

Diagnosis and beyond

Information brochure for cancer patients

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Brochure produced by the Réseau des Malades et des Proches de la Ligue Nationale Contre le Cancer, November 2006

“This initiative and the Ligue’s Réseau des Malades are a direct consequence of the first Etats généraux of November 1998. We must rejoice that this great historical moment in the social history of oncology has not been merely a moment of emotion. The tenacity of patients and the commitment of the Ligue, the Ministry of Health and INCa (the National Cancer Institute) are responsible for the existence of this initiative that will improve the treatment of cancer patients from diagnosis onwards. I thank all those patients who have contributed to the content of this programme and who will work towards its general implementation.”

Professor Henri Pujol
President of the Ligue Nationale Contre le Cancer

“To be there and to offer support at the time of diagnosis; to be more available to listen to the patient and his family and friends; to guarantee, at these significant moments, more humanity and better quality of treatment - these are the great improvements resulting from the implementation of this programme. Without the very strong commitment of the members of the Réseau des Malades, the conditions met by patients at the onset of their illness would be very different from what they are today. Through their actions, and by having constant recourse to the words and personal experiences of patients, they have been the relentless moving force behind the improvements effected. The Ligue Nationale Contre le Cancer has succeeded in sustaining and amplifying this message. We sincerely thank all those without whose dedication and energy this programme would not exist today.”

Dr Christine Bara, Advisor to the President of INCa, Director of the Department for improving the Quality of Treatment and Access to new Treatments.

Diagnosis and beyond

This programme is a consequence of the Plan cancer (2003-2007)⁽¹⁾, put in place at the request of patients at the time of the Etats Généraux of cancer patients organized by the Ligue Nationale Contre le Cancer. Under its terms, the patient must receive quality care from the moment of learning the diagnosis onwards.

The programme makes provision for adequate time for discussion and explanation of the illness and its treatment with a view to providing the patient with relevant, progressive and respectful information :

- **medical information** including the imparting of the diagnosis and of the proposed treatment,
- **nursing support** to enable the patient and his family to ask further questions about the illness and its treatment and to receive information about his rights and potentially helpful associations,
- **other support** including welfare considerations and access to ancillary treatment (psychologist, physiotherapist, pain management clinic, etc.),
- **interaction between GP and hospital team** to ensure optimal cooperation between the parties involved in the patient's treatment.

(1) Item 40

MEDICAL CONSIDERATIONS

Announcing the diagnosis

You have consulted a doctor about a health problem or during the course of a cancer screening programme.

This doctor has ordered some examinations and/or referred you to a specialist.

The tests and examinations you have undergone will enable the specialist to confirm the diagnosis and to put a name to your illness.

It is normal to be anxious and you may wish to have a friend or relative accompany you to this and subsequent consultations.

This is a special consultation (*la consultation d'annonce*) that will be a bit longer than most and take place in quiet and welcoming surroundings. Your doctor (oncologist or other specialist) will confirm your diagnosis in simple terms. He will answer all your questions and tell you about possible treatments.

He will explain to you that a treatment proposal tailored to your particular needs will be made to you after your case has been studied in a multidisciplinary meeting (RCP - *Réunion de Concertation Pluridisciplinaire*). (See p. 4)

The multidisciplinary meeting (RCP)

In order that you receive the very best treatment, your case will be presented to a multidisciplinary meeting by your oncologist or other specialist.

This meeting consists of at least three specialists in your particular type of cancer.

Their discussions, focusing on the type of cancer, its stage of development, your general health and your medical history, will enable them to draw up a treatment plan tailored to your needs that will be contained in your personal treatment programme (PPS - *programme personnalisé de soins*).

These discussions will be based on validated treatment standards. Discussion of your case by a multidisciplinary meeting is not obligatory if the treatment forms part of a recognized protocol or in the case of emergency.

The report of the multidisciplinary meeting will be recorded in your computerized medical record and will thus be available to all your treatment team. A copy will also be sent to your GP.

Your personal treatment programme (PPS)

After the multidisciplinary meeting, your doctor will propose to you your personal treatment programme and will explain its various stages (for example, surgery followed by chemotherapy, surgery and radiotherapy, or other combinations, depending on your case); he will also give you a treatment timetable.

This personal treatment programme will be given to you to take away. You may accept it, discuss it, refuse it or request a second opinion.

Take time to think about it and ask questions before you make up your mind. (See p. 6)

Your personal treatment programme will tell you the expected duration of the treatment(s) proposed.

It may, however, be modified, depending on your reaction to the treatment. Your doctor will always explain the reasons for such modifications. **Be aware that such modifications are commonplace.**

The second opinion

After taking into account everything you have been told, you may if you wish seek a second medical opinion. You will be assisted in this initiative, which will take place in a spirit of confidence and transparency.

You will have access to your medical record so as to be able to communicate all the relevant information to the doctor you choose for your second opinion.

The request for a second opinion should not delay prompt treatment if this is necessary.

Patients' rights

Law 2002-303 of 4th March 2002 relating to patients' rights underlines the importance of the following points:

access to quality treatment, the right to be informed, consent to treatment, access to one's medical record, respect of the patient's dignity, his private life and medical confidentiality, protection against discrimination, entitlement to no-fault insurance, access to palliative care, a designated confidant.

Clinical trials⁽²⁾

At the beginning of or during the course of your treatment, you may be invited to take part in a clinical trial. This is a controlled study that is open to certain patients according to strict criteria.

The purpose of clinical trials in oncology is the evaluation of new treatments against cancer. They have already been tested at length before being offered to you. They are administered and their effects monitored by the hospital team.

Before participating in any clinical trial, the patient must be given an information sheet so that he can decide whether he considers it to be in his best interest to participate.

The patient gives his fully informed consent by signing a form given to him by the doctor in charge of the trial, who also signs the form. It is therefore impossible to be included in a trial without your knowledge.

You are free to accept or refuse. If you accept, you can leave the trial at any moment without prejudicing the quality of your care.

(2) Clinical trials are governed by the Huriet law of 20th December 1988 and the law of 4th March 2002 relating to patients' rights.

NURSING AND WELFARE CONSIDERATIONS

The nurse consultation

You may be offered a consultation with a nurse immediately after your medical consultation or a few days later.

This consultation gives you the opportunity to express your feelings, your fears, your doubts and your questions; it is also the start of a relationship.

It will enable you:

- to get to know your treatment team,
- to gain a better understanding of what the doctor told you, of the information you have been given on your course of treatment and of the necessary administrative procedures (e.g. medical certificate, long-term disability cover),
- to mention any social, family or psychological problems you may be experiencing.

It will also be an opportunity for those looking after you to get to know you, which will in turn enable them to make a better job of caring for you during the course of your treatment and referring you, with your agreement, to other people or agencies who might be of help to you.

The nurse will explain to you the scheduling of your various appointments and give you information sheets about your illness. You can contact her by telephone if you have any queries.

Your welfare rights

We strongly advise you to make a check of your welfare rights. Certain procedures are essential and may take several weeks to put in place, so do not delay.

➤ **L'assurance maladie**

Cancer is considered a long-term disability (ALD - *affection longue durée*), giving you the right to 100% reimbursement by the *assurance maladie*. The appropriate declaration must be made by your GP to your local *caisse*. It is important that this is done as soon as possible.

If you have not yet designated your GP (*médecin traitant*), you are entitled to a temporary dispensation. In case of difficulty, there is an emergency procedure⁽³⁾.

➤ **La mutuelle (top-up insurance)**

This provides reimbursement for certain treatments to which your *caisse assurance maladie* applies a ceiling, and provides for various extras: private room, extra bed for companion, home-help, salary supplement, etc.

(3) CNAM communication of 5th June 2006.

OTHER SUPPORT

Insurance and loans

INSURANCE

In addition to your top-up insurance, you may have taken out other personal insurance. Don't forget to check your policies. Pension funds and superannuation funds provide welfare services. Whether you are retired or employed, don't hesitate to contact them.

LOANS

If you have taken out loans before you became ill, you need to check your contracts to see if you opted for an insurance against invalidity or incapacity to work that will partially or totally meet your repayments.

The waiting period is generally 90 days, but it is usually a good idea to make your declaration before 120 days have passed; if you leave it longer than that, you will only be reimbursed from the date of declaration. You have to complete a form and have your doctor answer a medical questionnaire.

Whatever your situation, we strongly advise you to reread your contracts or have a relative read them for you.

Social support

Depending on your age and situation, you may be entitled to various welfare rights and social support or to their enhancement.

A social worker can help you to assess your situation and to prepare the necessary paperwork.

Much assistance ensues from the holding of an **invalidity card (carte d'invalidité)**. This card entitles the patient and his family to fiscal and social benefits. It is allocated on medical grounds. You have to apply for it.

Other assistance may be available from your *mutuelle*, your family allowance office, your pension fund or a supplementary insurance policy. Find out! (See page 10)

Exceptional assistance may be granted by various welfare organizations or by associations such as the Ligue Nationale Contre le Cancer. Such assistance is normally means-tested and only available after official sources of assistance have been exhausted or while waiting for them to cut in.

Ancillary care

The purpose of this is to improve your comfort and quality of life during your illness.

Various types of care may be offered to you: psychological support, social support, pain management, nutritional advice, aesthetic aids, physiotherapy, acupuncture, ...

Your medical team will refer you for those treatments relevant to the symptoms of your illness or the side-effects of your treatment: pain, tiredness, nutritional problems, respiratory or urogenital problems, skin problems, ...

All these modalities of ancillary care may be prescribed as from your first consultation and continued throughout your illness for as long as you have need of them.

Ancillary care is provided in a hospital or clinic or within the framework of an oncology network. (See p. 17)

Day-to-day assistance

Your needs in this respect will depend on your state of health, your personal and family situation and your insurance status (*mutuelle*, pension fund, etc.)

Your local Community Centre for Social Work (CCAS - Centre Communal d'Action Sociale) or relevant associations provide the following assistance and services:

- **home help** - housework, shopping or meal preparation,
- **care assistance** - washing, help with eating,
- **welfare and family assistance** - seeing to the children's various needs,
- **meals on wheels** - if you are on your own and cannot get out.

The level of provision of these services (partial or total) will depend on your age and your means.

You are entitled to an assessment of your welfare needs and rights under the terms of this programme, so that you know where you stand. (See p. 11)

Psychological support

To help you all to come to terms with your illness, psychological support will be offered to you and your family. You can ask for this at any time during your treatment.

This support will enable you to be listened to by a compassionate ear, to express your feelings, to feel less alone and to achieve a higher degree of self-knowledge. You may make an appointment with a psychologist in your hospital or clinic or within the framework of your oncology network whenever you feel the need. (See p. 17)

There are also other possibilities:

- telephone counselling (See p. 20),
- visits at home or in hospital from voluntary workers,
- group therapy sessions run by a psychologist and encouraging dialogue and listening between patients or between patients and their relatives,
- internet forums set up by cancer-related associations,
- *Espace de Rencontres et d'Information* (ERI) (See p. 20).

Don't hesitate to contact your local branch of the Ligue Nationale Contre le Cancer.

LIAISON BETWEEN YOUR GP AND HOSPITAL TEAM

Your GP (médecin traitant)

Your GP plays an important role in your treatment. Your specialist sends him details of your diagnosis, a description of the intended treatment and foreseeable side-effects, information about possible inclusion in a clinical trial and an assessment of your prognosis.

He will also receive promptly reports of the special consultation with your specialist (*consultation d'annonce*) (See p. 3), of supplementary and surgical examinations and of the multidisciplinary meeting, along with a copy of your personal treatment programme.

Your GP is the person who:

- tells your *caisse assurance maladie* that you have a long-term disability (ALD) necessitating 100% reimbursement of your treatment costs,
- fills in and renews your medical certificates or requests for part-time work,
- assesses your day-to-day needs,
- deals with other relevant medical formalities and paperwork.

If you do not have a GP, your hospital treatment team will help you to find one. (See p. 9)

Treatment

AT HOME

After a stay in hospital, especially if you have undergone surgery, you may need some after-care at home. This normally takes the form of treatment by a nurse or a physiotherapist.

AS A DAY-PATIENT

Chemotherapy is usually carried out during a stay of just a few hours in a public or private hospital.

Radiotherapy sessions last only a few minutes and are spread over one to five days during a period of a few weeks. They take place in specialized centres which are sometimes located far from the patient's home.

HOME HOSPITALIZATION

In certain cases, a multidisciplinary team attached to a hospital can provide 24-hour-a-day treatment for you at home. This is an alternative to traditional hospitalisation.

The costs of treatment and transport will be reimbursed at 100% by the *assurance maladie*. (See p. 9) Your hospital and/or your GP will provide you with the necessary prescriptions, documents, information and request forms.

The oncology network⁽⁴⁾

The programme described in this brochure will be offered to you in the hospital where you are being treated or within the framework of an oncology (or cancerology) network.

This latter is a regional network that brings together all those parties - medical, technical and support - involved in the care of cancer patients.

The network's objective is to offer the patient the best possible holistic care as close to his home as possible, while respecting his free choice and allowing him to play a part in decision-making.

The network improves access to treatment through the cooperation of health professionals from public and private hospitals and independent practitioners.

The network also includes all the community health professionals (doctors, nurses, pharmacists, etc.), social workers, home-help organizations, user groups, former patient associations and voluntary support groups.

(4) also known as the cancerology network

Your family and friends

The diagnosis of your illness will disrupt not only your life but also those of your family and friends. Everyone reacts in his own way and that can sometimes cause difficulties and misunderstandings.

Talking openly about your illness will help you psychologically and enable your friends and family to know how best to help you

Being treated for cancer saps your energy. You will need to adapt your routine and your pace of life to your treatments. These will vary depending on your individual case. You may wish to ask your family and friends to:

- respect your routine,
- to help you in whatever ways they can,
- to come with you (or not) to medical consultations or examinations,
- to carry on as normally as possible, especially if you have young children or teenagers.

Don't forget the various types of support that are available both to you and to your friends and relatives. Your treatment team, your psychologist, your doctors and the voluntary support groups are all there for you. They will always give you good advice.

Further information and useful addresses

Your doctors and medical team will be able to answer most of your questions, but there is no reason why you should not seek further information. Here we list some references where you will find information, Internet links, brochures or videos:

Ligue Nationale Contre le Cancer
14 rue Corvisart
75013 Paris
Tél : 01 53 55 24 00
www.ligue-cancer.net (See p. 21)

The Ligue Nationale Contre le Cancer will give you the details of its branch in your *département*. This latter will put you in touch with local representatives of national associations that might be of help to you. Most branches offer discussion groups, home visits, the opportunity to speak to a psychologist, a welfare assessment, etc.

Institut National du Cancer - INCa
52 avenue André Morizet
92513 Boulogne Billancourt cedex
www.e-cancer.fr

L'Institut National du Cancer was created within the framework of the law of 9th August 2004. It plays a consolidating and co-ordinating role. Its mission is to initiate and support national policy on cancer care.

Jeunes Solidarité Cancer - JSC
14 rue Corvisart
75013 Paris
Tél : 01 53 55 24 72
www.jscforum.net

This internet forum, created and run by young patients, aims to put an end to the isolation experienced by young adults and teenagers suffering from cancer.

CANCERINFOSERVICE

Un service anonyme ouvert de 8h à 20h du lundi au samedi

0810 810 821

Prix appel local

Cancer Info Service offers telephone support at the price of a local call. It is a confidential service available from 8 am to 8 pm Monday to Saturday. It offers both information and support. It does not offer telephone consultations, nor diagnoses, nor prescriptions, but helps you to understand your cancer better in order to fight it more effectively.



Accompagnement et Information
pour le Droit à l'Emprunt et l'Assurabilité avec la Ligue

aidéa, tel: 0 810 111 101 is a service provided by the Ligue to help you obtain loans and insurance.



Cancer Support France is a support service created for English-speaking people living in France. Volunteers offer a listening service. Help is available with translation of medical documents. A drop-in centre is available in Benest (16). It is open every Tuesday morning from 10.00 to 12.30 or by appointment. Telephone/answerphone: 05 45 89 30 05. Internet: www.cancersupportfrance.info

ERIs: *Espaces de Rencontres et d'Information*. ERIs are places where cancer sufferers and their families can meet, obtain information and find support. There are about a dozen in France, all situated within cancer treatment centres. They put on debates and conferences, give advice and offer workshops on subjects like beauty, relaxation, art therapy, etc., aimed at enhancing your wellbeing.

What is the Ligue Nationale Contre le Cancer?

Created in 1918, the Ligue Nationale Contre le Cancer is a non-profit-making association governed by the law of 1901 and recognized as a useful public service. It is composed of 103 departmental branches.

Its mission ?

To provide information and support to anyone likely to be affected by cancer: patients, former patients and their friends and relatives, the general public, public health officials, doctors and researchers.

The activities of the Ligue and its branches fall into three main categories:

- research,
- information, prevention and screening,
- supporting patients and their families.

RESEARCH

Research, which is of the utmost importance if we are to improve our future cure rate, accounts for more than 60% of the Ligue's funding. This research is of several types: fundamental research, clinical research (aimed at improving treatments) and epidemiological research (studies risk factors with a view to improving the effectiveness of prevention and screening). It is guided by national, regional and departmental scientific councils.

INFORMATION, PREVENTION AND SCREENING

The second arm of the Ligue's activity is informing the public about prevention and screening. The objective is threefold: to make everyone aware of the dangers inherent in certain practices (smoking, alcohol consumption, prolonged exposure to the sun ...); to flag up risk factors; to tell people how to identify certain symptoms.

Numerous communications adapted to different sections of the general public have been put in place.

SUPPORTING PATIENTS AND THEIR FAMILIES

The branches of the Ligue offer material, moral and psychological support to patients, former patients and their families.

By organizing the Etats Généraux of cancer patients in 1998, 2000 and 2004, the Ligue gave a huge impetus to the movement for better care for cancer sufferers.

By giving cancer patients a high-profile platform, the Ligue enabled their needs and expectations with regard to the quality of their treatment and their quality of life to be heard and acted upon.

What is the Réseau des Malades et des Proches (Network of Patients and their Friends and Relatives)?

It is a forum for patients and their friends and relatives created by the Ligue Nationale Contre le Cancer in 2001.

Its mission is to improve the treatment and quality of life of cancer patients and of their friends and families.

Its chief objectives are to help patients to live with cancer and to continue to have a social life, and to promote the quality of cancer care.

It is natural that it should have come together with health professionals, their representatives and the relevant authorities in the elaboration of national recommendations for the implementation of this programme.

The Réseau des Malades et des Proches thought it important to publish a brochure intended to inform patients and their relatives about the principal points of the programme.

This brochure was produced in collaboration with the service “Actions pour les malades”, which is part of the Ligue Nationale Contre le Cancer.

You can contact the Réseau through the Ligue or your local branch.

JOIN THE LIGUE

The league's activities depend on the generosity of the French people and their commitment to the voluntary sector. You too can help in the fight against cancer:

- **by joining** the branch of the Ligue nearest to where you live;
- **by participating** in activities organized by your local branch;
- **by supporting** our activities through donations and bequests (the Ligue is authorized to receive donations and bequests free of tax, including inheritance tax).

RECOGNIZED AS TRUSTWORTHY AND TRANSPARENT

Since its creation, the Ligue has been a member of the Committee of the Charter of ethics for social and humanitarian organizations that depend on the public's generosity.

(Logo du Comité de la Charte)

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