

Patient Rights

– a guideline for patients and their family

List of contents

4	1. When you are referred to the hospital/mental health services of the Region
4	Referral for examination and treatment
4	Notice from the hospital
5	Free choice of hospital
6	Extended free choice of hospital
7	Extended right to examination and treatment in the mental health services of the Region
8	Brief information about transport if you use your right of free choice
9	Information about your options and waiting time
9	Treatment guarantee in case of life-threatening cancer diseases, etc.
11	2. Information specifically for patients receiving mental health care
12	3. If you need an interpreter
13	4. If you need a personal aide
13	5. If you need transport
13	Transport and transport cost refund
17	6. Cooperation with the healthcare professionals
17	A healthcare professional primary contact
18	You have the right to receive information
18	Your decision – your consent
20	How staff members cooperate with your family members?
21	7. Help us give you effective and efficient treatment
22	8. Information about you
22	You may see your own patient record (file access)
23	Recording of information about you
23	Who can get information about your health and your private situation?
24	Information about deceased patients
25	Who can retrieve information about your health from electronic systems?
26	9. You may seek compensation and complain
26	Compensation
28	Complaints
32	10. Your right to decide over your body
32	What happens to tissue samples? (bio-banks)
33	Are you prepared to participate in scientific trials?
34	Who decides about autopsy?
35	Who decides about organ donation?
35	How to make a Living Will
38	11. Useful addresses
39	12. Find and use your patient counselor
40	Telephone numbers for the patient counselors of the Capital Region of Denmark

Preface

The Capital Region of Denmark finds it important to give you relevant, understandable information about your rights as a patient.

Patient rights are a matter of your legal rights and thus about the obligations of the national health service towards you as laid down in law. Your rights help ensure that you have an optimal examination and treatment process.

We know it can be difficult to grasp all the many rules that apply in this field; in fact, some of the rules are very complicated. We have thus tried to make the information simple and relevant and we encourage you and your family to study the guideline – and to ask any questions you may have of use if there is something you find difficult to understand. Staff members at the hospital are happy to answer your questions – or to refer you to the right healthcare professional.

As we take you through the rules, we inform you about the formal complaint options; however, you may always contact the management at the department or clinic or mental health center, where you are undergoing treatment, if there is anything you are displeased with. You may also choose to send your complaint to the hospital executive management or the executive management of the Mental Health Services of the Capital Region of Denmark.

You are also welcome to contact the patient counselor. The patient counselor will help you with questions regarding free choice of hospital, access to your own medical records, secrecy obligations, complaint routes, compensation issues and other patient rights.

Furthermore, the Capital Region of Denmark has a central information and counseling unit. This unit caters for information to patients wanting to be referred to another place of treatment where the waiting time is shorter.

You may also seek information about patient rights from other sources:

- At the library,
- Legal information at www.retsinfo.dk,
- National Board of Health website www.sst.dk,
- Ministry of the Interior and Health website www.im.dk,
- www.sundhed.dk.

Telephone number and addresses are at the back of this guideline.

1. When you are referred to the hospital/the Mental Health Services of the Capital Region of Denmark

Referral for examination and treatment

For treatment at a hospital/mental health center, you need a referral from a GP or a private practice specialist.

Notice from the hospital

Not later than eight working days after the hospital/the Mental Health Services of the Capital Region of Denmark has received the referral from your physician, you must be notified about the following:

- the date and time of examination or treatment
- that we are able to examine and/or treat you within one month in case of physical illness or two months in case of mental illness
- that you have the right to choose another public hospital/another mental health center in the Mental Health Services of the Capital Region of Denmark
- that you have the right to choose a private place of treatment if we cannot offer you treatment within one month in case of physical illness or two months in case of mental illness
- that we offer you referral to somewhere else
- the waiting times at the Region's own and other regions' hospital/mental health services, as well as at any private hospitals/private clinics (private hospitals with which an agreement has been concluded)
- where you can go for information about the number of treatments given at public hospitals/mental health centers, as well as any private hospitals/private clinics (private hospitals with which an agreement has been concluded)

You must contact the Central Information and Counseling Unit of the Capital Region of Denmark (cf. Addresses) if you wish to be treated somewhere else that has a shorter waiting time. This Unit is able to tell you about waiting times for treatment all over the country.

Complaint access

You may complain to the Patient Ombudsman if you do not receive this information from the hospital/the Mental Health Services of the Capital Region of Denmark within eight working days.

You must file your written complaint about the lack of timely information to the Patient Ombudsman within four weeks. The complaint deadline normally counts from the time when you were informed about or otherwise became aware of your right to complain.

Incidentally, if special reasons exist, the Patient Ombudsman may process your complaint after the four-week deadline.

Free choice of hospital

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

The free choice of hospital applies to admissions, outpatient care and rehabilitation services.

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/mental health center you have chosen.

In a few cases, your choice is restricted

- If you need emergency treatment, you will be taken to the nearest hospital/mental health service emergency room.
- If you choose to be treated at a department in a public hospital/mental health center outside the Capital Region of Denmark, the department/mental health center you have chosen may refuse to take you in if they do not have a space for you.
- If considerations for your situation as a patient warrant it, your possibility of choosing a mental health service place of treatment may be restricted.
- If you choose to be treated at a hospital department with a highly specialized level and your illness does not require treatment at that level, the department you have chosen may refuse to take you in.

Complaint access

You may complain to the Patient Ombudsman about decisions regarding your free choice of hospital.

You must file your written complaint about the decision to the Patient Ombudsman within four weeks after you have received the decision. However, if special reasons exist, the Patient Ombudsman may process your complaint after the four-week deadline.

Extended free choice of hospital

Waiting time longer than one month

The extended free choice of hospital means that in certain cases you may choose to be treated at a private hospital/private clinic (private hospital with which an agreement has been concluded).

The possibility of choosing to be referred for examination and treatment to a private hospital/private clinic in this country or abroad depends on the waiting time at the hospital in the Capital Region of Denmark to which you have been referred. If we cannot offer you examination and treatment within one month at one of the Region's hospitals or one of the hospitals with which the Region cooperates (private hospitals/public hospitals in another region with which the Capital Region of Denmark has concluded an agreement) you have the possibility of choosing one such other facility.

The private hospital/private clinic that you choose must, however, have concluded an agreement with Danish Regions to carry out the examination or treatment that you will be going for.

The waiting time at the private hospital/private clinic may not be longer than the waiting time at the Region's hospitals or the hospitals with which the Region cooperates.

The waiting time runs from the time when the Region's hospital received the referral.

Complaint access

You may complain to the Patient Ombudsman about decisions regarding extended free choice of hospital (decisions on referral for treatment at a private hospital/private clinic, e.g. a hospital with which an agreement has been concluded).

You must file your written complaint about the decision to the Patient Ombudsman within four weeks after you have received the decision. However, if special reasons exist, the Patient Ombudsman may process your complaint after the four-week deadline.

Cancellation of surgery

If the hospital changes the date of your planned surgery, you have the right to be referred to a private hospital/private clinic which has concluded an agreement with Danish Regions about the surgery you are going in for. The waiting time at the private hospital/private clinic need not be shorter than the

waiting time at the Region's hospitals or at the hospitals with which the Region cooperates. Staff at the department will inform you about your options.

Extended right to examination and treatment in the Mental Health Services of the Capital Region of Denmark

Children and adolescents

Children and adolescents who are not yet 19 at the time of referral have the possibility of being referred for examination at private mental health clinics (hospitals with which an agreement has been concluded).

The possibility of being referred for examination at private mental health clinics depends on the waiting time at the child and adolescent mental health center of the Mental Health Services of the Capital Region of Denmark to which the child or adolescent has been referred. If the Mental Health Services of the Capital Region of Denmark cannot offer an examination within two months at one of the Region's child and adolescent mental health centers or another relevant department, the parents/custody holder of the child or adolescent person will be given the option of a choice.

The selected private mental health clinic must have concluded an agreement with Danish Regions to carry out the examination which is to be given to the child or adolescent person.

The waiting time at the private mental health clinic may not be longer than the waiting time at the Region's child and adolescent mental health center or another relevant department.

The waiting time runs from the time when the Mental Health Services of the Capital Region of Denmark received the referral.

If, at the examination at a private clinic, it turns out there is a need for quick treatment to avoid a worsening of the disease, the parents/custody holds of the child or adolescent person may choose to have such treatment at the same place where the examination was carried out if, the Region cannot offer treatment at one of the Region's child and adolescent mental health centers or another relevant department within two months from completion of the examination.

Regardless of whether the Mental Health Services are able to offer treatment within two months, the parents/custody holder of the child or adolescent person may choose treatment at the private clinic where the examination was carried out, provided treatment at that facility can be offered as an immediate extension to the examination, i.e. not later than ten days after the examination was completed.

Adults

If you suffer from a mental illness and are 19 or above at the time of referral, you may choose to be referred for examination and treatment at a private mental health clinic (hospital with which an agreement has been concluded) at home or abroad.

The possibility of being referred for examination at private mental health clinics depends on the waiting time at mental health center of the Mental Health Services of the Capital Region of Denmark to which the child or adolescent has been referred. If the Mental Health Services of the Capital Region of Denmark cannot offer you examination and treatment within two months at one of the Region's mental health centers or another relevant department, you will be given the option of a choice.

The selected private mental health clinic must have concluded an agreement with Danish Regions to carry out the examination which is to be given to you.

The waiting time at the private mental health clinic may not be longer than the waiting time at the Region's mental health center or another relevant department.

The waiting time runs from the time when the Mental Health Services of the Capital Region of Denmark received the referral.

Complaint access

You may complain to the Patient Ombudsman about decisions regarding the extended right to examination and treatment in the mental health services.

You must file your written complaint about the decision to the Patient Ombudsman within four weeks after you have received the decision. However, if special reasons exist, the Patient Ombudsman may process your complaint after the four-week deadline.

Brief information about transport if you use your right of free choice

If you choose to be referred either to another hospital/mental health center in the Capital Region of Denmark or to a public hospital/mental health center outside the Region in accordance with the rules on free choice of hospital, or a private hospital or private clinic (hospital with which an agreement has been concluded) at home or abroad in accordance with the rules on extended free choice of hospital or extended right to examination and treatment in mental health services, you will have to arrange your own transport to get to the examination and treatment. You find more information about the transport rules and the possibilities of getting a transport refund on page 13 of this guideline.

Information about your options and waiting times

You will receive information about your specific options when it comes to choosing examination and treatment at a private hospital/private clinic/private mental health clinic approaching the Central Information and Counseling Unit of the Capital Region of Denmark (cf. Addresses). You may do so by completing and sending in the form which is enclosed with the notice letter you receive.

The Information and Counseling Unit is the unit that can refer you for examination and treatment at a private hospital/private clinic/private mental health clinic.

You may phone or write to the Information and Counseling Unit to receive information about waiting times for examination and treatment and to learn to which other public hospitals and mental health centers in the Capital Region of Denmark and other regions you may choose to be referred.

Information on cooperation hospitals, private hospitals, private clinics and agreements

The hospitals with which the Capital Region of Denmark cooperates can be seen on the Region's website www.regionh.dk. The private hospitals and private clinics that have concluded an agreement with Danish Regions can be seen at www.sygehusvalg.dk. This website will also tell you the examinations and treatments for which agreements have been concluded.

Treatment guarantee in case of 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 treatment, and no more than four weeks after the department who will take care of your treatment received the referral.

- **Radiation therapy as primary treatment:**

Four weeks after the department who will take care of your treatment received the referral.

- **Radiation therapy as follow-on treatment:**

Four weeks after the department who will take care of your treatment 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.

Complaint access

You may complain to the Patient Ombudsman about decisions concerning the treatment guarantee.

You must file your written complaint about the decision to the Patient Ombudsman

within four weeks. The complaint deadline normally runs from the time when you were informed about or otherwise became aware of your right to complain.

However, if special reasons exist, the Patient Ombudsman may process your complaint after the four-week deadline.

Read more about it:

- Danish Health Act, Consolidated Act No. 913 of 13 July 2010, most recently amended by Act No. 1546 of 21 December 2010.
- Ministry of Health and Prevention Executive Order No. 62 of 20 January 2010 on hospital treatment rights, etc.
- Ministry of Health and Prevention Guideline No. 48 of 29 June 2009 on extended free choice of hospital and information to referred patients.
- Ministry of Health and Prevention Executive Order No. 787 of 16 July 2008 on extended right to examination and treatment for mentally ill children and adolescents, including referral procedure and documentation requirements from hospitals with which an agreement has been concluded, etc.
- Ministry of Health and Prevention Executive Order No. 1542 of 27 December 2009 on extended right to treatment for mentally ill adults, including referral procedure and documentation requirements from hospitals with which an agreement has been concluded, etc.
- Ministry of Health and Prevention folder: Choice of hospital
- Ministry of the Interior and Health Executive Order No. 1749 of 21 December 2006 on treatment of patients with life-threatening cancer diseases, etc.
- Ministry of the Interior and Health folder: Maximum waiting times for treatment for cancer and certain heart diseases.
- Consolidated Act No. 24 of 21 January 2009 on complaint and compensation access in healthcare. Subsequently amended by Act No. 706 of 25 June 2010.

2. Information specifically for patients receiving mental health care

The Mental Health Services of the Capital Region of Denmark consist of a number of mental health centers which carry out the public hospital-based treatment of mental illnesses in the Capital Region of Denmark.

At a mental health center of the Capital Region of Denmark, you have the same rights as other patients, unless reasons exist why the special rules of the Danish Mental Health Act are to be applied.

If you are admitted, retained or treated with coercive measures, a patient counselor will be allocated to you. The patient counselor will provide guidance and advice on your rights and on all matters relating to your admission, stay and treatment at a mental health center. The patient counselor will also assist you if you wish to complain. At the mental health center, you can get material and more information about your rights under the Danish Mental Health Act.

Read more about it:

- Danish Health Act, Consolidated Act No. 913 of 13 July 2010, most recently amended by Act No. 1546 of 21 December 2010.
- Consolidated Act No. 1729 of 2 December 2010 on the use of coercive measures in mental health services.
- Ministry of the Interior and Health Executive Order No. 1341 of 2 December 2010 on patient counselors.
- Ministry of the Interior and Health Executive Order No. 1343 of 2 December 2010 on information to and complaint guidelines for patients in connection with the use of coercive measures in mental health services.

3. If you need an interpreter

The hospital will provide an interpreter if required in connection with your treatment. From 1 June 2011, you may be charged for the assistance of an interpreter if you have lived in Denmark for more than seven years.

Complaint access

You may complain to the Patient Ombudsman about decisions regarding assistance from an interpreter.

You must file your written complaint about the decision to the Patient Ombudsman within four weeks. The complaint deadline normally counts from the time when you were informed about or otherwise became aware of your right to complain.

However, if special reasons exist, the Patient Ombudsman may process your complaint after the four-week deadline.

Read more about it:

- Danish Health Act, Consolidated Act No. 913 of 13 July 2010, most recently amended by Act No. 1546 of 21 December 2010.
- Ministry of the Interior and Health Executive Order No. 1339 of 8 December 2006 on interpreting assistance in pursuance of the Danish Health Act.

- Consolidated Act No. 24 of 21 January 2009 on complaint and compensation access in healthcare services. Subsequently amended by Act No. 706 of 25 June 2010.

4. If you need a personal aide

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.

5. If you need transport

Transport and transport cost refund

As mentioned in the preface, some rules are rather complicated; the rules about transport and transport cost refund are among them. We will now take you through the rules. If you have any queries, please contact the department/clinic or mental health center. Some hospitals have dedicated transport offices. You may also approach a patient counselor with any queries you may have about transport and transport cost refund.

As a main rule, you must arrange and pay for transport yourself if you are going in for treatment to a hospital or mental health center.

However, you may be entitled to transport or transport cost refund in accordance with the rules explained below.

Right to be transported or right to transport cost refund – who has these rights?

You have the right to be transported between your home and the hospital/the mental health center or to receive transport cost refund, if you were referred in accordance with the Region's triage criteria and you comply with one of the conditions outlined below:

- You receive a pension under social pension legislation.
- You live more than 50 km from the hospital/mental health center where the necessary treatment can be carried out
- You are called in for further outpatient treatment in connection with hospital treatment/mental health treatment or you are temporarily sent home by the hospital/mental health center and your physical or mental condition excludes the use of public transport.

The hospital/mental health center decides whether you are to be offered transport or whether you will be able to take care of your own transport. This is based on a healthcare professional assessment.

If you have been referred on the basis of the triage criteria of the Capital Region of Denmark to one of the Region's own hospitals/mental health centers, one of the Region's cooperation hospitals, or a hospital department with highly specialized functions, you have the same right to transport and transport cost refund as stated above.

Transport cost refund - minimum amounts

If you have the right to be transported, but you organize your own transport to and from the hospital/mental health center, you qualify for a transport cost refund, provided:

- you are a pensioner and your transport cost exceeds a total of DKK 25 (return).
- you have more than 50 km to the nearest hospital/mental health center in the region and your transport cost exceeds a total of DKK 60 (return).
- you have the right to be transported if you are called in for further outpatient treatment in connection with hospital treatment/mental health center treatment, or you are sent home by the hospital/center for a weekend stay, a brief holiday or similar, and your transport costs exceed a total of DKK 60 (return).

The transport cost refund corresponds to the cost of transport by the cheapest mode of transport that is responsible given the circumstances.

A transport cost refund can be given for the use of public transport, including bus, train and ferry, as well as for taxi, private vehicle, etc.

Transport and transport cost refund – how?

If you have the right to be transported, the hospital/mental health center will arrange for your transport from your home to the hospital/center and back. Transport will often be together with other patients who are going to the same place for treatment.

You must contact the department/clinic/center to hear about your possibilities of being transported or having a transport cost refund.

If you have the right to transport and if the department/clinic/center decides that you are able to arrange your own transport, you must apply for a transport refund at the hospital/center at which you are being treated or have been treated.

If you live in the island of Bornholm and you are going to one of the hospitals/centers of the Capital Region of Denmark on the island of Zealand, you must approach the Patient Travel office at Bornholm Hospital to learn more about transport and transport refund (cf. Addresses).

If you have chosen to be treated at a public hospital/mental health center outside the Capital Region of Denmark or at a private hospital/a private mental health clinic, you must send your application for transport cost refund to the Central Information and Counseling Unit of the Capital Region of Denmark (cf. Addresses).

Transport and transport cost refund – one hospital/mental health center refers you for treatment at another hospital/mental health center

If a hospital/mental health center in the Capital Region of Denmark refers you for treatment to another regional hospital/mental health center, you have the right to be transported or received transport cost refund to the same extent as above. This applies no matter if you were referred to a hospital/mental health center inside or outside the Capital Region of Denmark.

Transport and transport cost refund – free and extended free choice of hospital

If you have been referred to a hospital/mental health center on the basis of the triage criteria of the Capital Region of Denmark and you have the right to be transported to the treatment, but you yourself choose to be treated at:

- another regional hospital/mental health center of the Capital Region of Denmark or another region, or
- a private hospital/a private clinic (hospitals with which an agreement has been concluded),

you must pay for the difference in transport length compared with the Region's hospital/mental health center to which you were originally referred. This also applies when the physician/specialist has referred you to another hospital/mental health center than the one to which you were supposed to have been referred according to the Region's triage guidelines, since this is a situation in which a free choice of hospital has been applied.

If you have the right to be transported, because the distance from the home to the regional hospital exceeds 50 km, you only have the right to receive a transport cost refund for treatment at a hospital/mental health center outside the Region if the distance between your home and the hospital/center you have chosen is still over 50 km.

If you choose treatment at a hospital/mental health center outside the Region, you qualify for a transport cost refund, provided that:

- your transport costs to and from treatment at a hospital/mental health center in the Region would have exceeded a total of DKK 25 for pensioners and a total of DKK 60 for others, and

- your actual cost of transport to and from treatment outside the Region exceeds a total of DKK 25 for pensioners and a total of DKK 60 for others.

You must send your application for a transport refund concerning treatment outside the Region to the Central Information and Counseling Unit of the Capital Region of Denmark (cf. Addresses).

Transport schemes of the Capital Region of Denmark

The Capital Region of Denmark has a contract with carriers VBT to transport patients who reside in the Region.

If you live in the island of Bornholm and will be coming for treatment to one of the hospitals/mental health centers of the Capital Region of Denmark on the island of Zealand, you are covered by a transport agreement with Falck ambulance service and a flight transport agreement with Cimber Air.

Escort

If you have the right to be transported and if because of your age or health condition you need a healthy escort, the escort also qualifies for transport or transport cost refund.

The hospital/mental health center will decide if you have the right to have an escort.

Complaint over refusal

You may complain to the Patient Ombudsman over decisions that concern transport or transport cost refund.

You must file your written complaint about the decision to the Patient Ombudsman within four weeks after you have received the decision. However, if special reasons exist, the Patient Ombudsman may process your complaint after the four-week deadline.

If, following an examination or treatment at a hospital or a mental health center, you wish to complain that the hospital/mental health center did not offer you transport, the complaint deadline normally runs from the time when you were informed about or otherwise became aware of your right to complain.

If you wish to complain about a refusal of a request for transport cost refund, the complaint deadline runs from the time when you received the decision to refuse transport cost refund.

If you are dissatisfied with the way your transport was handled, please contact the hospital/mental health center.

Read more about it:

- Danish Health Act, Consolidated Act No. 913 of 13 July 2010, most recently amended by Act No. 1546 of 21 December 2010.
- Ministry of Health and Prevention Executive Order No. 1496 of 16 December 2009 on the right to be transported or receive a transport cost refund in pursuance of the Danish Health Act.
- Consolidated Act No. 24 of 21 January 2009 on complaint and compensation access in healthcare services. Subsequently amended by Act No. 706 of 25 June 2010.

6. Cooperation with the healthcare professionals

A healthcare professional primary contact

If you are coming in for more than two treatments as an outpatient, or if you are to be admitted to a hospital/mental health center for more than two days, one or more healthcare professionals will be connected especially with your treatment. If your treatment period is shorter than two days, you will be offered a primary contact if you have a special need for one. The physician who treats you will assess whether you have a special need for a primary contact.

Your primary contact will interact with the other staff involved in your treatment to ensure compliance with the plan of care. Furthermore, your primary contact will ensure that you are given information and that you are included in the entire process.

The same day that the hospital/mental health center offers you a primary contact, the hospital/mental health center must inform you verbally and in writing about the name and function of your primary contact.

If you are transferred to another department/another unit at a mental health center, another primary contact will be assigned to you at this new department/center.

Complaint access

You may complain to the Patient Ombudsman about decisions regarding a primary contact.

You must file your written complaint about the decision to the Patient Ombudsman within four weeks after you have received the decision. However, if special reasons exist, the Patient Ombudsman may process your complaint after the four-week deadline. If, after examination or treatment at a hospital or a mental health center, you wish to complain that the hospital/mental health center did not offer

you a primary contact, the complaint deadline normally runs from the time when you were informed about or otherwise became aware of your right to complain.

You have the right to receive information

In connection with treatment at a hospital/mental health center, you have the right to receive thorough information about your illness and your treatment. This information must be given individually and in a language you understand.

You must be given information about such elements as:

- which disease do you have
- which treatment options exist
- which possible complications and side effects may result from examination or treatment
- which options exist for prevention and care
- which consequences may result if you do not wish to receive treatment
- the expected treatment outcome

This right to receive information is valid from your first contact with the hospital/ the Mental Health Services of the Capital Region of Denmark. We encourage you to ask if you do not understand the information you are given, or if you would like to know more.

If there is information about your health condition you do not wish to receive, you may inform staff that you do not want such information.

Your decision – your 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. This can be done verbally or in writing. 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 special 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, your parents or the parent who has custody of you will give consent on your behalf.

If you are under 15, your parents or the parent who has custody of you 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

To the highest extent possible, you must be involved in decisions concerning examinations and treatment.

However, if you are not able to give consent yourself, e.g. if you are unconscious, have severe memory loss, severe dementia or a psychosis, another person must be given information about your health and give consent on your behalf.

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.

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 36.

How staff members cooperate with your family members?

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, and other private matters.

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, e.g. in case 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 on your decision – your consent, on page 18.

If a member of your nearest family or your guardian looks after your interests for you, this person will be entitled to your rights. However, the healthcare professionals will make a specific assessment of the extent to which your nearest family or guardian may have access to your medical records.

In such situations, your nearest family or guardian must receive information about your state of health and treatment options; the person or persons concerned may then give consent to the treatment on your behalf.

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. In such case, the officer of health is involved and his or her acceptance is required.

Children and adolescents

If you are between 15 and 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 18.

Read more about it:

- Danish Health Act, Consolidated Act No. 913 of 13 July 2010, most recently amended by Act No. 1546 of 21 December 2010.
- National Board of Health Executive Order No. 665 of 14 September 1998 on information and consent and on the exchange of health information, etc.
- National Board of Health Guideline No. 161 of 16 September 1998 on information and consent and on the exchange of health information etc.
- Ministry of the Interior and Health Guideline No. 155 of 14 September 1998 on access to your own medical records, etc.
- National Board of Health Guideline No. 9494 of 4 July 2002 on the secrecy obligation of healthcare professionals – dialog and cooperation with the patient's family.
- Consolidated Act No. 24 of 21 January 2009 on complaint and compensation access in healthcare services. Subsequently amended by Act No. 706 of 25 June 2010.

7. Help us give you effective and efficient treatment

For us to organize effective and efficient treatment of you, we ask you to:

- keep your agreements concerning your treatment and on agreed outpatient visits, examinations and operations.
- inform us in advance if you cannot come.
- inform us about all medication you are on, when you come in for examination or treatment. This may be OTC medication, natural herbs, dietary supplements, etc. This may have substantial impact on the medical treatment ordered for you by the physician.
- inform the physician if you have not taken the medication which the hospital or your own GP prescribed for you.

8. Information about you

You may see your own patient record (file access)

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

The record contains information, such as:

- Diagnosis
- Progression of the illness
- Results of examinations and treatment
- Correspondence with your GP, other hospital/mental health centers, authorities, your family members.

Normally, you have the right to see everything that is written in your medical record. A copy of the record material comprises such elements as entries concerning nursing, the result of blood tests, examinations and treatment, plus transcripts from computer registers. You may also receive a copy of X-rays; however, you will have to pay the costs of making copies of X-rays, audiotapes, etc.

You may see your record electronically, review it in the department following agreement, or you may have a copy of the record. The first copy of your medical record is free. If you wish more than one copy, a charge may be collected.

The medical record is a tool for the healthcare professionals and may thus be difficult to understand immediately. If you so wish, a physician or another healthcare professional will help you understand the contents of it.

Unless you have issued a power of attorney, only healthcare professionals involved in your examination and treatment have the right to see your medical record.

Children and adolescents

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

What to do

If you would like to have access to your medical record, you must request access from the relevant department/mental health center or healthcare professional. This can be done orally or in writing.

In regard to record information from before 1 January 2010, you may in rare

cases be denied access, wholly or in part. This will only occur if this is necessary out of consideration for you or others. Furthermore, parents' access to the record of a minor may be restricted if this is deemed crucial out of consideration for the minor.

The department/mental health center will decide on your request for a copy of your record. You must be given a reply to your request within ten days, or within ten days you must be informed when the department expects to reach a decision. If your request for access to your own file is denied, such refusal must always be in writing and must be reasoned. See chapter 9.

You may complain about the decision to the Patient Ombudsman (cf. Addresses).

Recording of information about you

For the hospital/the Mental Health Services of the Capital Region of Denmark to give you the best possible treatment, it is necessary to record various pieces of information about you. This is done in pursuance of the Danish Health Act and the Personal Information Act. You normally have the right to learn which information has been recorded about you.

Who can get information about your health and your private situation?

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 of health information to other healthcare professionals your own GP or a private practice specialist in connection with your treatment

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/mental health center 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/mental health center regarding the treatment you have received, unless you have asked the staff of the department/mental health center not to send such a discharge note.

This also applies if you were treated at one of the Region's cooperation hospitals (private or public hospitals with which the Region has concluded an agreement) or an agreement hospital (private hospitals/private clinics which have concluded an agreement with Danish Regions).

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 or are receiving treatment at the hospital/mental health center.

If you request that information about your treatment not be passed on to other healthcare professionals, you will be informed of the possible consequences for your treatment.

Passing on of 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/mental health center passes on health information, etc., about you for purposes other than treatment, you have the right to be informed thereof and of the purpose of passing on such information.

Information about deceased patients

If a patient dies at the hospital or mental health center, the physician may speak to the nearest family members about the progression of the disease, the cause of death and the way death occurred. Prior to this, the physician must assess whether giving this information to the nearest family would constitute an infringement of the interests of the deceased person, etc.

The physician may give more information about the deceased patient if the nearest family provides substantial reasons why this should be done.

Who can retrieve information about your health from electronic systems?

When you are undergoing a treatment process, it is possible for GPs, private practice specialists, physicians at hospitals and in the mental health services as well as other healthcare professionals, who participate in the ongoing treatment of you to retrieve the information they need for your treatment.

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

Electronic medical record, e-record at sundhed.dk

From 1 October 2008 onwards, your record data concerning hospital treatment or mental health treatment have been transferred to the e-record, which is a national, electronic medical record located at www.sundhed.dk. GPs, private practice specialists, physicians and hospitals and in mental health services, as well as other healthcare professionals are able to retrieve the information required for your current treatment from that source. You may request that the treating physician or other treating healthcare professional does not retrieve data from your e-record. You can access your own medical record data at www.sundhed.dk, provided you have the NemID (easy access password system) or a digital signature. Information is available to you 14 days after it has been entered.

Recording of the retrieval of electronic information by healthcare professionals

When healthcare professionals retrieve your information, this is always registered electronically. If your information is retrieved via sundhed.dk, you can use your NemID or digital signature to see who obtained what information and when. The Region does sampling to check that the retrieval of information was warranted.

Read more about it:

- Danish Health Act, Consolidated Act No. 913 of 13 July 2010, most recently amended by Act No. 1546 of 21 December 2010.
- Act No. 429 of 31 May 2000 on processing of personal information, as amended.
- Ministry of the Interior and Health Guideline No. 155 of 14 September 1998 on access to your own medical records, etc.
- Ministry of the Interior and Health Executive Order No. 664 of 14 September 1998 on changes for transcripts, prints and photocopies.
- National Board of Health Executive Order No. 665 of 14 September 1998 on information and consent for the exchange of health information, etc.
- National Board of Health Guideline No. 161 of 16 September 1998 on information and consent and the exchange of health information etc.
- On the electronic medical record: www.sundhed.dk and the Capital Region's website www.regionh.dk
- Consolidated Act No. 24 of 21 January 2009 on complaint and compensation access in healthcare services. Subsequently amended by Act No. 706 of 25 June 2010.

9. You may seek compensation and complain

Compensation

Compensation for injuries related to treatment or following accidents

You can apply to the Patient Insurance Association if you find that injury has been inflicted upon you in connection with examination or treatment. This also applies to dental injuries.

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.

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

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 qualify for 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.

Furthermore, compensation may be paid if the injury was caused by an accident. The accident must have occurred on the grounds of the hospital/mental health center in connection with examination and/or treatment, where the hospital/mental health center 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.

Compensation amounts below DKK 10,000

If the compensation amount is calculated to be below DKK 10,000, the hospital/ the Mental Health Services of the Capital Region of Denmark may still be liable to pay compensation if this results from using the normal compensation law rules. You must forward your claim for compensation for injuries calculated at less than DKK 10,000 to the hospital's executive management/the executive management of the Mental Health Services of the Capital Region of Denmark. Such claims are barred by limitation after three years.

Compensation regarding deceased patients

Injury to patients who subsequently passed away may be reported to the Patient Insurance Association by the surviving family. The surviving family that may qualify for compensation is the deceased person's spouse or cohabitant, as well as minor children. If the death was caused by injury, compensation may be paid for loss of breadwinner and for the costs of the funeral.

Compensation for injury caused by pharmaceuticals

A special compensation scheme has been established to address physical injury caused by a pharmaceutical, which

- was handed out after 1 January 1996.
- was handed out through a pharmacy, hospital/mental health center, physician or dentist.
- was used for examination, treatment or similar.

You will only receive compensation from the Patient Insurance Association if the compensation amount is DKK 3,000 or more.

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 mental health center.

You may report your injury by filling in a pre-printed form, which is available from the department, the Patient Insurance Association, or the patient counselor (cf. Addresses). You must send your claim to the Patient Insurance Association or the Patient Ombudsman.

The patient counselor may help and guide you when you fill in the claims form for the Patient Insurance Association. You may also ask the patient counselor to forward the claims form for you.

Read more about it:

- Consolidated Act No. 24 of 21 January 2009 on complaint and compensation access in healthcare services. Subsequently amended by Act No. 706 of 25 June 2010.
- Ministry of the Interior and Health Executive Order No. 1097 of 12 December 2003 on the areas covered by patient insurance.
- Ministry of the Interior and Health Guideline No. 125 of 25 June 1992 on compensation criteria in the Patient Insurance Act.
- Patient insurance folder: Your right to compensation for injuries from treatment or drugs.
- Patient insurance folder: How do we process your case?
- Patient insurance folder: How do we calculate your compensation?

Complaints

You have different possibilities when it comes to making a complaint. You may complain if you are dissatisfied with the service of the hospital/the mental health center, with the professionalism of a specific healthcare professional, the professional activities of the healthcare system, or with a decision concerning the rights you have in pursuance of the Danish Health Act.

Complaints about the hospital service

If you are displeased with your contact to the hospital/the mental health center, the level of service, the level of courtesy, the physical framework or the food:

- 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 counselor, who can help you and your family solve problems together with the staff of the hospital/mental health center

- you may send a complaint to the Directors of the department/mental health center or the hospital executive Directors/the executive Directors of the Mental Health Services of the Capital Region of Denmark.

Complaint about the professionalism of a specific healthcare professional

You may complain to the Disciplinary Board of the National Health Services (cf. Addresses) about the professionalism of a specific healthcare professional in connection with your examination, nursing or treatment. The Disciplinary Board of the National Health Services also processes complaints about specific healthcare professionals who did not respect your rights as a patient, e.g. the right to self-determination, patient involvement, information or breach of secrecy obligations. The Disciplinary Board of the National Health Services processes the complaint, but you must send your complaint to the Patient Ombudsman.

The Disciplinary Board of the National Health Services will decide whether the person you are complaining about lived up to good professional standards in the performance of his or her work. The decisions of the Disciplinary Board of the National Health Services cannot be appealed to other administrative authorities.

Complaints about the professional activities of the healthcare services

You may complain to the Patient Ombudsman (cf. Addresses) about the healthcare professional activities of the healthcare services, i.e. how the healthcare services handled your treatment/your treatment process from a professional perspective. The Patient Ombudsman will assess whether the healthcare services lived up to good professional standards.

The Patient Ombudsman also processes complaints about compliance by the healthcare service of your rights as a patient. These include the right of self-determination, patient involvement, information, access to your own medical record, breach of secrecy obligations, and complaints regarding transplants.

Choice between complaining about the professionalism of a specific healthcare professional or the professional activities of the healthcare services

If you are uncertain as to whether you wish to complain about the professionalism of a specific healthcare professional or the professional activities of the healthcare services, you should pay attention to the following:

- If you complain about a specific healthcare professional, you cannot subsequently complain about the professional activities of the healthcare services. This applies no matter if your complaint about a specific healthcare professional is upheld or not.
- If you complain about the professional activities of the healthcare services

and your complaint is upheld, you may subsequently complain about a specific healthcare professional.

- If you complain about the professional activities of the healthcare services and your complaint is not upheld, you cannot subsequently complain about a specific healthcare professional.

Dialog – if you complain about a specific healthcare professional or the professional activities of the healthcare services

When you have complained in writing to the Patient Ombudsman or the Disciplinary Board of the National Health Services about the professionalism of a specific healthcare professional or the professional activities of the healthcare services, you will be offered a meeting with the healthcare professionals of the hospital/mental health center within four weeks. The purpose of this meeting is to clarify and answer your questions and clear up any misunderstandings comprised by your complaint. After the meeting it is up to you whether you wish to maintain your written complaint. If you maintain your written complaint, the processing of your complaint by the Patient Ombudsman or the Disciplinary Board of the National Health Services will continue.

Deadlines for complaints about a specific healthcare professional or the professional activities of the healthcare services

There are deadlines for complaints about a specific healthcare professional, the professional activities of the healthcare services, and complaints about non-compliance with your rights as a patient. The Patient Ombudsman must receive your complaint within two years of the time when you knew or should have known about the matter which is the subject of your complaint. The latest deadline for a complaint is five years after the time when the matter that is the subject of your complaint occurred.

Complaints about other decisions regarding rights in pursuance of the Danish Health Act

You may complain to the Patient Ombudsman (cf. Addresses) about decisions regarding the following rights, which are comprised by the Danish Health Act.

- Interpreting assistance
- Treatment from private practice physicians, specialists, dentists, chiropractors, physiotherapists, chiropodists, psychologists, eyeglasses for children.
- Terms for the right to hospital treatment
- Free and extended free choice of hospital, extended right to examination and

treatment for mentally ill children and adolescents, and extended right to treatment for mentally ill adults.

- Maximum waiting times for treatment of life-threatening diseases (the treatment guarantee)
- Treatment abroad, including highly specialized treatment, research-related treatment and experimental treatment
- The Region's obligation to provide information about time and place of treatment, free choice, etc.
- Primary contact at the hospital/mental health center
- Amount for personal needs
- Subsidy for nutritional products
- Home transport of deceased patients
- Subsidy for dental care of cancer patients
- Subsidy for goods and services (treatment from physicians, specialists, dentists, chiropractors, physiotherapists, chiropodists, psychologists, eyeglasses for children) in another EU/EEA country
- Transport and transport cost refund in case of treatment at a hospital or mental health center
- Refund of costs of hospital treatment/mental health treatment in another EU/EEA country

You must file your written complaint about the decision with the Patient Ombudsman within four weeks after you received the decision. However, if special reasons prevail, the Patient Ombudsman may process your complaint after the four-week deadline.

In case of a missing letter with information about time and place of treatment, waiting times, etc., within eight days (the Region's duty to give information), missing compliance with the treatment guarantee in case of life-threatening diseases, or failure to offer the assistance of an interpreter or to provide a primary contact or transport, which means that you did not receive a given decision, the complaint deadline normally runs from the time when you were informed or otherwise became aware of your right to complain.

You may get assistance from the hospital's Patient Counselor, who can guide and possibly assist you with writing a complaint. You may also ask the Patient Counselor to send your complaint to the right receiving body.

Complaint about the use of coercive measures during your admission to a mental health center

If you are subjected to coercive measures in connection with your admission to or treatment at a mental health center, or you are coercively retained at a center, you have the right to have a patient counselor assigned to you. The patient counselor must guide you on all aspects of your admission, stay or treatment at a mental health center. The patient counselor must also help you if you wish to complain.

In connection with coercive measures, you may complain to the Patient Complaints Board of the Mental Health Services (cf. Addresses). You may give your complaint to the staff at the center; the staff will pass on your complaint for you. There is no deadline for complaints to the Patient Complaints Board of the Mental Health Services.

Read more about it:

- Danish Health Act, Consolidated Act No. 913 of 13 July 2010, most recently amended by Act No. 1546 of 21 December 2010.
- Consolidated Act No. 24 of 21 January 2009 on complaint and compensation access in healthcare services. Subsequently amended by Act No. 706 of 25 June 2010.
- Consolidated Act No. 1729 of 2 December 2010 on the use of coercive measures in mental health services.
- Ministry of the Interior and Health Executive Order No. 1341 of 2 December 2010 on patient counselors.
- Ministry of the Interior and Health Executive Order No. 1343 of 2 December 2010 on information and complaint guideline for patients in connection with the use of coercive measures in mental health services.

10. Your right to decide over your body

What happens to tissue samples? (bio-banks)

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.

Furthermore, you may request that:

- your blood and tissue specimens be destroyed
- 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.

You must register your decision with the Tissue Application Register. There is a special form for you to fill in; the form is available from the patient counselor. Forward the form to the National Board of Health, the Tissue Application Register (cf. Addresses).

Are you prepared to participate in scientific trials?

In connection with your treatment at a hospital/a mental health center in the Capital Region of Denmark, 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
- the methods used in the trial
- possible risks, side effects or nuisances from participating in the trial
- that you form part of the trial together 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 benefits 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 in part with external grants, e.g. from pharmaceutical companies
- the name of a primary contact who is able to give more 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 wish to talk to staff and your family about your thoughts on participating in the trial. You can always ask for more time to consider and ask for more information, e.g. with a member of your family 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.

Find more information at www.patientforsikringen.dk

Who decides about 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

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.

Who decides about 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 hospital’s patient counsellor or at the Donor Register (cf. Addresses).

How to make a 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 your Living Will

Write your Living Will by filling in a form that is attached to the Living Will folder. Send the form to the Living Will Register. The charge is DKK 50, which will be collected subsequently on a giro inpayment form. The form is also available from the pharmacy, your GP and the library.

It may be a good idea to tell your nearest family about your Living Will, so that they know your attitude and decision. Your family cannot put a ban on a living will that has been registered with 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 stating this verbally to a healthcare professional, or
- by electronically revoking your Living Will towards the Living Will Register at www.sundhed.dk if you have the NemID easy access password system or a digital signature.

You can get more information about Living Will from the staff or from the patient counselor. You may also request written material from the Living Will Register (cf. Addresses).

Read more about it:

- Danish Health Act, Consolidated Act No. 913 of 13 July 2010, most recently amended by Act No. 1546 of 21 December 2010.
- Executive Order No. 966 of 22 September 2004 on the Tissue Application Register.
- Ministry of the Interior and Health Guideline No. 83 of 22 September 2004 on bio-banks.
- Ministry of the Interior and Health folder: Guideline for you who had a blood sample or tissue sample taken after 1 September 2004. The folder also contains a form for recording in the Tissue Application Register.

- National Board of Health website www.sum.dk for rules on protection of your blood and tissue samples.
- Act No. 402 of 28 May 2003 on a science ethics committee system and processing of biomedical research projects, with amendments introduced in Act No. 440 of 9 June 2004, Act No. 544 of 24 June 2005 and Act No. 272 of 1 April 2006.
- Ministry of the Interior and Health Executive Order No. 806 of 12 July 2004 on information and consent if persons are included in biomedical research project trials.
- Folder from the Ministry of Science and Research: Before you make up your mind – persons participating in medical science trials.
- The Central Science Ethics Committee www.cvk.sum.dk
- National Board of Health Guideline No. 100 of 7 December 2006 on consent for medical science autopsies.
- Ministry of the Interior and Health folder: Make up your mind about autopsy.
- Ministry of the Interior and Health www.im.dk
- National Board of Health Guideline No. 101 of 8 December 2006 on consent for 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
- Ministry of Health and Prevention Executive Order No. 240 of 20 March 2007 on Living Wills.
- National Board of Health Guideline No. 158 of 15 September 1998 on the duties of physicians in relation to the contents of Living Wills.
- National Board of Health Circular No. 157 of 15 September 1998 on the duties of physicians in connection with Living Wills, etc.
- National Board of Health folder: Living Will. www.sundhed.dk

11. Useful addresses

**Donorregisteret
(the Donor Register)
Rigshospitalet
(Copenhagen University Hospital)**
Unit 9631, Blegdamsvej 9
2100 Copenhagen Ø
Tel.: (+45) 35 45 52 69

**Indenrigs- og Sundhedsministeriet
(Ministry of the Interior and Health)**
Slotsolmsgade 10-12
1216 Copenhagen K
Tel.: (+45) 72 26 90 00
E-mail: im@im.dk
www.sum.dk

**Livstestamenteregisteret
(Living Will Register)
Rigshospitalet
(Copenhagen University Hospital)**
Unit 9631, Blegdamsvej 9
2100 Copenhagen Ø
Tel.: (+45) 35 45 52 69

**Patientforsikringen
(Patient Insurance Association)**
Nytorv 5, 3.
1450 Copenhagen K
Tel.: (+45) 33 12 43 43
E-mail: pf@patientforsikringen.dk
www.patientforsikringen.dk

Patientombuddet (Patient Ombudsman)
Frederiksborggade 15, 2.
1360 Copenhagen K
Tel.: (+45) 72 28 66 00
E-mail: pob@patientombuddet.dk
www.patientombuddet.dk

**Patient Travel
(for patients from the island of Bornholm)**
Tel.: (+45) 56 90 90 99
E-mail: patientrejser@boh.regionh.dk

**Det Psykiatriske Patientklagenævn ved
Statsforvaltningen Hovedstaden
(Mental Health Patient Complaints Board
of the Regional State Administration of the
Capital Region of Denmark)**
Borups Alle 177
2400 Copenhagen NV
Tel.: (+45) 72 56 70 00
www.statsforvaltning.dk

**Region Hovedstaden
(Capital Region of Denmark)**
Kongens Vænge 2
3400 Hillerød
Tel.: (+45) 48 20 50 00
E-mail: regionh@regionh.dk
www.regionhovedstaden.dk

**Region Hovedstadens Psykiatri
(Mental Health Services of the Capital
Region of Denmark)**
Kristineberg 3
2100 Copenhagen Ø
Tel.: (+45) 45 11 20 00
E-mail: psykiatri@regionh.dk
www.psykiatri-regionh.dk

**Region Hovedstadens Centrale Informati-
ons- og Rådgivningsenhed
(Central Information and Counseling Unit of
the Capital Region of Denmark)
Rigshospitalet
(Copenhagen University Hospital)**
Afsnit 7561
Tagensvej 20, Opgang 75, 6.
2200 Copenhagen N
Tel.: (+45) 35 45 41 19
E-mail: fritvalg@rh.regionh.dk

**Sundhedsstyrelsen
(National Board of Health)**
Islands Brygge 67
2300 Copenhagen S
Tel.: (+45) 72 22 74 00
E-mail: sst@sst.dk
www.sst.dk

**Sundhedsvæsenets Disciplinærnævn
(Disciplinary Board of the National Health
Services)**
Cf. Patient Ombudsmand

**Vævsanvendelsesregisteret
(Tissue Application Register)
Sundhedsstyrelsen
(National Board of Health)**
Islands Brygge 67
2300 Copenhagen S
Tel.: (+45) 72 22 74 00
www.sundhedsdata.sst.dk

12. Find and use your patient counselor

As a patient and as a family member, you can seek information and guidance from the patient counselor as a supplement to your contact with the hospital staff.

The patient counselor may assist you, e.g. if you have questions concerning the free choice of hospital, access to your own patient record, or other patient rights. The patient counselor may also help solve any misunderstandings between you and the staff of the hospital or the mental health center.

The patient counselors of the Capital Region of Denmark are employed by the central administration of the region, but have their offices at the region's hospitals as well as the region's headquarters in Hillerød.

You thus have access to a patient counselor at all hospitals of the Capital Region of Denmark as well as at the region's head-quarters in Hillerød.

You can choose freely which patient counselor you wish to approach. You may also phone, write or send an e-mail.

If you write from an unsecured e-mail connection, the reply from the patient counselor may not contain any confidential information. However, you may send an e-mail via www.borger.dk, if you have the NemID (EasyID) password system, in which case you can receive an electronic reply to your query.

The opening hours and addresses of the patient offices can be found on the website of the Capital Region of Denmark, www.regionh.dk. The website will also tell you more about the work of the patient counselor.

Telephone numbers of the patient counselors of the Capital Region of Denmark

Amager Hospital	32 34 30 26
Bispebjerg Hospital	35 31 22 05
Bornholms Hospital	56 90 97 08
Frederiksberg Hospital	38 16 30 87
Frederikssund Hospital	48 29 52 37
Gentofte Hospital	39 77 30 22
Glostrup Hospital	38 63 26 46
Helsingør Hospital	48 29 22 89
Herlev Hospital	44 88 40 16
Hillerød Hospital	48 29 30 24
Hvidovre Hospital	38 32 27 70
Rigshospitalet (Copenhagen University Hospital)	35 45 55 90
Regionsgården (the Region's headquarters)	48 20 57 17

Amager Hospital

Italiensvej 1
2300 Copenhagen S
Tel.: (+45) 32 34 32 34
E-mail: amager.hospital@regionh.dk
www.amagerhospital.dk

Bispebjerg Hospital

Bispebjerg Bakke 23
2400 Copenhagen NV
Tel.: (+45) 35 31 35 31
E-mail: direktion@bbh.regionh.dk
www.bispebjerghospital.dk

Bornholms Hospital

Ullasvej 8
3700 Rønne
Tel.: (+45) 56 95 11 65
E-mail: bornholmshospital@boh.regionh.dk
www.bornholmshospital.dk

Frederiksberg Hospital

Nordre Fasanvej 57
2000 Frederiksberg
Tel.: (+45) 38 16 38 16
E-mail: frederiksberg.hospital@frh.regionh.dk
www.frederiksberghospital.dk

Frederikssund Hospital

Frederikssundsvej 30
3600 Frederikssund
Tel.: (+45) 48 29 50 00
E-mail: DirektionenFSH@fsh.regionh.dk
www.frederikssundhospital.dk

Gentofte Hospital

Niels Andersens Vej 6
2900 Hellerup
Tel.: (+45) 39 77 39 77
E-mail: genweb@geh.regionh.dk
www.gentoftehospital.dk

Glostrup Hospital

Nordre Ringvej 57
2600 Glostrup
Tel.: (+45) 38 63 38 63
E-mail: direktionen@glo.regionh.dk
www.glostruphospital.dk

Helsingør Hospital

Esrumsvej 145
3000 Helsingør
Tel.: (+45) 48 29 49 49
E-mail: hls@hlh.regionh.dk
www.helsingorhospital.dk

Herlev Hospital

Herlev Ringvej 75
2730 Herlev
Tel.: (+45) 44 88 44 88
E-mail: direktionen@heh.regionh.dk
www.herlevhospital.dk

Hillerød Hospital

Dyrehavevej 29
3400 Hillerød
Tel.: (+45) 48 29 48 29
E-mail: hilleroehospital@hlh.regionh.dk
www.hilleroehospital.dk

Hvidovre Hospital

Kettegård Allé 30
2650 Hvidovre
Tel.: (+45) 38 62 38 62
E-mail: hospitalsdirektionen@hvh.regionh.dk
www.hvidovrehospital.dk

Rigshospitalet

Blegdamsvej 9
2100 Copenhagen Ø
Tel.: (+45) 35 45 35 45
E-mail: direktionen@rh.regionh.dk
www.rigshospitalet.dk

Region Hovedstadens Psykiatri

Kristineberg 3
2100 Copenhagen Ø
Tel.: (+45) 45 11 20 00
E-mail: psykiatri@regionh.dk
www.psykiatri-regionh.dk

Region Hovedstaden

Kongens Vænge 2
3400 Hillerød
Tel.: (+45) 48 20 50 00
E-mail: regionh@regionh.dk
www.regionh.dk



**Region
Hovedstaden**

Region Hovedstaden

Kongens Vænge 2
3400 Hillerød

Tel.: 4820 5000

E-mail: regionh@regionh.dk