquor) per day." It's important to avoid alcoholic beverages during treatment, which can be difficult to do alone. A consultation with a professional can help you take stock of your consumption and be supported in stopping.

Cannabis

"I use cannabis regularly. For improved care (healing, treatment efficacy), cessation is strongly advised but can be difficult to achieve alone. A consultation with a professional is suggested.

Our missions:

When faced with a cancer diagnosis and treatments that may have side effects, you may wonder how to stop smoking, or how to reduce or stop the consumption of toxic products such as alcohol or cannabis. The Institut Curie offers an addictology consultation service to help you:

- _ Evaluate with an addictologist: your level of consumption, your previous eensumption history (attempts at withdrawal or reduction), your motivation and your personal resources.
- _ To help you to implement the means useful to better control this problem; medical consultations or hypnosis; prescription of substitutes; possible referral to a local addictologist for regular follow-up.

Who refers you to us?

The doctors, surgeons and caregivers you have met. You can also make a direct request.

Where can you meet our team?

Consultation only in Paris, but open to all patients

To contact us, for all patients at the Paris and Saint Cloud sites:

Secretariat: 01 44 32 40 33

Find out more

__ www.drogues-info-

__ service.fr

__ www.sfalcoologie.asso.fr

THE ONCOGERIATRICS TEAM

After the age of 75, cancer is often accompanied by other illnesses or disabilities. To decide on treatment In order to provide the most appropriate specific treatment and follow-up, it is essential to take into account all the medical, psychological and social difficulties and their repercussions on daily life. Aging and health status can have an impact on the tolerance of antitumor treatments, favoring toxicities and complications, and the decompensation of chronic pathologies. Skills oncology and geriatrics come together to care for vulnerable and frail elderly cancer patients.

Our team is made up of doctors (specializing in the elderly and with knowledge of cancerology), nurses and medical assistants.

Every day, we interact with doctors, nurses and paramedics at the Institut Curie.

Our missions:

- _ Take stock of your health problems and disabilities, your skills and resources.
- Inform the medical oncologist, surgeon or radiotherapist who has seen you about the possibilities of the treatment you are considering.
- Participate in initiating treatment and ensuring that it runs smoothly.
- Trigger interventions if necessary, e.g. nutrition, physiotherapy, support psychology, social work, speech therapy, etc.
- Adapt your medication prescription to suit the treatment of cancer and other pathologies.

- Prevent undesirable effects of treatment.

 Adjust care in the event of undesirable effects.
- __ Direct you to the care professionals best suited to your needs.
- _ Liaise and work with the various parties involved, both at the Institut Curie and in the community: private practitioners, care networks, GPs and specialists, outpatient facilities, etc.

Who refers you to us?

The doctors, surgeons, nurses and paramedics you have met at the Institut Curie. They spotted the the need for a precise assessment of your state of health in order to best adapt future treatment and care.

The G8 questionnaire

(validated by the Oncodage study)

This is a screening tool for geriatric frailties, recommended by INCa, to help care teams refer you to our team (see appendix).

Where can you meet our team?

In consultation or in day or full hospitalization.

__To contact us in Paris : Secretariat: 01 44 32 41 58

To contact us at Saint-Cloud: Secretariat: 01 47 11 23 80

WOUND AND HEALING UNIT

Cancer and its treatment can cause a variety of skin lesions and/or make it more difficult to treat existing wounds (pressure sores, ulcers, etc.).

Our missions:

- _ An assessment of the wound and factors contributing to delayed healing.
- __ Drawing up a care protocol.
- Advice and recommendations to promote healing and improve patients' quality of life.

All these tasks are carried out in collaboration with the medical and/or surgical teams, with advice given on how to apply dressings at home.

Who refers you to us?

Institut Curie doctors, surgeons, nurses or paramedical staff who have met you, as well as private nurses or doctors who are encountering difficulties in managing complex wounds, so that together we can decide how to proceed.

Where can you meet our team?

Consultation, hospitalization day or conventional. To contact

_us in Paris: 01 56 24 59 14

To contact us in Saint-Cloud:

Appointments office: 01 47 11 91 12

STOMA THERAPY NURSING CONSULTATION

Nurse stomatherapists hold a clinical certificate in stoma therapy and have acquired specific nursing skills for patients with digestive and/or urinary diversions, from

chronic carcinological wounds, pressure sores, fistulas, urinary or fecal continence disorders or sexual problems.

Our missions:

The stoma therapist's role is both technical, by assessing stoma care, and educational, with a view to fostering the ostomate patient's autonomy.

Education and the choice of the most appropriate appliance (watertight, comfortable, discreet, easy to use), taking into account lifestyle habits, will help the ostomate patient to come to terms more easily with this loss of control over bowel movements and the changes to his or her body image.

Who refers you to us?

The doctors, surgeons and caregivers you have met. You can also request them directly or from your healthcare team.

Where can you meet our team?

Consultation, hospitalization daytime or conventional.

To contact us in Paris:

BRV: 01 56 24 59 14

To contact us in Saint-Cloud:

BRV : 01 47 11 91 12

COMPLEMENTARY CARE

Body-mediated approaches at the Institut Curie

There are many different approaches involving the body, such as relaxation, sophrology, medical hypnosis, mindfulness meditation...

Sessions are run by trained professionals (doctor, psychologist, nurse). They are aimed at patients who suffer from chronic symptoms that impair their quality of life on a daily basis. These may include fatigue, nausea, hot flushes, chronic pain, anxiety and stress.

These procedures are not reimbursed by social security. That's why resources are limited. At the Institut Curie, you may be able to benefit from one of these approaches, but only for one or a few sessions.

We can help you find a relay with an outside association.

Talk to your doctor or a nurse on your care pathway, who will be able to guide you or contact the professionals concerned.

__ Relaxation Group

Indication: emotion management.

Format: 6 consecutive weekly sessions, either on Tuesdays or Thursdays in the late morning, in a group, led by a psychologist,

Contact the psycho-oncology unit **01 44 32 40 33**.

Sophrology sessions

Indication: management of chemotherapy symptoms: fatigue, stress, pain or chronic disabling symptoms.

Format: a series of 6 individual sessions in the chemotherapy day hospital on Monday afternoons.

Register with the hospital secretariat day chemotherapy.



Complementary mind-body care at both sites:

__ Medical hypnosis consultation:

Indication: fatigue, nausea, hot flushes, stress, pain or chronic disabling symptoms.

Format: a few sessions in a consultation, carried out by a doctor or nurse trained in hypnoanalgesia.

__ To contact us in Paris :

BRV: 01 56 24 59 14

To contact us in Saint-Cloud:

BRV: 01 47 11 91 12

Other practices at ERI (Paris site) or Maison des Patients et des Proches (Saint-Cloud site):

_ These practices are diverse in nature, and include Qi gong, yoga and mindfulness meditation. They are carried out by city professionals under contract, on a time-limited basis.

In Paris, the ERI:

01 44 32 40 81 or messagerie.eri@curie.fr

In Saint-Cloud, the Maison des patients and loved ones :

01 47 11 23 40

or sc.maison-des-patients@curie.fr

Acupuncture or auriculotherapy

Acupuncture, one of the branches of traditional Chinese medicine, is based on reestablishing the harmonious circulation of energy (Qi) in the body.

body. The acupuncturist uses needles on the meridians to influence yin and yang, which symbolize the two opposing parts of the same phenomenon, using the meridians that trace the circulation of vital energy.

Some acupuncture points are located on nerve pathways, others on blood or lymphatic pathways, and still others on specific dermal or bone pathways.

Most acupuncture needles are made of stainless steel. There is no risk of contamination, as acupuncturists use single-use needles for each patient. Needle insertion is well tolerated and usually painless.

Auriculotherapy is a very similar technique, with puncture points located in the ear. The acupuncturist, like the auriculotherapist, is a physician who has

followed a specific 2-year training course.

Some medical studies have shown positive results, particularly for nausea, hot flushes, asthenia and chronic pain.

These techniques are not currently used at the Institut Curie, but we are currently looking into the matter.

Homeopathy

To date, the efficacy of homeopathy, beyond the placebo effect, has never been scientifically proven. (Meta Analysis Lancet 2005, NHMRC Report 2015, Systematic Review Mathie et al 2017).

But "at worst", limiting the effectiveness of homeopathy to that of the placebo effect does not mean reducing it to an ineffective method. The placebo effect should no longer be associated with a negative connotation. The placebo effect is inherent in all medical practice, and used more or less consciously by conventional medicine. In "placebo effect", the word effect means the recognition of an efficacy; placebo simply means that this efficacy is not linked to a molecular medicinal principle. The placebo effect can be induced by a "good" health-care relationship, and works above all on socalled subjective symptoms (the only possible assessment is the patient's own feelings). Most patients can respond to the placebo effect, only the circumstances and amplitude of the response vary.



Herbal medicine

For the World Health Organization (WHO), herbal medicines include "plants, herbal materials, herbal preparations and finished products that contain as active ingredients plant parts, other herbal materials or combinations of plants."

We would advise you to exercise extreme caution before using this type of product, which is not only not scientifically validated but may also be responsible for undesirable side effects.

Talk to your doctor before use.

An application and a website can provide you with useful information:

www.mskcc.org/cancer-care/diagnosistreatment/symptom-management/ integrative-medicine/herbs

*** Some ill-intentioned people can take advantage of a sick person's weakness to manipulate them. Here are a few tips to help you identify them before speaking out the care team:

_ If they denigrate anti-tumor treatments or advise stopping them.

_ If they promise benefits superior to the results of the treatments proposed by the medical team.

If they offer free sessions to try out a method, or ask you to pay for sessions in advance.

If they use pseudo-scientific language or claim to have discovered a very simple principle.

Recharge your batteries: resources near you

benefit from complementary care such as psychocor- poreal approaches close to home:

Free of charge:

The Departmental Committees (CD) of the League against Cancer and the Espaces Patients: www.ligue-cancer.net/article/27777_espace-ligue

CD75 - Paris : PARIS

01 45 00 00 17

cd75@ligue-cancer.net

CD77 - Seine-et-Marne : MELUN

01 64 37 28 13 cd77@ligue-cancer.net

CD78 - Yvelines : VERSAILLES

01 39 50 24 51 cd78@ligue-cancer.net

Espace Lique 91: PALAISEAU

01 64 90 88 88 cd91@ligue-cancer.net

CD92 - Hauts-de-Seine : RUEIL-MALMAISON 01 55 69 18 18 cd92@ligue-cancer.net

CD93 - Seine-Saint-Denis : LE BOURGET 01 48 35 17 01 cd93@ligue-cancer.net

CD94 - Val-de-Marne : CRETEIL

01 48 99 48 97 cd94@ligue-cancer.net

CD95 - Val-d'Oise : ARGENTEUIL

01 39 47 16 16 cd95@ligue-cancer.net

After payment of a membership fee or flexible contribution

La maison rose, for women: maisonsrose.fr 27 rue de Rambouillet 75012 Paris 01 88 40 06 90

L'Atelier Cognacq-Jay: www.cognacq-jay.fr/ etablissements/centre-ressource-paris-75 58, rue de Vaugirard - 75006 Paris01 40 47 78 61

L'association Étincelle: www.etincelle.asso.fr 27 bis, boulevard Victor-Cresson 92130 Issy-les-Moulineaux. 01 44 30 03 03.

A website with many addresses and an interactive map - La Vie Autour:



SOCIO-AESTHETIC TREATMENTS

Socio-aesthetics, or "beauty and wellness care" in the medical environment, helps to preserve body image during treatment.

Socio-aesthetics, created in England in the early 1960s, can be defined as "the professional practice of aesthetic care for populations suffering and weakened by an injury or illness".

to their physical or psychological integrity, or by social distress".

There are several socio-aesthetics diplomas, from Certificat d'Aptitude Professionnelle to complementary training courses.

Since 2003, the French Cancer Plan has included socio-aesthetics as part of supportive care, due to its positive clinical impact, including improved self-image. and self-esteem, which can contribute to improving quality of life.

Our missions:

- __ Group or individual workshops,
- __ Facials, hand and foot care, and dermopigmentation.
- __ These treatments are free of charge

Who refers you to us?

The doctors, surgeons and carers you have met.

You can also make a request directly, or via your healthcare team.

We would like to thank our partners: CEW, Belle & Bien, Les Bonnes Fées.

For all hair-related questions (loss, regrowth, capillary prostheses) please contact

at our patient areas Maison des Patients et des Proches (Saint-Cloud), Espace

Rencontre et Information - ERI (Paris).

While you're in hospital, you can call on the services of a hairdresser for a fee, via one of the ward's caretakers.





Where can you meet our team?

These treatments can be carried out in cabins or in day or conventional hospitalization rooms.

Group workshops are organized by our patient areas: Maison des Patients et des Proches -(Saint-Cloud), Espace Rencontre et Information - ERI (Paris).

Individual care: please contact hospital care team

Group workshops:

_In Paris:

01 44 32 40 81 messagerie.eri@curie.fr

_In Saint-Cloud :

01 47 11 23 40

sc.maison-des-patients@curie.fr

Coordinating care paths

STAGES IN IDENTIFYING SUPPORTIVE CARE NEEDS

Announcement consultation

At the start of your treatment, Institut Curie doctors will provide you with information about your diagnosis and treatment pathway. At this stage, you receive a consultation with a nurse after completing a self-assessment questionnaire designed to identify your needs. During this consultation, you will be given a presentation of the different supportive care units, and you may be referred to one of them. The self-questionnaire can be consulted in the appendix.

Day hospital nurses chemotherapy

Nurses from the chemotherapy day hospital will be able to introduce you to and/or refer you to support care teams according to your needs.

A repository of identification criteria defined by the supportive care department, which we update regularly.

Patient coordination unit (C2P2)

After hospitalization in surgery or medicine, it is sometimes necessary to provide care at home. You can meet with a nurse and a social worker from the Cellule de

Coordination pour le patient en oncologie (C2P2). They will be able to introduce you to and refer you to the support care teams best suited to your needs.

Post-treatment monitoring unit breast cancer

At the end of your treatment, you will have a consultation to plan your monitoring program. Once again, you will be asked to complete a self-questionnaire to identify your support care needs (see appendix).

UNSCHEDULED RECEPTION UNIT

To meet medical needs for patients at the Institut Curie:

- An emergency consultation for patients undergoing treatment at the Institute is available Monday to Friday, 9am to 5:30pm. Please call the doctor in charge of the unscheduled consultation before coming to the Institute;
- At night and at weekends, a medical hotline advises and guides all medical requests in emergency situations
- _ If hospitalization is necessary, we will do our utmost to obtain a room for you.

Given the regular saturation of beds, you may be referred to the emergency services close to your home, or to the Institut's partner hospitalization services. Curie (Hôpital Saint-Joseph in Paris, Hôpital CH Quatre Villes in Saint-Cloud). Admission to medical and surgical specialties not represented at the Institut Curie is also possible. sometimes necessary.

To contact us in Paris: 24-hour medical emergencies 01 44 32 40 99

To contact us in Saint-Cloud: 24-hour medical emergencies
01 47 11 17 37

IN-TOWN CARE RELAYS

Accueil Cancer de la Ville de Paris

Accueils Cancer de la Ville de Paris (ACVP) are extra-hospital structures for cancer sufferers and their families. They are located in three separate areas, in the 4th, 10th and 15th arrondissements of Paris. They work in close collaboration with the UPO and the Institut Curie social service.

A specialized team of psychologists and social workers welcomes patients and their families, free of charge and by appointment, at any stage of the illness.

Psycho-oncology consultations can welcome patients or their relatives at any time during the course of treatment, and more particularly after active treatment, often as a follow-up to the treatment initiated at the Institut Curie, when necessary. We also offer discussion groups for post-treatment patients.

During interviews with assistants

We can provide you with information on your rights and the steps you need to take to assert them, as part of a personalized support program. If necessary, we can intervene at home.

Cancer care networks

In Paris and the Île-de-France region, networks territorial care centers offer patients

access to supportive and palliative care.

The care network team includes doctors, nurses, medical assistants and sometimes psychologists. Inclusion is at the request of the Curie medical team and with the agreement of the attending physician. Following a referral, which requires the transmission of a summary of the medical file, the network team makes a home visit to draw up a care plan based on your needs. You can consult the map of regional care networks (attached).

Home care

— Hospitalization at home (HAD)

A nursing team comes to your home to determine the appropriate equipment (medical bed, etc.) and carry out all your care and treatment.

Various organizations operate in the Paris region: Santé-Service, HAD Croix Saint-Simon, HAD de l'APHP.

_ Home nursing services (SSIAD).

You can call on the services of caregivers to help you with washing or a home care assistant.

— Home service providers.

A nurse performs intravenous infusions, with all the necessary equipment delivered to the patient's home.



Promoting patient rights

PROMOTING PATIENTS' RIGHTS IS ONE OF THE DECLARED AIMS OF SUPPORTIVE CARE

Democracy in healthcare: experiential knowledge versus theoretical and casuistic knowledge

The concept of health democracy, and soon health democracy, took shape after a period of maturation and mobilization by associations in favor of recognition of patients' rights, but also recognition of their knowledge. Associated with legislation (2002, 2016), the Compagnon report (2014) structured recommendations for involving citizens in the

healthcare system. To this end, the hospital project includes a "patient-partner" component, which is currently being rolled out. Health democracy is defined by the inclusion of users in the decision-making process, in conjunction with the Users' Commission (CDU):

The first point of entry, associations, often act as a resource for information and support.

The Institut Curie has developed partnerships with numerous associations.

To optimize patient training, we are developing therapeutic education to enable informed choices, which is the role of the UTEP mentioned above. The plan is to create a "school for cancer patients". following in the footsteps of the UTEP.

university diplomas from the Pierre et Marie Curie.

Health democracy applies to care, research, teaching and e-health.

Patient associations

In France, there are between 14 and 15,000 patient or patient-support associations. Their initial role is to break the isolation that can be caused by illness, and to raise awareness and recognition of conditions that are often poorly understood. Over time, however, patients' associations have become partners for doctors and healthcare institutions.

A patient association ensures that patients receive the right medical information, raises funds for medical research, participates in clinical studies and gives its opinion on the treatment proposed by doctors.

Patients' rights

__ The trustworthy person

From the very beginning of your care, we suggest that you designate a trusted support person, who can be very useful to you:

- _ to help you with your medical procedures and attend your medical appointments: she may be able to help you make decisions;
- __ if your state of health does not allow you to give your opinion, or to share your decisions, the doctor

will first consult the trusted support person you have designated. The advice thus obtained will guide the doctor in making his or her decisions.

The designation form must be signed jointly by the patient and his or her trusted support person. It must be a single person, adult and without legal protection. It can be revoked at any time.

Advance directives

Any patient who knows he or she is suffering from a potentially serious illness may, if he or she so wishes, make a written declaration. called advance directives, to specify one's wishes concerning the end of one's life. Anyone who is not ill can also do so in the event of a serious unforeseeable accident.

They may be revised at any time.

Advance directives are binding on medical teams if the patient is no longer able to express his or her wishes, even in the presence of a trusted support person.

If you are an adult, you can draw up your advance directives in the form of a written document on plain paper, or you can use the model below:

solidarites-sante.gouv.fr/IMG/pdf/ fichedirectivesanticipe_es_10p_exev2.pdf If you'd like to find out more, you can ask to meet the palliative care team.

The right to deep and continuous sedation maintained until death

The Claeys-Leonetti law introduced a new right for patients at the end of life, that of deep and continuous sedation maintained until death, requiring the gathering of several criteria: serious and incurable disease, short-term prognosis and patient facing refractory suffering.

If you'd like to find out more, you can ask to meet the palliative care team.

The User Commission

The Institut Curie's Users' Commission (CDU) ensures that users' rights are respected. It meets regularly and draws up recommendations to improve the quality of care for patients and their families.

It examines written complaints sent to the management of the hospital complex, remarks extracted from questionnaires sent to the staff, and any other comments received. and satisfaction surveys.

To contact the users' commission By post:

Management of the Institut Curie hospital complex:

26 rue d'Ulm - 75248 Paris cedex 05

Relatives' rights

The main rights of loved ones are to be a "voice" if the patient no longer has one (designation of a trusted support person). and to be given a copy of advance directives. But loved ones deserve attention and support in their role as caregivers, and the legislator has granted them other rights:

__ Obtaining information about a loved one's illness

Medical secrecy prohibits the disclosure of information about a person's state of health to third parties, on pain of penalty (Article 226-13 of the Criminal Code and L. 1110-4 of the Public Health Code). However, the French Penal Code allows for exceptions (Article 226-14 CP), and the French Public Health Code provides for situations in which relatives may receive information from a healthcare professional (Article L. 1110-4 CSP).

- When the patient is capable of expressing his or her wishes, he or she may authorize the physician to give information to persons designated by the patient or accompanied by the patient during the consultation. If the patient is opposed to providing information to a relative, the doctor cannot override this decision.
- When the patient is a minor or under guardianship.
- __ Unless the patient objects, in the event of a serious diagnosis or prognosis, confidentiality does not prevent the family, close friends or trusted support person from receiving information from the doctor that will enable them to provide direct support.

Entitlement to care leave :

Family support leave is available to employees with at least two years' seniority in a company when a close relative* suffers a particularly serious disability or loss of autonomy.

*Close relative = spouse, cohabitee, PACS partner, ascendant, descendant, dependent child, collateral up to 4th degree, ascendant or descendant.

An allocation journalière d'accompagnement d'une personne en fin de vie, created by law no. 2010-209 of March 2, 2010, is paid under certain conditions and when the patient is accompanied at home.

If you would like to find out more, please contact the Social Services Department.

Places of worship

Caregivers have access to a list of religious representatives to respond to specific requests. There is no dedicated space in the Institute, but these teams visit patients at their bedside and can use the spaces made available to families.

For Paris: Catholic

Head of Catholic Chaplaincy 06 25 37 57 63

Protestant : Pastor Thierry Lainel 06 14 73 26 59

Orthodox:
Temple at 4, rue St Victor (Paris 5ème)
01 30 39 20 57

Muslim : Grande Mosquée de Paris, 2bis, Place du puits de l'ermite 01 45 35 97 33

Mr Arnove (Rabbi), 1, rue de l'Abbé de l'Epée (Paris 5ème) 07 53 07 06 66 or 01 42 03 13 21

For Saint-Cloud:

Catholic: Catholic Chaplaincy Manager - Mrs Patricia De Guerre 01 77 70 71 50 (answering machine 7j/7) and 06 87 08 44 61

Protestant : Mrs Agnès Von Kirchbach 01 47 71 83 92 (Emergency: 06 31 12 19 07

Orthodox: (Russian Church Father Eugene Czapiuk 01 47 63 87 62

Muslim: Head of Chaplaincy -Mrs Leila MIKTAR 06 12 43 46 04

Israelite: Rabbi - Mr Ifrah and Mr Attia. Head of Chaplaincy - Mr Mimouni 06 66 70 22 28

Buddhist: Mr Luc Charles 06 09 12 74 04

The Ensemble Hospitalier Ethics Commission: the commission is structured around three distinct timeframes and modalities:

- Clinical support: at the request of the team in a complex situation requiring ethical reflection (3 members of the Institute conduct a reflection after after hearing the people and studying the file, according to an explicit methodology, and then return their ideas to the team).
- _ Training sessions on subjects that pose recurrently difficult problems, with the help of outside civilian personalities (4 to 6 times a year).
- An annual day of theoretical and practical training (casuistics), again with an outside speaker.

The link between this commission and supportive care is quite natural, given its cross-disciplinary nature and its link with the human and social sciences.

APPENDICES

Questions and answers on physical activity

N° 1 - I have an implantable chamber. that I can be physically active?

Yes - No

Yes, I can perfectly well do adapted physical activity with my implantable chamber; not all disciplines can be recommended, such as swimming, boxing, etc.

N° 2 - I have had an axillary curage. physical activity?

Yes - No

Yes, but I avoid muscle contractions and shocks to the operated arm.

N° 3 - I'm considering breast reconstruction. Can I be physically active after the operation?

Yes - No

Yes - Resumption will be gradual; it is particularly advisable to respect a time limit (1 month after the reconstruction operation and after medical advice from my oncological surgeon); activities in which the pectoral muscles are used (e.g. gymnastics, swimming, tennis) should not be resumed too quickly.

No. 4 - Physical activity during my treatments, why do it?

To feel good in my head, good in my body...

- __ to reduce fatigue, improve sleep and body image: my overall quality of life,
- __ to reduce stress, improve my concentration, improve my overall

cognitive functions,

- _ to improve my physical condition,
- _ to help me better tolerate my treatments and reduce any undesirable effects,
- _ to prevent overweight and obesity,_ to reduce the risk of recurrence,_ to reduce the risk of sarcopenia.

N° 5 - I need a medical certificate. Who can I ask?

The medical certificate of no contraindication to physical activity can be drawn up by my GP, following a medical check-up. It can also be discussed with an oncologist, right from the start of my treatment.

On the last page, I have a medical certificate stating that there are no contraindications to the practice of adapted physical activity, which I can have signed by my doctor.

Classification of physical activity as a function of effort intensity

Low intensity	Medium intensity	High intensity
1.6 to 2.9	MET3 to 6	MET6 to 9 MET
Office jobs Transport	Jobs: maintenance worker, gardener,	Jobs: carrying heavy objects
Artistic hobbies	store or factory	
Walking your dog	employee, bartender, hairdresser, cook, construction worker	Sports: fast stair climbing, running at 8 km/h, cycling at 20 km/h, cross-country skiing,
	Sports: moderate walking, swimming,	repeated pumps
Normal conversation	doubles tennis, golf, cycling	
No shortness of		
breath	HR from 55 to 70% of max HR	HR of 70-90 of max heart rate
	Conversation possible Slight shortness of breath Moderate sweating	Difficult conversation Shortness of breath heavy sweating

MET (= Metabolism Equivalent Task) or metabolic equivalent is a unit of measurement for assessing the amount of energy consumed per unit of time and weight Joule/kg/hour)

Ricci-Gagnon self-questionnaire assessing physical activity and sedentary lifestyle.

Ce questionnaire d'auto-évaluation va vous permettre de déterminer votre profil : inactif, actif, ou très actif?

Calculez en additionnant le nombre de points (1 à 5) correspondant à la case cochée à chaque question.

	POINTS					
(A) ACTIVITES PHYSIQUES QUOTIDIENNES	1	2	3	4	5	SCORES
Quelle intensité physique votre travail requiert-il ?	Légère	Modérée	Moyenne	Intense	Très intense	
En dehors de votre travail régulier, combien d'heures consacrez-vous par semaine aux travaux légers : bricolage, jardinage, ménage, etc. ?	< 2h	3 à 4h	5 à 6h	7 à 9h	> 10h	
Combien de minutes par jour consacrez-vous à la marche ?	< 15 min	16 à 30 min	31 à 45 min	46 à 60 min	> 60 min	
Combien d'étages, en moyenne, montez-vous à pied chaque jour ?	<2	3 à 5	6 à 10	11 à 15	> de 16	
					Total (A)	
(B) ACTIVITES PHYSIQUES DE LOISIR (Dont sports)	1	2	3	4	5	SCORES
Pratiquez-vous régulièrement une ou des activités physiques ?	Non				Oui	
A quelle fréquence pratiquez-vous l'ensemble de ces activités ?	1 à 2 fois / mois	1 fois / semaine	2 fois / semaine	3 fois / semaine	4 fois / semaine	
Combien de minutes consacrez-vous en moyenne à chaque séane d'activité physique ?	< 15 min	16 à 30 min	31 à 45 min	46 à 60 min	> 60 min	
Habituellement comment percevez-vous votre effort ? (Le chiffre 1 représente un effort facile et le 5, un effort difficile)	1	2	3	4	5	
(C) COMPORTEMENTS SEDENTAIRES	1	2	3	RESUL	TS	
Combien de temps passez-vous en position assise par jour ? (Loisirs, télévision, ordinateur, etc)	> 5h	4 à 5h	3 à 4h	Less Inactive	than Betw	18: een

18 and 35: Active

More than 35: Very

active

Example of a medical prescription for adapted physical activity

PRESCRIPTION FOR ADAPTED PHYSICAL ACTIVITY

Including certificate of no contraindication to practice As part of treatment for an ALD30 illness

I, Doctor		Address Mad	ame/ Monsieur,
	Born on .	/	
So that he/she can benefit from adapted plits pathology.	nysical activity wit	hin the framewor	rk of
I certify that Mr / Mrsno contraindication* to the practice of an educator or adapted physical activity teac (interministerial instruction March 2017).	adapted physica	activity superv	ised by a sports
Certificate validity duration 1 month □	3 months 🗖	6 months □	1 year □
Paris,			
Tampon			

*Contra-indications: extreme fatigue - symptomatic anemia - Hb ≤8 gr/dl - early post-surgery, infectious syndrome, decompensation of cardiopulmonary pathology, lytic bone lesions of the spine and long bones (the IC refers to the location of the affected limb). These contraindications do not preclude the use of rehabilitation treatments, which can help maintain joint mobility and muscle mass.

Since 2011, the French National Authority for Health (HAS) has recognized the benefits for patients with chronic illnesses of prescribing physical activity as a non-medicinal therapy (not reimbursed by Social Security); Physical activity and/or sports must be adapted to your state of health and your needs - Document to be given to the PA teacher before the start of the 1st session.

Self-questionnaire for identifying supportive care needs in the announcement consultation and monitoring unit

Da	tiont	ID	



Document to be completed by the patient

Interdisciplinary Department of Patient Support Care in Oncology

Dear Sir/Madam,

In the context of your illness, you may have identified or already encountered a number of difficulties, whether practical, physical, family-related or psychological...

You can let us know by filling in this questionnaire. This will help us prepare for your consultation with the nurse, during which we can discuss the various issues raised and refer you to the appropriate professionals.

Thanking you in advance for your participation, Kind regards,

Support Care Department (DISSPO)

Tick the appropriate boxes. After completing this document (both sides), hand it to the nurse at the start of t h e nursing consultation.

Practical problems with :			Physical problems of:			
	YES	NO		YE S	NO	
- Accommodation			- Pain			
- Financial (loans, insurance, etc.)			- Fatigue			
- Work - School			- Sleep			
 Logistics (childcare, help needed, etc.) at home, etc.) 			- Power supply			
at nome, etc.)			- Addiction problems (tobac	co, alcoho	l, etc.)	
			- Would you like some help?			
Family problems with:			Psychological problems of :			
- Spouse			- Worries - preoccupations			
- Children			- Sadness			
- Others			- Depression			
			- Irritability			
Other problems						
If so, which ones?:						
				Please turn	the page	,

D.I.S.S.P.O 10/2018 - Patient grid - announcement system - referral to DISSPO - SDol/BBois Contact: Tel: 01 44 32 40 98 B. Boistard - Head of Support Care Missions

The scale below is one way of assessing your psychological state.

We ask you to <u>put a cross on the line that best corresponds to your psychological</u> <u>state over the last week.</u>

Extreme distress



No distress

Please date the document

D.I.S.S.P.O 10/2018 - Grille patient - consultation d'annonce - orientation vers le DISSPO - SDol/BBois Contact : Tél : 01 44 32 40 98 B. Boistard - Head of Supportive Care Missions

G8 questionnaire (validated in national Oncodage study, recommended by Inca)

Echelle G8

Items	Réponses possibles (items)
Le patient présente-t-il une perte d'appétit ? A-t-il	0 : anorexie sévère
mangé moins, ces 3 derniers mois, par manque	1 : anorexie modérée
d'appétit, problèmes digestifs, difficultés de	2 : pas d'anorexie
mastication ou de déglutition	
	0 : perte de poids > 3 Kg
Perte récente de poids (< 3 mois)	1 : ne sait pas
	2 perte de poids entre 1 et 3 kg
	3 : pas de perte de poids
	0 : du lit au fauteuil
Motricité	1 : autonome à l'intérieur
(CAN) (LONG 10, 1 p.m.	2 : sort du domicile
	0 : démence ou dépression sévère
Problèmes neuropsychologiques	1 : démence ou dépression modérée
	2 : pas de problème psychologique
	0 : IMC < 18,5
Indice de masse corporelle (IMC)	1: 18,5 ≤ IMC < 21
	2:21 ≤ IMC < 23
	3 : IMC ≥ 23
Prend plus de 3 médicaments	0 : oui
	1 : non
Le patient se sent-il en meilleure ou moins	0 : moins bonne
bonne santé que la plupart des personnes de	0,5 : ne sait pas
son âge ?	1 : aussi bonne
	2 : meilleure
S0 (55) 97	0:>85
Age (ans)	1:80 - 85
	2: < 80
Total	0 - 17

Caractéristiques du test G8 :

Population évaluée : **1425 patients** (sur 1668 inclus) de plus de 70 ans, âge moyen de la population : 78 ans, PS entre 0 et 1 pour 75% des patients inclus, 70% sont des femmes, plus de la moitié (53,7%) avec cancer du sein et près dans près de la moitié des cas (49,6%) la maladie n'était pas métastatique.

Temps moyen de remplissage du test (IDE ou Oncologue) : **4,4 mn (+/- 2,9 mn)** Se : 76,6% (74,0 –79,0) – Spe : 64,4% (58,6 –70,0) VPP : 89,6% (87,6 –91,5) – VPN : 40,7% (36,1–45,4)

<u>Interprétation</u> : **un total ≤ 14** fait considérer le patient comme **vulnérable** et conduit à demander une évaluation gériatrique complète

Person form of trust



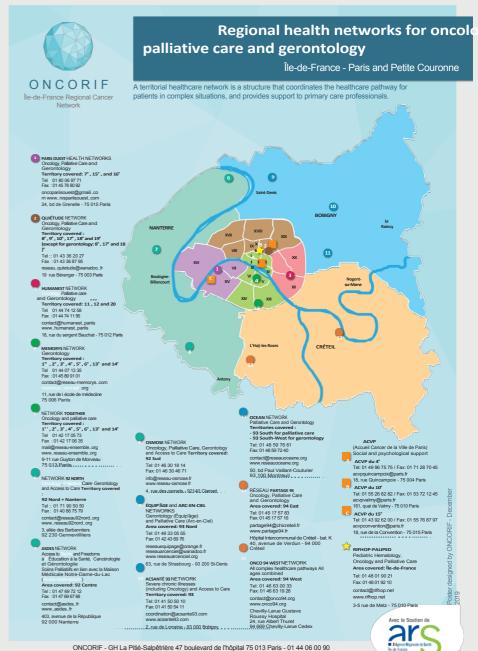
FORMULAIRE DE DESIGNATION D'UNE PERSONNE DE CONFIANCE

Désignation initiale	
☐ J'ai reçu l'information médicale co souhaite pas en désigner pour l'instant	oncernant la désignation d'une personne de confiance et je ne
Je souhaite désigner une personi moment.	ne de confiance pour une durée illimitée mais révocable à tout
Nouvelle désignation annulan	nt la déclaration précédente
PATIENT	
Nom / Nom de jeune fille	Prénom :
Date de naissance ://	
PERSONNE DE CONFIANCE	
Lien avec le patient (ex : père, ami, médec	cin traitant) :
Nom :	Prénom :
Adresse :	
Téléphone(s) fixe/portable :	
☐ J'ai informé cette personne que son n	nom et ses coordonnées figureront dans mon dossier médical
	hangement de la personne de confiance désignée et dans ce cas, is concernées ainsi que l'établissement (remplir une nouvelle fiche ince).
Fait à :le :	

 $\mathbf{46}$

List of support care networks in lle de France

More information at www.oncorif.fr





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