Federal Ministry for
Family Affairs, Senior Citizens,
Women and Youth

Federal Ministry
of Health

# Charter of Rights for People in Need of Long-Term Care and Assistance

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# Foreword

In 2003, the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ) in collaboration with the then Federal Ministry for Health and Social Security (BMGS) initiated the “Round Table for Long-Term Care” to improve conditions for people in Germany who are in need of long-term care and assistance. Some 200 experts from responsible associations, the federal and Länder governments, municipal authorities, the long-term care sector and the science and research community were involved, the aim being to develop practical recommendations for action. The results of the Round Table for Long-Term Care were presented in autumn 2005. Of these, the Charter of Rights for People in Need of Long-Term Care and Assistance proved especially important and of lasting value.

The Charter was first published in 2006. It has since been reprinted 11 times unchanged, providing a sound foundation on which to design dignified forms of long-term care and assistance, and serving as a source of stimulus for the care sector overall. The Charter acts as a guide for people in need of long-term care, their relatives and those wanting to train as care professionals.

The eight articles the Charter contains have stood the test of time. But after almost 12 years, it was time to review the explanatory notes. The reviewers looked for passages that needed to be adapted and aligned in relation to changes that had occurred both in long-term care legislation and in other legislative areas. It was also felt that the Charter needed a full editorial review. This work was assigned to a group of representatives from long-term care insurance funds and providers, care professionals, people in need of long-term care and assistance, their family members, policy-makers and members of the science and research community, and was supervised and managed by the Centre for Quality in Care (ZQP).

The wording used in this version of the Charter was agreed on following intensive talks. The explanatory notes on the Charter now use more simplified language and – wherever possible – are shorter. Duplications have been removed and paragraphs rearranged to aid comprehension and ensure consistency. The Charter no longer differentiates between services and institutions. Further amendments, alignments and additions are contained in the Annex along with additional information and links, in particular with regard to enduring powers of attorney and advance directives.

The rights set out in the Charter's eight articles back in 2005 have not been altered in any way. The aim of the Charter remains to improve the role and the legal position of people in need of long-term care and assistance by summarising the fundamental and indisputable rights of people in need of long-term care and assistance in a brief, easy-to-understand catalogue containing comments and explanatory notes for practitioners. The Charter remains in great demand even today and is still available online and in printed form. The editorial changes made are designed to ensure that this Charter of Rights continues to provide guidance and direction, thus setting the trend in all areas involving the provision of long-term care.

Berlin, October 2018

# Contents

# Preamble

All human beings have an unqualified right to respect for their dignity and uniqueness. People needing assistance and long-term care have the same rights as everybody else and should in no way be disadvantaged because of their special circumstances. Since they are often unable to represent themselves, the state and society have a special responsibility to protect the human dignity of those in need of assistance and long-term care.

The aim of this Charter is to strengthen the role and the legal position of people in need of long-term care and assistance. In its eight Articles, the fundamental rights of people in need of assistance and long-term care are summarised[1] and explained. The wording used speaks directly to people in need of assistance and long-term care.

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[1] The rights set out in the Charter are broadly mentioned in numerous international and European texts and in some cases have been bindingly incorporated into these documents. These include in particular the European Social Charter and the EU Charter of Fundamental Rights. Certain German legislation also guarantees general rights for people in need of long-term care and assistance. In addition to the rights contained in the Basic Law, these are notably the right to participate in society (Section 1 SGB IX), the right to self-determination and independence (Section 2 SGB XI), to the priority of care at home (Section 3 SGB XI), to the priority of prevention and rehabilitation (Section 5 SGB XI), to information and counselling (Sections 7 and 7a SGB XI) and the rights included in social welfare legislation, the right to individual benefits which applies to social legislation as a whole (Section 33 SGB 1) and the ban on discrimination (Section 33c SGB I).

The Charter also sets out quality criteria for good provision of long-term care and support. It thus serves as a guideline for those responsible for providing long-term care, support and treatment. The Charter addresses caregivers, physicians and all those involved either professionally or privately in ensuring the well-being of people in need of long-term care and assistance. This also includes organisations in the health and social welfare sectors, providers of long-term care and healthcare services, as well as those responsible in local government, health and long-term care insurance funds, private insurance companies and charitable associations. They should all be guided in their actions by the contents of the Charter. Those with political responsibility at all levels and the funding bodies likewise are called upon to further develop and safeguard the framework required to uphold the rights, and especially the financial conditions, set out in this Charter of Rights.

The responsibility held by the state and society towards people in need of long-term care and assistance does not release individuals themselves from their obligation to adopt a healthy and responsible lifestyle which in itself can play a significant role in delaying, mitigating or overcoming the need for long-term care and assistance.

# Articles of the Charter with explanatory notes

## Article 1: Self-determination and self-help support

**Everyone in need of long-term care and assistance has the right to self-help support and to assistance to enable them to live a life which is as self-determined and independent as possible.**

Free will and decision-making, advocacy and care

You have the right to respect for your free will and freedom to make decisions as well as to advocacy and support. Those responsible for your care, support and treatment must respect your will and act accordingly. This also applies if you are not able to express your wishes verbally, but do so, for instance, through your behaviour and the way you act. If your mental ability is impaired, you have the right to be included in decision-making processes that affect you and in a way commensurate with your ability to understand, and to receive assistance in reaching your decisions. Even if you are not able to reach decisions alone or cannot express your wishes yourself, any action taken must be in keeping with your interests. Those responsible for your care, support and treatment must ensure that this is the case.

**Self-determined life**

You are entitled to expect that any discussions on how your individual goals and wishes can be achieved, given the prevailing legal and actual circumstances, will include you, any trusted persons and those responsible for your care, support and treatment. This involves, for instance, the choice of where you live and spend your time, who you can have contact with, how you go about your daily routine and the habits you usually pursue, how and when you wash, and what you eat. If your health condition allows it, it must be ensured that you can enter, leave and lock the door to your living accommodation at all times. This also applies if you live in a residential institution.

**Choice of care services and providers**

You have the right to choose the care service you would like to use, say from whom you would like to receive your care, support and treatment, and what form the services provided should take.

**Respect for chosen way of life**

You have the right to respect for your chosen way of life and your sexual identity, and to sexuality. No one may discriminate against you on grounds of your sexual orientation. You have the right to decide on your intimate and sexual relations and activities.

**Preventive healthcare and health promotion**

You have the right to receive advice and support to enable you to live as far as possible without having to rely on help. The help, care and treatment you receive should be such that they promote your mental and physical abilities, maintain or improve your well-being and quality of life, and enable you to manage your daily routine to the extent possible by yourself. You are entitled to have all necessary measures taken to improve your situation, prevent further deterioration or compensate for any impairments or negative effects. This applies regardless of your age, disability, physical or mental impairments, or the degree of care you need. This means, for example, that you are entitled to access to preventive check-ups and vaccinations, individual health-promoting guidance, (specialist) medical care, diagnostic procedures, medical treatment and rehabilitation. You must also receive information and advice about the measures involved.

**Dealing with financial, official and legal matters**

Your right to self-determination also extends to your financial, official and legal matters. This means that you should receive the support you need to handle such matters, for example, when making applications, filling out forms or being accompanied on visits to government authorities. Those advising and supporting you must act in your best interests. They may not take any action which goes against your interests and would cause you financial or legal harm.

**Compliance with enduring powers of attorney and advance directives**

In the event that you may not be able to express your wishes at some later date, you have the right to draw up advance directives in the form of an enduring power of attorney, the appointment of a legal representative or an advance healthcare directive.[2] The wishes you express and the instructions you give therein must be respected and taken into account provided they are still current at the time in question. An assessment must be made to determine if this is the case.

**Restrictions**

Self-determination has its limits, for example in cases where the rights and opportunities of others are affected or violated. Should a conflict of interest arise between your right to self-determination and the care obligations of those involved in your treatment and care, you can expect that your situation will be discussed with all involved and an assessment made as to how your right to self-determination can be upheld.

Financial and structural circumstances, such as personal funds or a lack of care facilities in a given region, can narrow the options in some cases. Nonetheless, the aim of upholding to the extent possible the self-determination rights of people in need of long-term care and assistance places all involved in their support, care and treatment under a legal obligation to ensure that this occurs.

# Article 2: Physical and mental integrity, freedom and security

**Everyone in need of long-term care and assistance has the right to protection against any physical or mental threats.**

**Protection against violence**

You have the right to protection against violence. This means, for example, that no one may care for you or treat you against your will. No one may manhandle, push, hit, hurt or abuse you in any way. Nor may anyone humiliate, insult, threaten, disregard or ignore you.

**Protection against neglect**

You have the right to protection against physical or mental neglect. This means, for example, that you must receive the help you need in a timely manner and should not be kept waiting for an unreasonable length of time. This applies especially at times when you want something to eat or drink, if you are in pain or have other pressing or uncomfortable symptoms, need to relieve yourself, or want to get up, lie down or move about.

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[2] See the Annex for more information on drawing up advance directives.

If you are unable to do so yourself, you must be protected from the effects of direct sunlight, sheltered from draughts and be suitably dressed to cope with excessive cold or heat.

**Protection against inappropriate medical treatment and care**

You also have the right to protection against harm caused by poor or inappropriate medical treatment and care. Care professionals must act with due care and attention. This means, for instance, that everything must be done to ensure you do not develop bedsores or contract infections. Your medication should be provided and, where appropriate, administered in a responsible and appropriate manner. You are entitled to expect that caregivers, doctors and therapists pay particular attention to the possibility of adverse side effects or interactions and respond in a timely manner.

**Protection against unwarranted restrictions on freedom of movement**

Protection against violence means that measures may not be taken to restrict your freedom of movement. Unless there is a specific medical need, no one may hinder you from moving around, either by locking you in, restraining you with belts or straps, or administering tranquilising medication. Such measures may only be taken in the absence of other options to prevent risk. Your consent is required at all times. If you are unable to give your consent yourself, the person of trust holding your power of attorney or your legal representative must be consulted and a court order must be obtained. Only in cases of acute danger to life and limb are short-term freedom-restricting measures permitted without a court order. As serious interventions of this nature can endanger your health, a qualified person must continuously monitor and observe the measures in place. Checks should also be made to assess whether the measures are still required or justified.

**Help in coping with violence**

There is no need for you to tolerate any form of violence, neglect, mistreatment or inappropriate care, or measures that restrict your freedom. You are entitled to expect caregivers, doctors and therapists to recognise concrete signs or indications and – after consulting you if possible – react in an appropriate way. This means, for example, that immediate qualified help is offered, medical examinations are initiated, the responsible investigative and supervisory authorities are informed, and measures are put in place for your protection. You can also expect that psychological assistance to help you cope with the experience of violence will be made available should you so wish.

# Article 3: Privacy

**Everyone in need of long-term care and assistance has the right to the safeguarding and protection of their privacy and intimate personal space.**

**Respect for privacy**

You have the right for your privacy and intimate personal space to be treated with consideration and respect. This applies whether you live in your own home or in a residential institution. This means that those who wish to enter your home or room should normally ring or knock and – if you are able to answer – await your response. You have the right to decide who enters your home or living space, and to decide at any time whether you wish to receive visitors or refuse to see them.

**Opportunities for privacy**

You must be given the opportunity to spend time alone and to talk undisturbed, even if you live in a residential institution and do not have a private room. Should you wish to talk to a medical, psychological or spiritual adviser in confidence, you have the right to expect that this will be arranged.

**Using personal belongings in residential institutions**

If you live in a residential institution, you should be able to furnish your personal space with your own things (small items of furniture, pictures, table cloths and bed linen). You should also be able to keep your valuables safe, for example in a cupboard that you can lock.

**Consideration of feelings of modesty and self-respect**

You are entitled to be treated by your caregivers with the highest possible degree of sensitivity and discretion. They must respect your sense of privacy and intimate personal space, your need for dignity and your sense of modesty and self-respect. Should you find the care or treatment given by a particular person disagreeable, you do not have to endure or accept it. You can expect that in such cases the institution involved will exhaust all possibilities in order to assign staff to your care who will treat you in a way you consider appropriate and which takes account of your feelings and needs.

**Upholding postal secrecy and personal correspondence**

Your letters or electronic mail may not be received, opened or read by third parties without your consent. If you are unable to receive or open your post personally or use the channels of communication without help from others, you should name a trusted person to assist you.

To make provisions for the event that you lose your capacity to deal with your correspondence at a later date, you can do this in advance in an enduring power of attorney.

**Protection of personal data/data privacy**

Your data and documents must be treated as confidential. Documents and data concerning you may only be processed with your prior consent or that of the person you have chosen as the holder of your power of attorney or as your legal representative, and in accordance with statutory provisions.

**Restrictions**

Depending on the degree of long-term care and assistance needed and the prevailing conditions in care institutions, it may not always be possible to guarantee an entitlement to privacy or respect for your intimate personal space. It should nonetheless be the goal of all involved in support, care and treatment to keep any and all restrictions to the minimum possible extent.

# Article 4: Care, support and treatment

**Everyone in need of long-term care and assistance has the right to qualified, health-promoting care, support and treatment that is tailored to their personal needs.**

**Competent, dedicated care, support and treatment**

You have the right to competent, patient-centric care, support and treatment. You are entitled to be attended to by suitably qualified staff with the training needed to perform the task at hand and meet your specific needs. Methods and measures applied must comply with the prevailing knowledge and standards of practice in medical and nursing care. You have the right to be informed about this in detail if you so wish.

**Needs-based care**

You are entitled to expect that your care, support and treatment take account of your needs, background and previous experience, abilities and impairments or limitations. This includes consideration being given to your habits and routines – your resting and sleeping patterns, and preferences concerning personal hygiene and dressing, for example.

**Planned care**

You are entitled to expect that, to the extent possible, your care is purposeful and planned. Care-related goals and measures and the respective results must be documented, monitored and reviewed at regular intervals, revised where appropriate and discussed with you in person.

**Dedicated points of contact**

You can expect to have dedicated points of contact, meaning persons who are familiar with your situation and responsible for all your needs and concerns, permanently assigned to provide your care, support and treatment. Where possible, rotation of staff attending to you should be kept to a necessary minimum.

**Activating care**

You have the right to expect that, to the extent possible, the care services provided help you to live an independent and self-determined life. You will be helped to maintain or regain your abilities. This means that your need for mobility and need for movement must be supported and encouraged, provided there are no medical reasons that prevent this. You should be given access to suitable aids which you can use to increase your independence, for example to help you walk, eat and drink without the need for help.

**Needs-based nutrition**

You have the right to expect your preferences and dislikes in respect of eating and drinking to be taken into account. Meals served should be sufficient, age-appropriate and healthy. You can expect that if wished, your meals will be provided outside regular mealtimes. Snacks and drinks should be available to you at all times. If you are bedridden, you can expect food to be placed within reach so you are always able to eat or drink at any time. If you need help with eating and drinking, you are entitled to have someone feed you the portions you need at the times you need them. If you have nutritional problems, recognised medical, ethical and legal guidelines must be adhered to in dealing with them. Artificial feeding measures (stomach tube, intravenous drip) should only be undertaken with your explicit consent or that of the holder of your power of attorney or legal representative.

**Professional treatment and alleviation of symptoms**

Any acute or chronic pains and distressing symptoms you may have, such as shortness of breath or nausea, must be treated professionally and alleviated to the greatest possible extent. This includes that, as part of your care, support and treatment, any signs of pain or distressing symptoms are recognised and that adequate treatment is administered and, where necessary, coordinated. This includes the provision of specialist medical care.

**Communication and cooperation**

Everyone involved in your care, support and treatment should, in your best interest, communicate and cooperate with one another and closely align the services they provide. This means, for instance, that they exchange information which concerns you and affects your care, support and treatment. Statutory data protection provisions must be adhered to in this process. Your data may only be passed on with your prior consent.

Cooperation with family members and voluntary helpers

You are entitled to expect that – if you so wish – your relatives, other trusted persons and any volunteer helpers are involved in your care, support and treatment. This means, for example, that the persons you name are kept informed of measures and changes made which relate to your care and health, and are involved in any decisions and consultations concerning your treatment. The experience and expectations of family carers must be taken up and respected by the staff responsible for your care, provided that your needs are taken into account and you receive the care you need.

Responding to complaints

You have the right to lodge a complaint.[3] You can expect that management and staff respond to your concerns and suggestions quickly and considerately, and treat them as confidential if you so wish. No one may disadvantage you or treat you badly on grounds of your complaint. You are entitled to receive timely information regarding the action taken or to be taken as a result of your complaint.

# Article 5: Information, counselling and informed consent

**Everyone in need of long-term care and assistance has the right to be fully informed of the possibilities and opportunities available for counselling, support, care and treatment.**

Comprehensive counselling and advice

You have a right to comprehensive, professional, independent and personal counselling and advice regarding your entitlement to care and treatment, and the services on offer. This includes information about housing possibilities and alterations to your living accommodation. You may also receive advice about the services available to your family carers, such as short-term and holiday stand-in care, breaks to enable reconciliation of work and respite care for a family member, or to provide terminal care. The counselling and advice should help you to the extent possible to manage your long-term care and assistance needs yourself, decide on the care you receive, prevent health problems and arrange care for you in the best possible way. The counselling and advice should take account of your housing situation, your environment and your values. The goals arising from the consultation should be agreed with you.

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[3] See the Annex for more about expressing criticism and lodging complaints.

**Choosing a counsellor**

You can expect to be given the name of a contact person to advise you. You can change to a different person or to a different provider if you wish.

**Training for family carers**

Family carers are also entitled to receive free guidance and training in order to be able to care for you as competently and properly as possible.

**Transparency concerning costs and services provided**

You are entitled to full and easy-to-understand information on the type and quality of professional long-term care and assistance services available and what they cost. It should be clear from this information which portion of these costs is covered by a statutory long-term care insurance fund or a private long-term care insurer. The services and fees agreed in contracts drawn up by long-term care and residential nursing homes and services are binding. This means that before concluding or amending an agreement, you must be fully informed on the subject matter of the agreement and the possibility of making future amendments to it. This should include making available to you in advance a list of services with fees, a sample contract and, when possible, a copy of the home's regulations.

**Information and advice on medical and long-term care services and treatment**

Talking to you openly, understandably and tactfully about care and medical diagnoses and measures, as well as the possible risks and alternatives involved, is part of your right to information and to giving informed consent. You also have the right to be fully informed in an easy-to-understand way of the effects, side effects and interactions of medicines to be administered. This also applies to participation in research projects. Prior to its commencement, you must be fully informed about the mode of implementation, benefits, risks and alternatives to any treatment whose effectiveness and safety is not scientifically proven. Should you decide not to participate, you should not be disadvantaged in any way. Should you not be in a position to decide yourself, the consent of the holder of your power of attorney or your legal representative must be obtained for each case in point. These parties may only agree to you participating in the research project if it is expected to be of benefit to your health.

**Viewing documents and records**

You have the right at all times to view your care-related documents and any other medical records relating to you and have copies made. This right also applies to persons holding your power of attorney or to legal representatives.

# Article 6: Respect, communication and social participation

**Everyone in need of long-term care and assistance has the right to respect, interaction with others and to participate in society.**

Regard and respect

You have the right to be shown regard and respect. This also means that you should be spoken to by name at all times.

Attention to communication needs and requirements

You are entitled to have your communication needs and requirements taken into account, for instance speaking or gesturing slowly and clearly, or using a speech facilitator or interpreter. Should you need to use medical or technical aids, such as a hearing aid or a writing tool, you should be helped to obtain and use them correctly.

Social participation

You have the right to structure your everyday life in accordance with your abilities and interests, and to participate in social life. This includes having the opportunity to perform professional or volunteer work. You are also entitled to free access to informational and educational offerings and programmes, including those involving politics, culture and current affairs. You can expect to receive help with this. Carers and support staff should work with you or those representing you to find ways to structure your daily life in line with your wishes and needs for an occupation and social participation. Your wishes must also be respected should you decide not to take up offers for daytime activities and participation in social life.

Codetermination in institutions

If you live in a residential institution, you have the right to influence important decisions affecting life in the institution either yourself or via a codetermination body (i.e. residents' council). This includes, for instance, drawing up menus or recreational programmes. You also have the right to use the residents' council to participate in preparatory decisions concerning operational measures in the residential facility. Both institution managers and the residents' council must inform you of your right to be consulted and involved.

Voting in public elections

You also have the right to exercise your citizen's right of participation. Primarily, this means your right to vote in public elections. If you have a physical impairment, you can be assisted in voting by a person nominated by you and/or submit a postal vote. The person assisting you is required to respect your freedom of choice and to maintain secrecy concerning your vote.

# Article 7: Religion, culture and beliefs

**Everyone in need of long-term care and assistance has the right to live in keeping with their culture and beliefs, and to practice their religion.**

**Culture-sensitive care, support and treatment**

You are entitled to expect that your care, support and treatment take a culture-sensitive approach to ensure that your culture, beliefs and religious values, and also your habits and needs, are respected to the greatest possible extent. Should you wish to observe any religious acts (such as prayer, fasting, ablutions), you should be assisted in doing so. If you so wish, a member of your religious community or someone who represents your beliefs should be consulted.

# Article 8: Palliative care, end-of-life care and death

**Everyone in need of long-term care and assistance has the right to die with dignity.**

**Personalised end-of-life care**

You have the right to personalised end-of-life care. You can expect that everything possible will be done to make the process of dying as dignified and tolerable for you as possible. This includes the application of effective measures and relief of pain and other distressing symptoms. Should you so wish, psychological or religious guidance should be made available to you throughout this phase. Regardless of whether you die at home, in a hospital, a hospice or in a nursing or residential home, you are entitled to expect that the institution involved will exhaust all possibilities to see that this happens in an environment which comes closest to your idea of what constitutes a dignified death.

**Support from family members**

You are entitled to expect that, if you so wish, doctors and care staff will include your relatives and other trusted persons in your end-of-life care and offer them professional support.

**Self-determination at the end of life**

You have the right to determine yourself whether and to what extent treatment should be initiated or continued in view of the possible imminence of death or whether life-prolonging measures should be implemented or omitted. However, no one may take measures which would induce your death even if you should explicitly wish them to do so. You are entitled to have your advance directives respected should you no longer be able to express your wishes yourself.[4]

**Respect for the deceased**

The deceased also have a right to be treated with dignity and respect. You are entitled to expect that your relatives and persons close to you are given sufficient time to take their leave. You also have the right to determine in advance how you wish to be treated after your death and what should be done with your body. This relates, for instance, to laying out the type of burial and whether your body should be donated to science. You may also decide whether to donate your organs, for example by filling out an organ donor card.

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[4] See the Annex for more information on enduring powers of attorney and advance directives.

# Annex

## Information, counselling and advice

Counselling centres

Counselling and advice concerning long-term care and assistance is offered, for example, by long-term care insurance funds, long-term care support centres, compass private long-term care advisory services, municipal authorities, mobile care services and social welfare institutions. These can give you information concerning services in the area in which you wish to live and the costs involved. You can also receive advice about how your care-related wishes can be implemented and fulfilled.

Long-term care insurance funds, the responsible state agencies and those involved in the provision of care are under obligation – in addition to their own counselling and advice services – to provide information about other counselling and advice services. Private long-term insurers can also provide information.

Online service portal and Care Helpline

**www.wege-zur-pflege.de**

Information on all aspects of long-term care is available from the website **www.wege-zur-pflege.de** (Paths to Long-Term Care) operated by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ). You can use the website, for example, to obtain information about opportunities for counselling and support, legal and financial entitlements, care support allowance (Pflegeunterstützungsgeld), care leave (Pflegezeit) and family care time (Familienpflegezeit). The experts on the Care Helpline can answer questions concerning all aspects of long-term care, and offer individual help and advice, even in critical and stressful situations. You will also receive information about advice and assistance in your area. Calls are anonymous and confidential. The Helpline is open from Monday to Thursday from 9 a.m. to 6 p.m. Call 030 20 179 131.

Current information from the Federal Ministry of Health (BMG) on the topic of long-term care and assistance is available on the Ministry's website at: **www.bundesgesundheitsministerium.de/pflege**. The Ministry also publishes information and explanatory notes on long-term care, reports from everyday long-term care practice and details of available services at **www.pflegestaerkungsgesetz.de**. BMG employees at the Citizens' Helpline in Rostock can also answer questions concerning long-term care, health and preventive health care.

**www.bundesgesundheitsministerium.de/pflege**

**www.pflegestaerkungsgesetz.de**

The Citizens' Helpline commissioned by the Federal Ministry of Health is open from Monday to Friday from 8 a.m. to 6 p.m., and on Friday from 8 a.m. to 12 noon, and can be reached on the following numbers:

- Citizens' Helpline on health insurance:
  030 3 40 60 66 01
- Citizens' Helpline on long-term care insurance:
  030 3 40 60 66 02
- Citizens' Helpline on preventive healthcare:
  030 3 40 60 66 03
- Telephone service for the deaf and for people with hearing difficulties:
  030 3 40 60 66 07 Telefax
  030 3 40 60 66 08 ISDN video telephone
  info.gehoerlos@bmg.bund.de

The Citizens' Helpline is operated by the communications centre Telemark Rostock and only collects, processes and uses personal data in line with the provisions of the Federal Data Protection Act (Bundesdatenschutzgesetz). For further information see:
**www.bundesgesundheitsministerium.de/service/buergertelefon**

Choosing an institution

To help you choose the right institution for you, take the opportunity to visit those you are interested in. You can also try them out by booking a short trial stay. Such stays are usually subject to a charge.

# Concerns and complaints

If your complaints are not taken seriously by the care provider's responsible staff members, you can contact your long-term care insurance fund or your private long-term care insurer. They have a vested interest in ensuring that the services they fund are performed correctly and as contractually agreed, and will thus follow up on complaints.

**www.zqp.de/ beratungsdatenbank**

Complaints may also be submitted to the German Health Insurance Medical Service (MDK) and to the Internal Audit Service of the Association of Private Health Insurers (Prüfdienst des Verbandes der privaten Krankenversicherung). These regularly assess the quality of care services and institutions, and they also do so whenever a complaint is received. There are also Länder-specific supervisory authorities (Heimaufsicht) which monitor and inspect care providers and institutions. Some municipal authorities also operate complaint offices or have dedicated ombudsmen. Regional and super-regional initiatives operated by social welfare or charitable associations offer contact points for complaints concerning long-term care. Complaint office addresses can be found, for example, in the ZQP database: **www.zqp.de/beratungsdatenbank**.

# Enduring powers of attorney and advance directives

For the event that you are no longer able to make decisions for yourself, you can document your wishes in the form of an enduring power of attorney or advance directive. You can give instructions as to what should and should not be done, and name a person or persons who should reach decisions and act on your behalf. Enduring powers of attorney and advance healthcare directives are binding at all stages of illness and dying. They must be made in writing and be dated and signed.

If you have not drawn up an enduring power of attorney or advance healthcare directive, or if you have done so but your will is not entirely clear, your assumed will must be ascertained. This is done on the basis of your previously expressed wishes. Trusted persons or those who have cared for you so far are consulted. Their statements are then used to assess the permissible scope of medical treatment to be administered or care measures to be taken.

**Enduring power of attorney**

With an enduring power of attorney, you decide who should make decisions and act on your behalf should you no longer be able to do so yourself. You should inform the person or persons involved and discuss your wishes and expectations regarding the type and scope of the power of attorney.

As a general rule, advance directives should specify as clearly as possible exactly what they empower. Your enduring power of attorney can cover decisions and actions relating to specific matters or to matters overall. They give you the opportunity to avoid having a legal guardian assigned by the courts. You should, however, only appoint a person whom you trust implicitly and if you are sure that they will act in your best interests.

**Appointment of legal representative**

By appointing a legal representative, you decide who should be your court-appointed legal guardian should this be necessary. You can also determine who should not be named under any circumstances. It is also possible to give specific instructions about, for instance, who you would like to care for you, where and how. The appointment of a legal representative can also be combined with an enduring power of attorney and would then be applicable if the enduring power of attorney should not be valid for any reason.

**Advance healthcare directive**

In an advance healthcare directive, you can determine whether you consent to or refuse certain types of medical treatment or measures. You should also specify as clearly as possible your wishes regarding medical treatment and long-term care measures, and also your expectations as to what constitutes a dignified death. The doctor must then assess whether your wishes apply to the current living and treatment conditions. If this is found to be the case, the doctor must follow the instructions contained in the advance healthcare directive without hesitation. With an advance healthcare directive, you can also decide who should consent to medical treatment on your behalf or who should carry out your previously determined will if you are no longer able to do so yourself. Your instructions are binding for the treatment team, holders of powers of attorney and carers if these apply to the actual decision-making situation and there are no concrete indications that your previously expressed will no longer reflects your current will.

It is thus advisable that you review your advance healthcare directive at regular intervals of, for example, one year to assess if your documented will is still current. If it is, you should add a note to indicate the fact. If not, you should amend the passage concerned. This makes it easier for the persons who wish to act in your interest to determine if your previously expressed will corresponds to the actual situation and if it can be assumed that the written advance directives can be assumed to prevail. It is also advisable to talk to your care provider about your wishes regarding end-of-life medical treatment, care provision, and psycho-social and spiritual support.

Further information

Further information about enduring powers of attorney and advance directives can be obtained, for example, from the Federal Ministry of Justice and Consumer Protection, the public health authorities, the health and long-term care insurance funds, consumer protection organisations, the physicians' chambers (Ärztekammern), the Church, patient organisations, guardianship authorities and associations, and welfare organisations. You should also seek personal advice. When drawing up advice directives, lawyers and notaries can provide assistance for a fee.

The brochure entitled "Patientenverfügung" (Advance Healthcare Directives) published by the Federal Ministry of Justice and Consumer Protection sets out key information about advance healthcare directives and is designed to aid those wanting to draw up an advance healthcare directive.

The brochure entitled "Betreuungsrecht" (Guardianship Law) published by the Federal Ministry of Justice and Consumer Protection provides information about the principles of guardianship law and about enduring powers of attorney, and contains the respective forms.

The self-help guide entitled "Ratgeber für Patientenrechte" (Guide on Patients' Rights) published by the Federal Ministry of Justice and Consumer Protection, the Federal Ministry of Health and the Federal Government Representative for Patient Interests offers an easy-to-understand outline of and information on patients' rights.

**These publications can be ordered from:**
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* For general questions to all government offices and agencies, the general public service number 115 is also available. In the participating regions, the 115 service number is open from 8 a.m. to 6 p.m. between Monday and Friday. Calls to the 115 service number from a German landline and many mobile networks are charged at local rate and are therefore toll-free for flat rate holders. Deaf persons can access information by dialling the SIP address 115@gebaerdentelefon.d115.de. To find out if the 115 service number is available in your region and for more information on the general public service number please visit http://www.d115.de.

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