

Patient Rights

– a guide for patients and their family

Valid from 1 July 2009



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Preface

At Mental Health Services, we find it important to give you as our patient relevant information in all situations. We want to establish contact between you, your family and the healthcare professionals on the basis of trust, respect and understanding.

This guide provides information especially about your rights as a patient, but is relevant for both patients and their family.

After reading this guide, you may still have unanswered questions.

The Acts of Parliament and other bylaws to which reference is made after each section in this guide are available at the library or from Retsinformation (Rights Information) at www.retsinfo.dk, from the Sundhedsstyrelsen (National Board of Health) website www.sst.dk or from the Ministry of Health and Prevention website www.sum.dk. You may also look for information about rules at the health portal www.sundhed.dk.

Furthermore, staff will be happy to answer any questions you may have or refer you to a relevant professional.

You are also welcome to contact the hospital's patient counsellor, who will be able to advise you on the free choice of hospital, treatment options, patient rights such as file access, secrecy obligations, information, complaint paths and possibilities for obtaining compensation, etc.

Finally, the Capital Region of Denmark has a central information and counselling unit that provides information to patients wishing to be referred to another treatment facility where waiting times are shorter.

You find telephone numbers and addresses in the back of this guide.

Referral for hospital treatment

To receive treatment at a hospital, you need a referral from a GP or a private practice specialist, unless you require emergency treatment.

Free choice of hospital

When the physician finds that you need treatment at a hospital you can choose the public hospital or private special hospital with an operating agreement with the regions where you wish to receive treatment.

If you choose to receive treatment in a department at a public hospital outside the Capital Region of Denmark, the department you have chosen may, however, refuse to take you in if they do not have a space available.

The free choice of hospital applies to admissions, outpatient care and rehabilitation services. However, the possibility of having a free choice in regard to highly specialised departments depends on your illness.

You will be given advice and guidance by the referring physician. Your GP or private practice specialist may send their referral straight to the hospital you have chosen.

If the hospital changes the date of a planned surgical procedure, e.g. the hospital cancels your appointment for a surgical procedure, you also have the possibility of choosing to receive treatment at a private hospital. In this case as well, this can only be done if a contract has been concluded with the private hospital concerning the treatment you are to receive.

In a few cases, there are no free choice:

- If you are taken ill suddenly and need emergency treatment without a prior referral from a physician. In that case, you will be taken to the nearest hospital by ambulance.

- If warranted by considerations for you as a patient, the possibility of choosing a place of treatment for mental health disorders may be restricted.
- If you have chosen a highly specialised department and your illness does not require treatment at that level.

Extended free choice of hospital

You have the option of choosing to be referred for evaluation and/or treatment at a private hospital or clinic in Denmark or abroad, provided the Capital Region of Denmark cannot offer you a pre-evaluation, including a diagnostic evaluation, or treatment within one month at one of the Region's hospitals or one of the Region's associated hospitals.

It is a condition that a contract has been made between the private hospital or the private clinic and Danish Regions on the examination or treatment you are to receive.

Furthermore, the waiting time for treatment at the private hospital or the private clinic may not be longer than the waiting time at the Region's hospitals or the Region's associated hospitals.

You can find the hospitals associated with the Capital Region of Denmark on the Region's website www.regionhovedstaden.dk.

You need a referral from the Central Information and Counselling Unit of the Capital Region of Denmark. You will get more information about your specific possibilities of choosing your place of treatment as the hospital tells you when it will be able to examine or treat you and/or perform surgery on you. You can get further information about the scheme by approaching the Central Information and Counselling Unit of the Capital Region of Denmark. The phone number of the Unit is at the back of this guideline.

Information about the private hospitals and clinics that have made a contract with Danish

Regions is available on a website of Danish Regions www.syggehusvalg.dk. Here, you will be able to check whether a given hospital or clinic has a contract for the evaluation or treatment you are to receive.

Please understand that if you choose to be referred to a public hospital outside the Capital Region of Denmark or a private treatment facility in Denmark or abroad, it is up to you to organise your transport to get to the examination or treatment. Page 21 of these guidelines has the rules concerning transport and the possibilities of obtaining a partial refund of transport costs.

Children and adolescents – extended free choice of hospital in mental health services

Examination

Children and adolescents who are not 19 years of age at the time of referral, may choose to be referred for an examination at one of the private hospitals or clinics that have concluded an agreement about these services with the regions (Danish Regions), provided the region is not able to offer an examination at one of the region's child and adolescent mental health centres within two months.

The waiting time counts from the time when the referral is received.

Examination and treatment

If the examination in a private facility identifies a need for early treatment to avoid deterioration, the child or adolescent may choose to receive treatment at the same facility where the examination was carried out, provided the region is not able to offer treatment at one of the region's child and adolescent mental health centres within two months from the date when the examination was concluded.

Regardless of whether the region is able to offer treatment within two months, the child

or adolescent may choose to receive treatment at a private facility if the private facility where the examination was carried out is able to offer treatment immediately after the examination.

If the waiting time is longer at the private facility

If the waiting time is longer at the private hospitals or clinics than at the region's child and adolescent mental health centres, the right to opt for referral for examination and treatment at a private facility does not exist.

How do you get referred for treatment at a private facility?

You need a referral from the Central Information and Counselling Unit of the Capital Region of Denmark if you wish to avail yourself of the possibility of receiving treatment in a private facility. The region will only pay your costs for examination or treatment at a private facility if you have been referred by the Information and Counselling unit.

Please note that if you choose to be referred to a hospital outside the Capital Region of Denmark, you will have to arrange for transport for examination or treatment yourself. You can find detailed rules on transport and the possibility of getting a partial transport refund on page 20 of this guide.

Information within 8 weekdays

The hospital is obliged to inform you about rules, waiting times, etc.

No later than eight weekdays after the hospital has received a referral from your physician, the hospital must inform you about

- date and place for examination or treatment
- your right to free choice of hospital
- waiting times for treatment at the region's hospitals and associated hospitals

- your right to be told the number of treatments made at the region's hospitals and associated hospitals
- your right to be referred, if you so wish, to another hospital in the region or a public hospital outside the region.

In connection with the referral of children and adolescents for examination and/or treatment in a mental health department, information must also be given about

- whether the child or adolescent can be offered examination and/or treatment within two months
- that the child or adolescent will be offered a referral for examination and/or treatment at a private facility in accordance with the rules on the extended free choice of hospital if the waiting time is exceeding two months.

You can obtain information about number of treatments and waiting times for treatment throughout the country from the Central Information and Counselling Unit of the Capital Region of Denmark. This is also the Unit to contact if you want to be treated at another facility with shorter waiting times. The telephone number for the Information and Counselling Unit is printed at the back of this guide.

Read more about this subject in

- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064 of 6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.
- Ministry of Health and Prevention order no. 867 of 26 August 2008 on transport or transport allowance in pursuance of the Health Act.
- Ministry of Health and Prevention order no. 594 of 11 June 2009 on the right to

hospital treatment, etc. (the Hospital Order).

- Order No. 787 from 16 July 2008 from the Ministry of Health and Prevention concerning the extended right to receive examination and treatment if you are a mentally ill child or adolescent, including the referral procedure and documentation requirements for contracted hospitals, etc.
- Ministry of Health and Prevention folder: Free choice of hospital.

Treatment guarantee in regard to life-threatening cancer diseases, etc.

If you suffer from a life-threatening cancer or cardiac disease, special rules apply regarding maximum waiting time for examination and treatment. The hospital must review your possibility of being examined and treated sooner elsewhere in the country or abroad if the hospital is not able to comply with the maximum waiting periods laid down.

If, however, the physicians at the hospital find that because of your health condition you should be offered treatment sooner or that you should wait longer, the maximum waiting time in question does not apply.

Cancer diseases

As regards cancer diseases, the following maximum waiting times apply:

- **Pre-examination:**
Two weeks after the hospital received the referral.
- **Surgery:**
Two weeks after you were informed about the diagnosis and the treatment options and you consented to the surgery.
- **Medical treatment as primary treatment:**
Two weeks after you were informed about the diagnosis and treatment options and you consented to medical cancer treat-

ment, and no more than four weeks after the department received the referral.

- **Radiation therapy as primary treatment:**
Four weeks after the relevant department received the referral.
- **Radiation therapy as follow-on treatment:**
Four weeks after the relevant department received the referral.

Cardiac diseases

The following maximum waiting times apply to cardiac diseases:

- **In case of established left main stem disease:**
Two weeks from the date when the specialised department received the referral until the date of surgery (revascularisation). The diagnosis must have been established by examining the coronary arteries (coronary arteriography).
- **In case of established unstable angina pectoris:**
Three weeks in all for examining the coronary arteries (coronary arteriography) and performing surgery (revascularisation) from the specialised department received the referral. The referral must come via an intensive care cardiology unit.
- **In case of angina pectoris immediately after acute myocardial infarcts (post-AMI angina):**

A total of five weeks for examining the coronary arteries (coronary arteriography) and performing surgery (revascularisation) from the specialised department received the referral. The referral must come via an intensive care cardiology unit.

Read more about this subject in

- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064 of

6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.

- Ministry of the Interior and Health order no. 1749 of 21 December 2006 on the treatment of patients with life-threatening cancer diseases, etc.
- Ministry of the Interior and Health folder: Maximum waiting times for treatment of cancer and certain cardiac diseases.

Right to information

In connection with treatment at a hospital, you have the right to be thoroughly informed about your illness and treatment. This information must be given individually and in a language you understand.

You must be informed about such things as:

- which disease do you have
- which medical appropriate treatment options exist
- which possible complications and side effects may be involved with examination or treatment
- which options exist in regard to prevention and care
- the possible consequences if you decide against treatment
- the expected outcome of the treatment.

Your right to receive information runs from your first contact with the hospital. We urge you to ask if you do not understand the information you receive – or if you would like to have additional information.

You may also choose not to receive information about your health condition.

You must be informed of the possible consequences in regard to treatment options, including the risk of complications and side effects and if in connection with examination and treatment, you have asked that health

information not be passed on to other health-care professionals and that health information about you should not be obtained from elsewhere.

Personal aide and interpreter

You have the right to have a family member or another person you have chosen to be with you as your personal aide at interviews in the hospital. However, this does not apply for example in connection with surgery, where sterile conditions must be maintained.

The hospital will make an interpreter available if you need translation in connection with your treatment.

Read more about this subject in

- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064 of 6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.
- National Board of Health order no. 665 of 14 September 1998 on information and consent, as well as the passing on of health information etc.
- National Board of Health guideline no. 161 of 16 September 1998 on information and consent, as well as the passing on of health information, etc.

Contact persons

One or two healthcare professionals will be specially linked to your treatment if you have to be hospitalised for more than 24 hours or have to come more than once as an outpatient for treatment. One of the contact persons will be a physician.

Your contact person will interact with the other staff involved in your treatment to ensure compliance with the plan of care.

Furthermore, your contact person will ensure that you are given information and that you are involved in the entire process. If you are moved to another department, another contact person from that department will be assigned.

Read more about this subject in

- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064 of 6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.

Self-determination and consent

You decide about (give your consent to) any offered examination or treatment. This also applies if there is only one treatment option. You may request at any time that the treatment be discontinued.

If the physician changes your treatment, you have the right to be informed accordingly and you must again give your consent to treatment. Your consent may be withdrawn at any time. In such case, the physician will talk to you again and possibly agree on a different treatment.

Children and adolescents

The right to self-determination and consent applies from the age of 15. If you are between 15 and 17, you are able to give consent to treatment yourself. Normally, however, your parents will also be given information and be involved in deciding about the treatment. In some situations, information to your parents may, however, be restricted to take your best interest into account.

If the physician finds that you are not capable of making a decision about treatment yourself, the parent who has custody of you will give consent on your behalf.

If you are under 15, your parent or parents that has/have custody will give the final consent. However, you are entitled to be involved and be given information.

Emergency treatment without consent

In special situations, the physician may start up initial treatment without your consent. This applies for example in life-threatening situations, where immediate treatment of you is required and where you are not able to give or decide about consent.

If you cannot give consent yourself

If you are not able to give consent yourself, e.g. in case of unconsciousness or severe loss of memory, another person must be given information about your healthsituation and make a decision for you.

Normally, this will be your nearest family stepping in and giving consent – that is your spouse, cohabitant, grown children or other relatives. However, it does not have to be a family member; it could also be another person to whom you are closely linked. The healthcare professional will make an assessment of this in the individual case.

If you have no family or guardian, treatment may be carried out if a healthcare professional who has professional insight into the area, but has not previously participated in and will not participate in your treatment, agrees.

However, to the highest extent possible you must be involved in decisions regarding the examination and treatment process.

Special situations

If death is unavoidable in your situation, you may refuse treatment that will merely extend the occurrence of death. If, in this situation you are no longer able to say what your wishes are, the healthcare professional may refrain from starting treatment or from continuing life-extending treatment.

Furthermore, you are entitled to receive the pain medication, sedatives or similar pharmaceuticals that are necessary in order to alleviate your condition even if the administration thereof may advance the time of death.

If you have made up a living will in which you have stated that you do not wish to receive treatment if death is unavoidable in your situation, the physician must respect this. You can read more in the section about living will on page 19.

Read more about this subject in

- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064 of 6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.
- National Board of Health order no. 665 of 14 September 1998 about information and consent, as well as on the passing on of health information etc.
- National Board of Health guideline no. 161 of 16 September 1998 on information and consent, as well as on the passing on of health information, etc.

Staff information to and cooperation with your family

Staff must maintain secrecy, even towards your nearest family.

Nearest family may be your spouse, grown children or parents, but may also be a cohabitant or close friend. It is up to you to determine who may receive information about your health situation.

You will be asked to state and give consent as to whom of your family that staff may speak to and how much they are allowed to say about your admission and illness. You will be

asked the names and telephone numbers of the person or persons you have stated. You may be asked to sign a consent form and you may withdraw your consent any time you so wish.

If you are not able to look after your own interests

Your nearest family or a guardian may give an informed consent for your treatment if you are permanently unable to give consent yourself.

This will be done if you are permanently unable to look after your own interests, e.g. because of long-term illness, a congenital condition or a condition with pervasive, chronic memory loss. You will find more information about such situations in the chapter about self-determination and consent on page 8.

If a member of your nearest family or your guardian looks after your interests for you, this person will be entitled to your rights.

In this situation, the member of your nearest family or your guardian must be informed about your health condition and the treatment options. On your behalf, this person may give consent to treatment on the basis of the information given by the physician.

However, the concrete situation determines the extent to which your family member or guardian may have access to your medical record.

However if by word or action you make it clear that you do not wish to receive treatment, the treatment may not be carried out, regardless of any consent from your family member or guardian.

Incidentally, if the healthcare professional finds that the family member or guardian acts in a way that is clearly to the detriment

of the patient, the healthcare professional may carry out a given treatment, provided the medical officer of health concurs.

Children and adolescents

If you are 15-17 years of age, your parents must be informed about your treatment. More details about the rules on self-determination and consent in regard to the treatment of children and adolescents are printed on page 8.

Special situations

In case of death, the physician may tell the nearest family members the cause of death, unless this is against the interests of the deceased.

Read more about this subject in

- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064 of 6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.
- National Board of Health order no. 665 of 14 September 1998 on information and consent, as well as on passing on health information etc.
- National Board of Health guideline no. 161 of 16 September 1998 on information and consent, as well as on passing on health information etc.
- Ministry of the Interior and Health guideline no. 155 of 14 September 1998 on file access, etc., to health information
- National Board of Health guideline no. 9494 of 4 July 2002 on the secrecy obligation of healthcare professionals – dialogue and interaction with the patient's family.

You may see your medical record (file access)

If you are 15 years of age, you have the right to know what your medical record contains.

The medical record contains information about such elements as:

- Diagnosis
- Progression of the illness
- Outcome of examinations and treatment
- Correspondence with GP, other hospitals, authorities and family members.

Normally, you have the right to see everything that is written in your medical record. The medical record is a tool for the healthcare professionals and may thus be difficult to understand immediately.

You may have a copy of the medical record and if you so wish a physician or another healthcare professional will help you understand the contents of it.

Other people normally have no right to see your medical record, unless you have given them power of attorney to do so. Subsequently, the person to whom power of attorney has been given has access to all or parts of your medical record, depending on the power of attorney you have given.

Recording of your data

For the hospital to give you the best possible treatment, it is necessary to record various items of data about you. This is done in pursuance of the Health Act and the Act on the Processing of Personal Information. Generally, you are entitled to know which information that has been recorded about you.

How to get file access to medical record

If you would like to have access to your medical record, you must request access from the relevant department or healthcare

professional. This can be done orally or in writing. You must be given a response to your request within ten days, or within ten days you must be informed when a decision about your request is expected to be made.

In rare cases, your request for file access to your medical record may be fully or partially declined. This will be done only if crucial considerations for yourself or others make it necessary. A refusal must always be in writing and must always be reasoned. You may complain about the decision to the Patient Complaints Board of the National Health Service (the address is at the back of this guide).

The right to file access and to have a copy of the medical record material comprises for example replies regarding blood samples, examinations and treatment, as well as transcripts from computer-based registers.

The right to file access also comprises entries regarding nursing care. You are entitled to access all documents that concern your treatment process and your illness.

The first copy of the medical record material is free. For subsequent requests, a charge may be made. You may also receive copies of x-rays, but you will be charged the costs of copying x-ray images, audio entries, etc.

Children and adolescents

If you are under the age of 18, the person or persons that have custody will have the right to file access to your medical record – unless considerations for your best interest disallow your parents from having file access. For example, your parents may be refused access to information about birth control, abortion or treatment for venereal diseases.

Read more about this subject in

- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following

Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064 of 6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.

- Ministry of the Interior and Health guideline no. 155 of 14 September 1998 on file access, etc., to health information.
- Act No. 429 of 31 May 2000 on processing personal information.
- Ministry of the Interior and Health order no. 664 of 14 September 1998 on payment for transcripts, computer printouts and photocopies.
- On e-records: www.sundhed.dk and the website of the Capital Region of Denmark www.regionh.dk

Secrecy obligation and passing on health information

All healthcare professionals are obliged to maintain secrecy. This means that healthcare professionals may only pass on information about your health situation and other personal information with your consent.

Passing on health information to other healthcare professionals, your own GP or private practice specialist, without consent

Healthcare professionals may pass on information, including outpatient record entries, to other healthcare professionals, who are currently to be involved in your treatment. This means that if you are transferred to another department or another hospital for treatment, relevant information about your treatment will be passed on.

Your GP or the private practice specialist who referred you for treatment will receive a discharge note from the hospital regarding the treatment you have received, unless you have asked the staff not to send such a discharge note. This also applies if you have

been treated at one of the privately owned specialised hospitals following the rules on free choice of hospital.

If you request that no information be sent about your treatment to other healthcare professionals, you will be informed about the possible consequences in regard to your treatment.

In all other cases it is normally necessary for staff to obtain your consent before they pass on information about the fact that you received treatment at the hospital.

Passing on health information, etc., for purposes other than treatment

Your written consent is required if your health information, etc., is to be passed on for purposes other than treatment, e.g. to other public authorities, your employer, insurance companies or similar.

However, there are certain exceptions, such as:

- processing of certain social cases, e.g. cases about special support for children or adolescents under the Service Act, repayment of social benefits, as well as certain cases in regard to early retirement.
- extraordinary situations in which considerations for you are deemed to have to give way to considerations representing other significant interests, e.g. in the case of investigations of serious crime or if the life or health of others, including your nearest family, is exposed to imminent danger.

If the hospital passes on health information, etc., about you for purposes other than treatment, you have the right to be informed thereof and of the purpose thereof.

Read more about this subject in

- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064

of 6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.

- National Board of Health order no. 665 of 14 September 1998 about information and consent, as well as about passing on health information, etc.
- National Board of Health guideline no. 161 of 16 September 1998 on information and consent, as well as on passing on health information, etc.
- National Board of Health guideline on the secrecy obligation of healthcare professionals - dialogue and cooperation with the patient's family from July 2002.

Retrieval of health information from electronic systems

When you are currently undergoing treatment, GPs, private practice specialists, hospital physicians and other healthcare professionals that participate in your treatment may retrieve the information they need for your treatment from electronic systems.

You have the right to request that information not be retrieved.

Electronic medical record (e-record) at sundhed.dk

From the autumn of 2008, some of the information in your medical record is accessible in electronic format via www.sundhed.dk. You will be able to see the contents of your record from the website www.sundhed.dk, provided you are over 15 years of age and have acquired a digital signature. Record entries will be accessible 14 days after being entered.

If you do not wish that a health care professional during the treatment of you retrieves health information from the electronic medical record on sundhed.dk you need to inform the person hereof.

Recording of the retrieval of electronic information by healthcare professionals

When healthcare professionals retrieve your information, this is always registered electronically. If information about you is retrieved via sundhed.dk, it is possible by using your digital signature to see who retrieved which information and when. The Region carries out sample checks to ensure that the retrieval of information was warranted.

Read more about this subject in

- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064 of 6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.
- Act No. 429 of 31 May 2000 on the processing of personal information as subsequently amended.
- Ministry of the Interior and Health order no. 664 of 14 September 1998 on payment for transcripts, computer printouts and photocopies.
- National Board of Health guideline no. 161 of 16 September 1998 on information and consent, as well as on passing on health information, etc.
- About the e-record: www.sundhed.dk and on the website of the Capital Region of Denmark www.regionh.dk

Use of tissue (biobanks)

As a patient you have the right to decide that your blood and tissue specimens may only be used for your own treatment and for purposes closely associated herewith.

It is up to you to ensure that your decision is recorded in the Tissue Application Register. You must fill in a special form, which must be sent to the Tissue Application Register of the

National Board of Health. You will find the address of the National Board of Health at the back of this guide.

The form is available at the patient office.

Furthermore, you may request

- that your blood and tissue specimens be destroyed
- that the specimens be handed out to you if you are able to demonstrate special interest therein.

However, your request for destruction or hand-over of the specimens may be denied if your interest is deemed to have to give way to decisive considerations for public or private interests. The healthcare professional in charge of storing the specimens will decide if your request can be met.

Read more about this subject in

- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064 of 6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.
- Order no. 966 of 22 September 2004 concerning the Tissue Application Register.
- Ministry of the Interior and Health guideline no. 83 of 22 September 2004 about biobanks.
- Ministry of the Interior and Health folder: Guideline for persons who have had a blood sample or tissue specimen taken after 1 September 2004. The folder also contains the form for recording in the Tissue Application Register.
- The National Board of Health website www.Sundhedsstyrelsen.dk/vaev may be consulted regarding rules for protection of your blood samples and tissue specimens.

Participation in research trials

In connection with your treatment at a hospital, you may be asked if you are prepared to participate in a research trial. Trials are necessary in order to develop new treatments with higher efficacy and with a gentler impact on patients. Before a trial can be launched, it must be approved by a research ethics committee. The committee will assess the contents of the individual trial project and ensure project compliance with legislation.

Right to be informed about the trial

Before you can decide whether you want to participate in a research trial, you must be given adequate information about the trial. You must be informed orally as well as in writing and the information given must contain the following elements:

- the purpose and main contents of the trial, including the methods used in the trial
- possible risks, side effects or drawbacks involved in participating in the trial
- that you are participating in a trial with other patients or trial participants
- whether the division into the trial groups is done by drawing lots
- that participation in the trial is voluntary
- the expected benefit of the trial for you and/or future patients
- which treatment you will receive if you do not participate in the trial
- the economy of the trial if it is financed fully or partially with external grants, eg. from pharmaceutical companies
- the name of a contact person who is able to give further information about participation in the trial.

In research trials with testing of medication the information given must also include the following:

- whether an inactive substance (placebo) or medication not yet approved by the Danish Medicines Agency is part of the trial
- whether there are periods during the trial when you will receive no medication.

You cannot participate in a trial without first giving your written consent. You can always – also during the trial – withdraw your consent and participation in the trial.

You may want to talk to staff and your family about your considerations on participating in a trial. You can always ask for extra time to consider and also request further information having a family member or another person present.

If the trial has an injurious effect

If you are a person of good health, but an injury is inflicted on you in connection with a trial, you can get compensation. Read more at www.patientforsikring.dk

Read more about this subject in

- Act No. 402 of 28 May 2003 on a research ethics committee system and the processing of biomedical research projects.
- Ministry of the Interior and Health order no. 806 of 12 July 2004 on information and consent when including trial persons in biomedical research projects.
- Folder from the Ministry of Research: Before you make up your mind – trial persons for research trials.
- The National Committee on Biomedical Research Ethics www.cvk.sum.dk

Compensation

Compensation for treatment injuries and injuries following adverse events

You can apply to the Patient Insurance Association for compensation if injury is inflicted

on you in connection with examination or treatment.

A healthcare professional who becomes aware of an injury that may qualify for compensation must assist you in reporting the injury.

It is a condition for compensation to be paid that the injury occurred in connection with examination, treatment or participation in biomedical trials, or if you have been a donor.

The compensation scheme applies to injuries occurring after 1 July 1992.

Deadlines for reporting injuries to the Patient Insurance Association

- Injuries occurring on 1 January 2008 or subsequently must be notified within three years after you became aware of the injury
- Injuries occurring in 2007 must be reported within three years after you became aware of the injury
- Injuries occurring before 1 January 2007 must be notified within five years after you became aware of the injury.

You can get compensation if:

- it is to be assumed that an experienced specialist in the field in question would have acted differently, thereby avoiding the injury
- the injury was caused by error or failure in the technical equipment
- the injury could have been avoided by using another equally effective technique or treatment method
- the injury is so serious and rare that it goes beyond what a patient would reasonably have to tolerate in relation to the illness that was the cause of the treatment.

In addition, compensation may be granted if the injury was inflicted through an accident occurring within the perimeter of the hospital

in connection with examination and/or treatment, where the hospital is liable to pay compensation in accordance with the normal compensation rules.

You will only receive compensation from the Patient Insurance Association if your injury is priced at DKK 10,000 or more.

Injuries to patients who subsequently passed away can be notified to the Patient Insurance Association by the patient's family.

Family members that can qualify are the deceased's spouse or cohabitant, as well as children who are minors. They can obtain compensation for loss of breadwinner and for the funeral costs if the death was caused by the injury.

If the injury is priced at less than DKK 10,000, the hospital will only be liable if this is specified in the normal compensation law rules. Claims are barred by limitation after three years.

Claims for compensation for injuries priced at less than DKK 10,000 should be forwarded to the hospital management.

Compensation for injury caused by pharmaceuticals

A special compensation scheme has been established to address physical injury caused by a pharmaceutical handed out after 1 January 1996.

The pharmaceutical must be handed out through a pharmacy, a hospital, a physician or a dentist and must have been used for examination, treatment or similar. The size of the compensation must be in excess of DKK 3,000.

The injury must be reported not later than three years after you became aware of it and ten years at the latest after the pharmaceutical was handed out to you.

Compensation cannot be paid in the case of

natural herbs, homeopathic drugs, vitamin or mineral products, or injury caused by the pharmaceutical not having any effect in relation to the illness.

How to report an injury to the Patient Insurance Association

An injury must be reported to the Patient Insurance Association if you want to apply for compensation for a treatment injury, a pharmaceutical product injury or an injury caused by an accident at the hospital. The insurance claim must be written on a form that is available from the department, the Patient Insurance Association or at the hospital's patient office. Addresses are given at the end of this guide.

The patient office can help with advice and guidance and with completing the claims form for the Patient Insurance Association. You may also ask the patient office to forward your claim to the Patient Insurance Association.

Compensation for dental damage

If you have dental damage in connection with surgery, treatment or examination at the hospital, you may apply for compensation from the Patient Insurance Association.

The Patient Insurance Association will only pay for damage that exceeds DKK 10,000. If the dental damage amounts to less than DKK 10,000, you can report the damage to the hospital.

Read more about the subject in

- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064 of 6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.
- Consolidated Act No. 24 of 24 January 2009 on complaint and compensation access in the health sector.

- Ministry of the Interior and Health order no. 1097 of 12 December 2003 on the scope of cover of the Patient Insurance Act.
- Ministry of the Interior and Health guideline no. 125 of 24 June 1992 on compensation criteria in the Patient Insurance Act.
- The Patient Insurance Association folder: Your right to compensation for injury related to treatment or pharmaceuticals.
- The Patient Insurance Association folder: How do we process your case?
- The Patient Insurance Association folder: How do we calculate your compensation?
- you wish to complain about the work of a healthcare professional in relation to your examination, care and treatment
- you believe something wrong is written in your medical record or in a medical certificate.

The decisions from the Patient Complaints Board represent an assessment of whether the healthcare professional you complained about has lived up to good professional standards in the performance of his or her work.

The Patient Complaints Board also deals with

- complaints concerning your rights as a patient, e.g. right of self-determination, information, file access or breach of secrecy, as well as the right to have the assistance of an interpreter
- decisions concerning the conditions for your right to hospital treatment and your right to transport in pursuance of the Health Act.

Complaints

You have different possibilities of making a complaint, if you as a patient, are dissatisfied with conditions in connection with your admission or the treatment you receive from the healthcare professionals.

Complaint about the hospital service

If you are dissatisfied with your contact with the hospital, your stay at the hospital, waiting times e.g. as an outpatient, or with the staff:

- you may tell the staff directly involved, so that they may immediately try to improve conditions
- you and/or your family may approach the hospital's patient office, which can help you and your family solve problems together with the hospital staff
- you may send a complaint to the management of the department concerned or the hospital management.

Complaints about the work of healthcare professionals

You may send a complaint to the Patient Complaints Board of the National Health Service if:

Complaints about errors by healthcare professionals and complaints about failing compliance with your rights as a patient must be filed with the Patient Complaints Board of the National Health Service within two years of the time when you were aware or should have been aware of the circumstance that is the subject of complaint. However, the deadline is five years after the time when the circumstance you wish to complain about occurred.

The address of the Patient Complaints Board is at the back of this guide.

If you wish to complain to the Patient Complaints Board of the National Health Service about a decision concerning the conditions for your right to hospital treatment or refusal of transport or transport refund for an examination and/or treatment at the hospital, you must forward your complaint about the decision to the agency that made the decision

no later than four weeks after you received the decision.

The agency will then reassess the case. If your complaint is not fully or partially upheld, it will be passed on to the Patient Complaints Board of the National Health Service, which will then make a decision.

Only you yourself or a person with a power of attorney from you – or the family member of a deceased person – may complain to the Patient Complaints Board.

The patient office may assist you and inform you about the right complaint path and possibly help you write your complaint.

You may also ask the patient office to send your complaint to the right agency.

Read more about this subject in

- Consolidated Act No. 24 of 21 January 2009 on complaint and compensation access in the health sector.
- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064 of 6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.
- Folder from the Patient Complaints Board of the National Health Service: Do you wish to complain about the national health service?

Autopsy

In an autopsy, physicians examine the deceased to gain more knowledge about such things as disease mechanisms – and, in case of doubt, to identify the precise cause of death.

Autopsy requires consent

For an autopsy to be performed, legislation specifies that physicians must ask for permission from the surviving family. A medical autopsy of the deceased may only be performed if the deceased had given written consent or if the nearest family has given permission for the autopsy. In this case, oral acceptance is adequate.

The deceased may have made his or her consent dependent on the acceptance of the surviving family. Before the surviving family consents to or accepts the autopsy, they must receive information about the purpose and scope of the autopsy.

If the deceased has granted his or her body to a university as a last will and testament, the nearest family must accept this – and have no right to make objections.

Saying no to autopsy

An autopsy may not be performed if the deceased has refused autopsy or if the autopsy must be deemed to be in conflict with the philosophy of life of the deceased or the nearest family.

Forensic autopsy

In certain situations, e.g. in case of an unexpected death in the home or death in a work accident, the police may request a forensic autopsy following a medico-legal inquest.

Read more about this subject in

- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064 of 6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.
- National Board of Health guideline no. 100 of 7 December 2006 on consent for medical autopsies.

- Ministry of the Interior and Health folder: Make up your mind about autopsy.
- Ministry of Health and Prevention at www.sum.dk

Organ donation

If a patient is declared brain-dead at a hospital, the physician may in some instances ask the nearest family permission to remove one or several organs from the deceased for the purpose of a transplant.

Organ donation requires consent

If physicians wish to remove an organ for transplantation, the physicians must have obtained permission either from the deceased him- or herself or from the nearest family. This permission may be in the form of a written consent in that the patient has joined the Donor Register, or it may be permission from the nearest family.

The family cannot object to a possible organ donation if the deceased has made a decision about this in writing, unless the deceased has decided that the intervention requires acceptance from the family.

The Donor Register has the following request: "Make up your mind – together with your nearest family".

So, please discuss the question of a possible organ donation/transplant with your family:

- Tell your family about your wishes
- Fill in a donor card, which you must carry at all times
- Join the Donor Register.

You may choose to donate one or several organs. You can also decide that the removal of organs is not to be permitted.

You can learn more about organ donation from the staff, the patient counsellor or at the Donor Register. Addresses are printed at the back of this guide.

Read more about this subject in

- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064 of 6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.
- National Board of Health guideline no. 101 of 8 December 2006 on consent to transplant from deceased persons.
- Ministry of the Interior and Health folder: Organ donor. Make up your mind together with your family.
- www.sundhed.dk and www.tagstilling.nu

Living will

In a living will, you can decide that you do not wish to receive treatment merely to extend life if death is unavoidable in your situation. The physician must respect your decision.

You may also state that you do not wish to be treated to extend your life if your illness has caused such severe disablement that you will be permanently unable to take care of yourself and that there is no hope of recovery. In this case, the physician must include your wishes in his or her deliberations concerning treatment.

Your living will only comes into effect if you are irreversibly dying or end in a situation in which you will be permanently unable to take care of yourself physically and mentally. A living will does not allow active euthanasia.

How to write a living will

Fill in a living will form (attached to the living will folder) and send it to the Living Will Register. The charge is DKK 50, which will be collected subsequently on an in-payment

giro form. The living will form is also available at the pharmacy, at your GP's clinic and at the library.

You need not tell your nearest family that you have written a living will. However, it may be a good idea to tell them about the decision, so that they may know your attitude and decision. Your family cannot deny a living will that has been entered in the Living Will Register.

If you have second thoughts

A living will can always be revoked or changed if you have second thoughts about your decision. The living will can be revoked either:

- by writing a letter to the Living Will Register
- by revoking it orally towards a healthcare professional
- by electronically revoking it towards the Living Will Register at www.sundhed.dk provided you have a digital signature.

You can get more information about living will from the staff and at the patient office.

You may also ask for written material from the Living Will Register. The address is given at the back of this guide.

Read more about this subject in

- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064 of 6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.
- Ministry of Health and Prevention order no. 240 of 20 March 2007 on living wills.
- National Board of Health guideline no. 158 of 15 September 1998 on physicians' obligations in regard to the contents of living wills.

- National Board of Health circular no. 157 of 15 September 1998 on physicians' obligations in regard to living wills.
- National Board of Health folder: Living will www.sundhed.dk

Transport and transport refund

You have the right to be transported by ambulance or a specially fitted vehicle for the transport of sick persons if this is necessitated by your health condition.

In all other cases the main rule is that you yourself have to pay for transport from your residence to the hospital and back.

Right to be transported

However, you have the right to be transported or to receive a transport refund if one of the following conditions are met:

- You receive a pension in pursuance of social pension legislation
- You live more than 50 km from the hospital where the necessary treatment can be carried out
- In connection with hospital treatment you are convened for further outpatient treatment or sent home by the hospital on a weekend stay, a short holiday or similar and your physical or mental condition do not allow the use of public transport, including busses, trains and ferries.

If you have the right to be transported and if because of your age or health condition you need a fit companion, your companion may also be transported or receive a transport refund.

Transport – whereto?

You have the right to be transported or to receive a transport refund for travel between your residence and the hospital if you meet one of the above-mentioned conditions and

have been referred following the Region's referral criteria for treatment at one of the Region's own hospitals, or a hospital with which the Region cooperates, or a hospital with specialised functions.

In any event, you must be transported using the cheapest, secure means of transport that your condition allows. Consequently, your health condition decides the mode of transport.

If you are a pensioner and your health permits you to take a bus or train to the hospital, you can get a refund of your expenses for bus or train ticket, provided the amount exceeds DKK 25.

If you have arranged for transport yourself, but would be entitled to be transported, you may have a refund of your costs, but only for the cheapest, secure means of transport and only if the amount exceeds DKK 60. If the distance from your residence to or from the nearest hospital in the Region exceeds 50 km, a transport refund will be granted at the price of the cheapest, secure means of transport, provided the cost of transport to and from the place of treatment exceeds DKK 60.

The rule concerning the right to be transported or to receive a transport refund if the distance is longer than 50 km does not apply, however, if you are temporarily discharged following your own wish.

The Region must pay the cost of transporting patients for hospital treatment and it is the Region that decides whether it wants to offer transportation or a transport refund.

The Region's transport scheme

The Capital Region of Denmark has an agreement with the transport company VBT for sitting transport of patients residing in the Region.

If you live on the island of Bornholm, you are covered by an agreement with the ambulance company Falck concerning sit-

ting transport and Cimber Air concerning air transport for treatment in the Region's other hospitals on the island of Zealand.

Transport – how?

The hospital will arrange for you to be picked up and brought home; often you will be transported together with other patients that are going to the same place for treatment.

Treatment outside the Region

If following referral from a hospital in the Region you are treated outside the Region, you have the right to be transported to the same extent as if you were treated in a hospital in the Region.

If you have the right to be transported for treatment at a hospital in the Region, but use the rules concerning free choice of hospital to choose treatment at a hospital outside the Region, you yourself must pay for the part of the transport that exceeds the length of transport to the Region's hospital.

If you are entitled to be transported because the distance to the Region's hospital exceeds 50 km, however, you are only entitled to a transport refund for treatment at a hospital outside the Region if the distance to that hospital also exceeds 50 km.

You can only receive a transport refund for treatment at a hospital outside the Region if the cost to and from the chosen place of treatment, as well as to and from the Region's hospital, exceeds DKK 25 in all for pensioners and DKK 60 in all for others.

Transport refund

If you wish to apply for refund of the costs of transport in connection with treatment at one of the Region's hospitals, you must approach the hospital where you received treatment.

If you wish to apply for a full or partial refund for the costs of transport in connec-

tion with treatment at a place of treatment chosen by yourself outside the Region, you must send your refund request to the Central Information and Counselling Unit of the Capital Region of Denmark. The address is printed at the back of this guide.

Special rules for Bornholm – treatment outside the island

If you live on the island of Bornholm, you must approach the Patient Travel Office (Patientrejse) at Bornholm's Hospital with your transport request or request for a transport refund in connection with transport to and from treatment at the Region's hospitals on the island of Zealand.

Complaint about refusal

If you wish to complain to the Patient Complaints Board of the National Health Service regarding full or partial refusal of transport or a transport refund, you must forward your complaint not later than four weeks after you have received the decision of the agency that made it. If this agency still finds that you do not have the right to be transported or to receive a transport refund, your complaint will be forwarded to the Patient Complaints Board of the National Health Service.

Read more about this subject in

- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064 of 6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.
- The Ministry of Health and Prevention order no. 867 of 26 August 2008 on the right to be transported or to receive a transport refund in pursuance of the Health Act.

Special aspects and rules in regard to mental health patients

The mental health departments have been segregated from the hospitals and form part of the Mental Health Service of the Capital Region of Denmark.

In a mental health department, you have the same rights as a patient, unless special rules are laid down in the Mental Health Act.

If you are admitted, retained or treated compulsorily in a mental health department, you are assigned a patient advisor, who can advise and counsel you about your rights. In the mental health department, you can get material and more details about your rights in pursuance of the Mental Health Act.

Read more about this subject in

- The Health Act, consolidated act no. 95 of 7 February 2008 as amended following Act No. 319 of 30 April 2008, Act Nos. 538 and 539 of 17 June 2008, Act No. 1064 of 6 November 2008, Act No. 100 of 10 February 2009 and Act No. 288 of 15 April 2009.
- Consolidated act no. 1111 of 1 November 2006 on the use of coercive measures in mental health services
- Ministry of the Interior and Health order no. 1499 of 14 December 2006.
- Ministry of the Interior and Health order no. 1497 of 14 December 2006 on information and complaint counselling of patients in connection with the use of coercive measures in mental health services.
- Ministry of Health and Prevention order no. 787 of 16 July 2008 on the extended right to examination and treatment given to mentally ill children and adolescents, including information about the referral procedure and documentation requirements in regard to agreement-covered hospitals, etc.

Addresses

Donorregisteret (the Donor Register)

Rigshospitalet
(Copenhagen University Hospital)
Unit 9631
Blegdamsvej 9
2100 Copenhagen Ø
Tel.: (0045) 35 45 52 69

Livstestamenteregisteret (the Living Will Register)

Rigshospitalet
(Copenhagen University Hospital)
Unit 9631
Blegdamsvej 9
2100 Copenhagen Ø
Tel.: (0045) 35 45 52 69

Ministeriet for Sundhed og Forebyggelse (Ministry of Health and Prevention)

Slotsholmsgade 10-12
1216 Copenhagen K
Tel.: (0045) 72 26 90 00
E-mail: sum@sum.dk
www.sum.dk

Patientforsikringen (Patient Insurance Association)

Nytorv 5, 3.
1450 Copenhagen K
Tel.: (0045) 33 12 43 43
E-mail: pf@patientforsikringen.dk
www.patientforsikringen.dk

Region Hovedstaden (Capital Region of Denmark)

Kongens Vænge 2
3400 Hillerød
Tel.: (0045) 48 20 50 00
E-mail: regionh@regionh.dk
www.regionhovedstaden.dk

Region Hovedstadens Centrale Informations- og Rådgivningsenhed (Central Information and Counselling Unit of the Capital Region of Denmark)

Rigshospitalet, Unit 7561
Tagensvej 20, Entrance 75, 6th floor
2200 Copenhagen N
Tel.: (0045) 35 45 41 19
E-mail: fritvalg@rh.regionh.dk

Sundhedsstyrelsen (National Board of Health)

Islands Brygge 67
2300 Copenhagen S
Tel.: (0045) 72 22 74 00
www.sst.dk

Sundhedsvæsenets Patientklagenævn (Patient Complaints Board of the National Health Service)

Frederiksborggade 15
1360 Copenhagen K
Tel.: (0045) 33 38 95 00
E-mail: pkn@pkn.dk
www.pkn.dk

Vævsanvendelsesregisteret (the Tissue Application Register)

Sundhedsstyrelsen
(National Board of Health)
Islands Brygge 67
2300 Copenhagen S
Tel.: (0045) 72 22 77 91
www.Sundhedsstyrelsen.dk/vaev

Mental Health Services of the Capital Region of Denmark cater for psychiatric examinations and treatment in the Region. The services consist of 13 mental health centres, as well as three centres for child and adolescent psychiatry.

Treatment is carried out both in bed units, where the patients are admitted, and as outpatient services, where the patient receives treatment during the day. Outpatient treatment is carried out at outpatient clinics at the mental health centres or at district psychiatry centres, as well as by the outreach mental health teams.

Patient counsellor

As a patient or family member at Mental Health Services of the Capital Region of Denmark, you can get further information and guidance from the patient counsellor as a supplement to your contact with the hospital staff.

For example, the patient counsellor can help you if you have questions regarding the free choice of hospital, waiting times, file access, informed consent or complaint paths. Furthermore, the patient counsellor can help you if you have questions regarding private hospitals and clinics. The patient counsellor may also assist in solving misunderstandings between you and the hospital staff.

You may contact the patient counsellor in person at the patient office within the opening hours posted on the website, or you may write a letter, make a phone call, or send an e-mail.

The patient counsellors for the mental health services are connected to the hospitals near which the mental health centres are physically located. You can find your patient counsellor either by asking the staff or by consulting the website of Mental Health Services of the Capital Region of Denmark:
www.psykiatri-regionh.dk/patientvejleder.

Find more information at: www.psykiatri-regionh.dk

Tel.: 45 11 20 00
psykiatri@psv.regionh.dk

Region Hovedstadens Psykiatri
– Mental Health Services of the
Capital Region of Denmark
Kristineberg 3
2100 Copenhagen Ø