

Round Table for Long Term Care
Working Group IV

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

September 2005

with updated Annex/as at 15 September 2005

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

From Practical Responsibility to Everyday Practice – from Entitlement to Living Reality

People in various situations during their lives can be in need of long-term care and assistance. This Charter of Rights for People in Need of Long Term Care and Assistance is intended to strengthen the role and the legal position of people in this situation and their relatives and to provide information and suggestions for those involved in supplying care and assistance.

The Charter is a result of the work of the “Round Table for Long Term Care” initiated in the autumn of 2003. This body was set up by the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth and the former Federal Ministry of Health and Social Security with the aim of improving conditions for people in Germany who are in need of long-term care and assistance. Some 200 experts from all areas responsible for care in old age (including the federal states, local government, bodies responsible for care institutions, charitable associations, associations of responsible bodies, nursing home supervisory bodies, long-term care insurance funds, advocacy groups for the elderly, researchers, foundations) were all involved. In the period up to the autumn of 2005, working groups formulated recommended courses of action to improve home and residential care and to reduce bureaucracy, and developed as a central measure this “Charter of Rights for People in Need of Long-Term Care and Assistance”. The Charter gives a detailed catalogue of the rights of people in Germany who are in need of long-term care and assistance.

Now is the time for the recommendations of the “Round Table for Long-Term Care” and the Charter to be put into effect in order that those involved in care and in particular the beneficiaries of long-term care services may benefit from the work done by the Round Table. Some organisations and bodies responsible for care institutions already are successfully implementing the Charter. The all-important **step from entitlement to living reality** can only be achieved with wide scale commitment on the part of all actors and beneficiaries in the long-term care sector. The propagation of this “Charter of Rights for People in Need of Long-Term Care and Assistance” is a key component in the **implementation strategy** initiated by Federal Minister Dr. von der Leyen and Federal Minister Ulla Schmidt.

A coordinating office has been established at the German Centre of Gerontology (DZA) in Berlin in order to monitor this implementation process. Information on the coordination office can be found after its inauguration in early 2007 at www.dza.de. The office can be contacted by E-Mail at leitstelle-altenpflege@dza.de. The DZA will also be able to help with questions and suggestions by telephone and the coordinating office can be contacted by calling ++49 (0)30/260 740 90.

Detailed information on the Round Table for Long Term Care with a special focus on implementation can be found online at www.bmfsfj.de and www.bmg.bund.de.

Table of Contents

Preamble	Page 3
Articles of the Charter	Page 4
Articles with explanatory notes	Page 5
Annex	
Selected contacts and addresses	Pages 20 - 38

Preamble

All human beings have an unqualified entitlement 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 as a result of their special circumstances. The state and society have a special responsibility to protect the human dignity of those in need of long-term care and assistance since this group is often not in a position to represent its own interests.

The aim of this Charter is to strengthen the role and the legal position of people in need of long-term care and assistance by summarising the basic and indisputable rights of those people in need of assistance, support and care. These rights are an expression of respect for human dignity and are thus also anchored in numerous national and international legal texts¹. They are elaborated on in the explanatory notes to the articles in relation to various key aspects and situations in the lives of those needing long-term care and assistance. The Charter also formulates quality criteria and objectives which should be the goals of all good long-term care and support.

People can be in need of long-term care and assistance in various periods in their lives. This is why the rights contained in the Charter basically apply to people of all age groups. In order to explain these rights to people in need of long-term care and assistance, they are addressed directly in the explanatory notes to the articles.

The Charter is also designed as a guideline for people and institutions that have responsibility for long-term care, support and treatment. It appeals to caregivers, physicians and all those who are involved either professionally or as part of their social involvement in supporting the wellbeing of people in need of long-term care and assistance. This also includes those providing out-patient care, residential and semi-residential care facilities as well as those responsible in local government, health and long-term care insurance funds, private insurance companies, charitable associations and other organisations in the health and social sector. They should all be guided in their actions by the Charter. Those with political responsibility at all levels and the funding bodies likewise are obliged to further develop and safeguard the framework required to uphold these rights described in the Charter, especially the financial preconditions.

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.

¹ The rights listed in the Charter are broadly mentioned in numerous international and European texts and in some cases are bindingly incorporated in these documents. These include in particular the European Social Charter and the EU Charter of Fundamental Rights. Several German laws also include legal guarantees for people in need of long-term care and assistance. In addition to the rights contained in the Basic Laws, these are notably the rights to participate in the life of society (Section 1 SGB IX), the right to self-determination and independence (Section 1 SGB XI), to information and counselling (Section 7 SGB XI) to the priority of prevention and rehabilitation (Section 5 SGB XI) the priority of care at home (Section 3 SGB XI) and the rights included in social welfare laws and the Act on Residential Accommodation and finally, the right to individual benefits which applies to social legislation as a whole (Section 33 SGB 1).

Articles of the Charter

ARTICLE 1: SELF-DETERMINATION AND SUPPORT FOR SELF-HELP

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

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.

ARTICLE 3: PRIVACY

Everyone in need of long-term care and assistance has the right to the safeguarding and protection of his or her private and intimate sphere.

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 tailored to his or her personal needs.

ARTICLE 5: INFORMATION, COUNSELLING, 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, care and treatment.

ARTICLE 6: COMMUNICATION, ESTEEM AND PARTICIPATION IN SOCIETY

Everyone in need of long-term care and assistance has the right to esteem, interaction with others and participation in the life of society.

ARTICLE 7: RELIGION, CULTURE AND BELIEFS

Everyone in need of long-term care and assistance has the right to live according to his or her culture and beliefs and to practice his or her religion.

ARTICLE 8: PALLIATIVE SUPPORT, DYING AND DEATH

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

Articles of the Charter with Explanatory Notes

ARTICLE 1: SELF-DETERMINATION AND SUPPORT FOR SELF-HELP

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

You have the right to respect for your free will and freedom to make decisions as well as to advocacy and care. Those people responsible for your support, care and treatment are obliged to respect your will and adapt their actions accordingly. This also applies if you are not able to articulate verbally and express your wishes and do so, for instance, by the way you act. Individuals whose mental ability is impaired must be included in decision-making processes involving them in a way commensurate with their competence.

Free will and decision making, advocacy and care.

You are entitled to expect that any deliberation on how to achieve your individual goals and wishes under the legal and actual circumstances will include you, any trusted persons and those responsible for your support, care and treatment. Even if you yourself are not in a position to make decisions on your own or articulate your wishes, the people named above are obliged to ensure that any action taken is in accordance with your wishes. This involves, for instance, the choice of where you live, the care service to be responsible for you, the residential facility, the physician, the management of household, care and therapeutic measures and the organisation of your daily routine. You should also be able to be treated by your own doctor and dentist and receive your medication from your usual chemist if you are living in a residential care facility.

Choice of living location, care and treatment and organisation of daily routine.

The right to self-determination also extends to your financial and legal business and transactions with the authorities (making applications, filling out forms or being accompanied on visits to government authorities) and you should receive the support you require to handle these matters. Those advising and supporting you are obliged to act in your best interests and may not undertake any action which could be to your economic or legal detriment.

Settlement of financial business and dealings with legal bodies and authorities.

You have the option of making advance directives (instructions on action to be taken and enduring powers of attorney) for the eventuality that you may not be able to express your wishes at some later date. Wishes expressed by you in this way must be taken into account. Additionally, it is advisable to stipulate in advance who should be appointed as your legal representative by a guardianship court in the event that you should require a legal representative (appointment

Consideration of advance directives

of legal representative). (You can find further details under Article 8).

It is not unusual for conflicts to develop between the goal of respecting a dependent individual's right to self-determination and certain care obligations on the part of caregivers and the people treating you (typical situations are refusal to eat or the danger of falling). Should such a situation arise, you can expect an appraisal of the circumstances to be undertaken involving all parties.

The balance between self-determination rights and care obligations

The scope of self-determination and freedom of decision and conduct is, for example, restricted in situations where the rights and self-expression potential of others are involved. Financial and structural circumstances (i.e. personal funds or a lack of care facilities in a region) can narrow the options in some cases. Nevertheless, all involved in the support, care and treatment of those in need of long-term care and assistance are obliged to implement the right of those in care to self-determination as far as is possible.

Restrictions

You have the right to receive the support you need to be able to lead a life which is as independent and self-determined as possible. Even where there is considerable impairment to health or a high-level requirement for long-term care, you have the right for all necessary measures to be taken to prevent further deterioration or to bring about an improvement. This means, for example, that you are entitled to access to a (specialist) physician, to diagnostic procedures, medical treatment, preventive check-ups and vaccinations – regardless of your age or any disablement. This also applies to the access to individual health-promoting guidance designed inter alia to help you be as independent as possible of assistance by others. Nursing care and assistance, as well as medical and therapeutic treatment should be designed to support and enhance mental and physical abilities. They should aim to maintain or improve your quality of life and well-being and serve to assist you in managing your everyday activities yourself as far as possible.

Support for self-help, preventive and health-promoting measures

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.

You have the right to protection against physical violence such as being detained or restrained, hit, injured or having pain inflicted, against unwanted medical interventions and sexual abuse. Nobody may behave towards you in a way which is disrespectful, insulting or humiliating. This also means that you should always be addressed by

Protection against physical and mental violence

your name.

Neglect and lack of diligence in providing support, care or treatment, failure to provide the necessary assistance or insufficient attentiveness are also forms of violence. Specifically this means, for example, that you must receive timely assistance, you should not be kept waiting for an unduly long period if you are hungry or thirsty, want to get up or lie down or need to perform excretory functions. It also includes protection against bedsores and stiffening of the joints. You must also be protected against excessive cold or heat (over- or under-heated rooms, direct sunshine, draughts in the corridors, unsuitable clothing) if you are not able to attend to this yourself.

Protection against neglect

You have the right to protection against any harm caused by inappropriate medical and care treatment. This means, for instance, that your medication should be administered in a responsible and appropriate manner. Doctors are obliged to brief you clearly and fully on the effects, side effects and interaction between medications. Your perceptions and comments on signs of any possible side effects and interaction during any treatment or care measures should receive special attention and timely response from medical staff and caregivers.

Protection against inappropriate medical and care treatment.

As a general rule, you are entitled to move freely in your surroundings. If your state of health so permits, you must be able to enter, leave and lock your living quarters at all times. If you are in a residential institution and can leave your room of your own accord, you should be given a front door key and room key of your own. Any measure that restricts you in your freedom of movement and to which you have not consented is subject to court approval.

Protection against unwarranted measures restricting freedom of movement.

Measures which restrict your freedom can be necessary in exceptional circumstances. This could be the case if you are endangering yourself and others, and all other options for protection have been exhausted. Measures restricting your freedom, such as being locked in, restrained or the administration of tranquillizing medication, can constitute severe stress and endanger your health. This is why a qualified person must be present for the duration of the treatment. Checks should also be made at regular intervals on whether the treatment is still required or justified.

Restrictions

There is no need for you to tolerate any neglect or lack of respect you may encounter and you should not do so. If this does occur, you or a trusted person should make a complaint (you will find contact details

Help in coping with violence

on bodies dealing with complaints and emergency telephone numbers in the Annex). You are also entitled to expect caregivers, doctors and therapists to recognise any signs of violence, mistreatment and abuse in the course of their care, support and treatment and – if possible after consulting you – react in an appropriate manner. This could mean, for example, that immediate medical examinations should be initiated if there are clear signs of violence having been used. If signs of violence are discovered, the authorities responsible (nursing home supervisory body, police) must be informed and measures 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 his or her private and intimate sphere.

Your personal sphere must be treated with solicitude and respect. This also applies if you are looked after by a caregiver in your home or if you live 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 call out – await your response.

*Respect for
privacy*

You are entitled to respect for your need for privacy and the possibility of conversing in private. If you live in a residential institution and do not have a single room, you must nevertheless be given the opportunity of being alone for a while or being able to talk in a secluded place with persons of your choice. This also means that you must have the opportunity to make telephone calls undisturbed. Should you wish to talk to a psychological or spiritual adviser in confidence, you have the right to expect that this will be made possible.

*Opportunity for
privacy*

You should also be able to feel as much as possible at home living in a residential institution. This means, for example, that you can have your own personal things (small items of furniture, pictures, linen) even if you are sharing the room with somebody else. Agreements on these matters can usually be concluded in contracts with the residential home, including, for instance, the cost of laundering residents' own linen. Should you wish to keep valuables in safe custody, you are entitled to advice and support on the best way of doing so.

*Using items of
your own
in residential
institutions*

Privacy also means that you are able at all times to receive visitors. Should you share a room, the other occupant's need for peace and quiet must also be taken into consideration. Should it be necessary, you may ask the care staff to deny admission to visitors you do not

*Receiving
visitors*

wish to see.

Respect for the sphere of intimacy is also reflected, for instance, in the regard and consideration given to your feelings of modesty. You are entitled to be treated by your caregivers with the highest possible degree of sensitivity and discretion. This applies in particular to personal hygiene. Should you find the treatment by a particular person disagreeable, you should not accept this but voice your concern directly or to other staff members. 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 as you consider appropriate.

*Respectful
attitude to
feelings of
modesty.*

Your letters or electronic mail may not be received, opened or read by third parties without your consent. Should you live in a residential institution, a pigeon hole or mailbox of your own, for instance, can provide a high degree of discretion because your post will not be handled by several people. Should it not be possible for you to receive or open your post personally or use the channels of communication without help from others, you should determine which trusted person is to assist you (you can determine this in advance in an enduring power of attorney).

*Preservation of
privacy of
correspondence*

The right to privacy must also be reflected in the confidential handling of your data and documents. Documents and data concerning you may only be processed with your prior consent or that of your representatives and on the basis of statutory provisions.

*Protection of
personal data*

Everybody has a basic right to his or her sexuality and respect for his or her sexual identity and lifestyle – regardless of age or the degree of care and assistance required. No one may discriminate against you on the grounds of your sexual orientation. You alone decide on the kind of sexual relations and activities you pursue, provided you do not infringe on the rights of others. The scope for acting out your intimate relations is naturally dependent on the circumstances and surroundings in the setting in question. In this context too it may be advisable to obtain information on the institution before concluding a contract.

*Respect for
sexuality, sexual
orientation and
life-style.*

Depending on the degree of long-term care and assistance needed, it may not always be possible to guarantee an entitlement to privacy or respect for the sphere of intimacy. It should nonetheless be the goal of all involved in support, care and treatment to keep any restrictions to a minimum.

Restrictions

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 tailored to his or his personal needs.

If you need professional help, you must receive care, support and treatment from a qualified source that is adapted to your needs. You are entitled to be attended to by staff who have received training, further or advanced training or guidance for the task in hand, who have the necessary qualifications corresponding to your need for support, care and treatment. Methods and measures applied must be in accordance with the current state of the art in medicine and care.

Competent, dedicated care, support and treatment

All institutions and professional groups involved in your care, support and treatment should, in your interest, communicate and cooperate with one another and closely align the services they provide. This means, for instance, that when a service provider changes, information which concerns you and affects your care, support and treatment is passed on in an appropriate manner. Statutory data protection provisions must be adhered to in this process.

Cooperation between those involved in care, support and treatment

Your relatives and other trusted persons and any volunteer care persons should – if you so wish – be involved in your care, support and treatment and kept informed of measures and changes made which relate to your care and health. These groups should be involved in any consultations on your treatment with a service provider or institution and in any decisions made prior to conclusion of a contract if this is what you wish and agree to. Should you so wish, ongoing cooperation should be sought between your relatives/trusted persons and/or volunteer care persons and the service provider or institution.

Cooperation with relatives and volunteer care persons

If possible, the care you receive must be agreed upon with you as part of a targeted process. Measures taken should primarily support you in maintaining or regaining your independence and mobility. It is also the responsibility of long-term care to ensure that your medical complaints are alleviated and that you should not feel left to your own devices. Individually planned care is determined by your abilities, limitations, experiences and expectations. Specific objectives and measures should be planned on the basis of this. The objectives, measures and results are to be documented, checked at regular intervals and newly formulated if required.

Individually planned care

Care services and institutions should ensure that you have long-term contacts who are familiar with your situation and responsible for all your concerns. There should be a minimum of rotation of staff attend-

Long-term assignments

ing to you. Should you not accept any person assigned to your care and support, this should be taken into consideration in planning schedules.

Should you wish that certain aspects of your background or routines that are important to you (rest and sleeping patterns, personal hygiene, habits of dressing) be taken into consideration during long-term care, you should ensure that you inform the service personnel or institution of these wishes, or have them informed thereof. You are entitled to these being taken into consideration. Those in need of long-term care and assistance who cannot speak for themselves and in particular those suffering from dementia should be offered the opportunity of recognising habitual and familiar things in order to enhance their wellbeing

Consideration of personal background and habits

Your need for movement must be given support and encouragement, as long as there are no medical reasons that prevent this. Your personal movement routine (getting up, walking) must be supported and if necessary suitable aids should be placed at your disposal to ensure that your agility is maintained and to guard against any confinements (i.e. being bedridden). You should also have assistance in going out in the fresh air, should you so wish and if your state of health so permits.

Support for need for mobility

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 extent possible. This includes any signs of pain or distressing symptoms being recognised and the co-ordination and implementation of adequate therapies as part of your care and treatment.

Professional treatment and alleviation of distressing symptoms

You have the right to expect your wishes and needs in respect of eating and drinking to be taken into consideration. Meals served should be sufficient, appetising, varied, suitable for the elderly and healthy. Your preferences and dislikes should be taken into consideration as far as possible. Care should be taken not to serve anything known to disagree with you.

Food and drink adapted to individual needs and requirements

If possible you should also be able to take your meals outside regular mealtimes – according to your routine and appetite. Snacks between meals and beverages should always be available. Meals and beverages should be served in a way that makes them easily accessible. If you are being cared for at home and are bedridden, it is particularly important for your caregiver to see that food is placed in your immediate vicinity so that you are always able to eat and drink if no help is

Flexibility in serving food and beverages

at hand. Should you require special utensils or dishes to be able to eat and drink unaided, this must be made available. If you need help with eating and drinking, you must be sure of receiving the portions you want within the time you require to eat them.

*Help with eating
and drinking*

Special attention should be given to the diets of people with dementia, who often require individual enticement and motivation to eat and drink and frequently have a heightened energy requirement.

*Eating, drinking
and dementia*

Artificial feeding measures (stomach tube, intravenous drip) should only be undertaken with your explicit consent and after a process of appraisal involving the medical, care, ethical and legal aspects. If necessary the consent of your healthcare proxy or your legal representative should be obtained. You have a right to expect recognised ethical and legal guidelines to be adhered to in dealing with nutritional problems.

Artificial feeding

If you express criticism and suggestions to the institution and staff members, you are entitled to a timely and sensitive reaction and for these comments to be handled in confidence if you so desire. You should be able to express complaints without having to fear any disadvantages and be informed promptly what action was or will be taken as a result of the complaint. You may lodge your complaints via institutional complaints bodies in the community, the home supervisory body, the district medical association or your health or long-term care insurance fund or private insurance company (you will find further information on complaint channels in the Annex).

*Dealing with
complaints*

ARTICLE 5: INFORMATION, COUNSELLING, 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, care and treatment.

You have a right to comprehensive counselling on the possibilities of help, support and care available and on accommodation issues, if relevant also accommodation adaptation measures. The aim of counselling should be to enable you to remain living in your own four walls in spite of the need for long-term care, should you so wish. If your perceptions of assistance and care are to be realised to the fullest extent possible, you should make an early start in enquiring about the facilities in the region in which you want to live and give timely thought and planning to your individual wishes, the costs involved and the practicality of your ideas. In addition to the counselling and assistance services they offer, long-term care insurance funds, responsible state bodies and also to a certain extent service providers, are obliged to provide information on the counselling and assistance

*Comprehensive
counselling - the
first step in
making sensible
decisions*

options available. Private long-term care insurers also have information available. In addition to this, you can also make it easier to come to a decision by making trial visits and if necessary trial stays (usually for a fee). (You will find a selection of contact addresses of institutions that offer information and counselling on long-term care and assistance options in the Annex).

If long-term care is partially or wholly the responsibility of your relatives, they must be included in all your considerations regarding care, support and treatment. The experiences and ideas of family carers should be taken up and respected by the professional staff, providing that your needs are taken into account and the requisite care is guaranteed.

*Information,
relief,
guidance and
training of family
carers.*

Should family carers be temporarily unable to fulfil this function, statutory regulations provide an entitlement to replacement caregivers (for instance by services provided at home, short-term care, day or night care and in certain cases cost reimbursement for care services). Family carers must also have the opportunity to receive guidance and training in order to be able to care for you as competently and properly as possible. (You will find contact details for counselling for family members in the Annex).

You are entitled to full and understandable information on the type of services available and what they cost when you use a service or a facility. It should be clear from this information what services are rendered, the quality and cost of these services, which portion of these costs are covered by a long-term care insurance fund or private long-term care insurer and which portion is to be paid by you or recovered from a social assistance agency. Contracts drawn up by nursing homes and services contain individual regulations and the agreements they contain on services and fees are binding; this means that before concluding or amending an agreement with a service or institution, you must be fully informed on the subject matter of the agreement and the possibility of making any future amendments to the agreement, services and fees. This should include making available to you in advance a list of services with fees, a sample contract and when possible the home's regulations.

*Information on
content of
agreements,
costs and
services*

Talking to you openly, understandably and tactfully on 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.

*Information on
medical and care
measures*

Any participation in research projects is subject to the same prior consent provisos on your part as for any treatment. You should not be disadvantaged in any way should you not wish to participate. You must be fully informed about the mode of implementation, benefits, risks and alternatives to any treatment whose effectiveness and safety is not scientifically supported prior to the commencement of treatment. Should you yourself not be in a position to decide, the consent of your healthcare proxy or legal representatives must be obtained for each case in point. These parties may only agree to you participating in the research project if there is the expectation that it is beneficial to your health.

Thorough information on participation in research projects

You have the right to inspect your care documentation and any other documents relating to you and have copies made. This right also applies to your representatives. Your relatives, legal representatives and other persons also have a right to see these documents should they be so empowered, provided they can demonstrate a legitimate interest. Health and long-term care insurance funds only have the right to inspection to the extent permitted by law.

Inspection of documents

You can obtain further details on information to be given by doctors, participation in research projects and inspection rights from the "Charter of Patients' Rights" published by the Federal Ministry of Justice and the Federal Ministry of Health and Social Security (see Annex).

Details on further information

ARTICLE 6: COMMUNICATION, ESTEEM AND PARTICIPATION IN SOCIETY

Everyone in need of long-term care and assistance has the right to esteem, interaction with others and participation in the life of society.

You are entitled to certain communication needs and requirements being taken into consideration, for instance speaking or gesturing slowly and clearly. Should you need support in the use of aids (hearing or writing aids), you should be assisted in obtaining, using and if necessary correctly utilising these aids. If required, you may and should nominate someone as a speech facilitator or interpreter as the need may be. Some associations offer these services free of charge. (Contact details on these services can be obtained from the long-term care information hotlines, senior citizen organisations, local citizen information centres and charitable associations listed in the Annex).

Attention to communication needs and requirements

You should be given the opportunity to participate in social life in accordance with your interests and abilities. This includes having the

Participation in social life

opportunity to perform professional or volunteer work in line with your strengths and possibilities, as well as taking part in training measures.

If you are interested in politics and current affairs, culture or education, you should be made aware of the available opportunities (a fee may be charged for this).

In order for your needs to be satisfactorily met, you should inform your care and support staff, or have them informed, of your wishes and then – perhaps together with them – look for ways of structuring your time in the way you envisage.

Wishes and ideas

If you live at home and are in need of long-term care, you can enlist the support of volunteer or charitable organisations in order to be able to attend entertainment or educational events or if you want to go out for other reasons. You can also receive advice on the possibilities of receiving financial contributions or cost coverage from the social benefit agencies for these offers. The goal is for participation and communication offers to be readily open to people in need of long-term care who live at home to a greater extent than hitherto.

Opportunities in your own home

If you are living in a residential institution, you are entitled to possibilities for activity corresponding to your interests and abilities and which you enjoy. These include, for instance, participation in household or handicraft tasks, communal activities, celebrations and functions. At the same time, your wish not to participate in events should also be respected.

Opportunities in a nursing home

Should you be living in a residential institution, you have the right to exert influence on important decisions affecting life in the institution either yourself or via a corresponding body (i.e. nursing home advisory council or ombudsman). This includes, for instance, a voice in drawing up model contracts for the home and home rules of procedure, influence on service agreements, quality and remuneration agreements with the long-term care insurance funds and social assistance agencies, a voice in amendments to fees charged in the home and in organisation of everyday routines (i.e. composition of menus) as well as recreation and support options.

Participation and involvement opportunities in residential institutions

Through the residents' representative body, you can also participate in the preparation of decisions, for instance on repairs, renovations or consolidation measures. You should also have the opportunity to influence the selection of your fellow residents.

In addition, you are also entitled to the opportunity to exercise your citizen's right of participation. Primarily, this means your right to take

Participation in political elections

part in general elections. If you have a physical impairment, you can be assisted in voting by a person nominated by you and/or postal vote. The person assisting you is obliged to respect your freedom of decision 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 according to his or her culture and beliefs and to practice his or her religion.

Your cultural and religious habits and requirements should be respected as far as possible. You should therefore inform or see that those responsible for your care, support and treatment are informed of any forms of conduct, values, rituals or religious acts that are important to you.

Respect for cultural and religious values

Should you wish to observe any religious acts (such as prayer, fasting, ablutions) you should be assisted in doing so. When selecting a service or institution, please bear in mind that organisations with a religious or ideological orientation are guided by certain values and ideas.

Practising religious acts

You have the right to expect that your fundamental questions about life and your fears will be taken seriously. If you so wish, a member of the clergy or qualified counsellor should be consulted.

Help with fundamental questions about life

You can still expect to be treated with respect if you have a belief which is not shared by those supporting you.

Respect for beliefs

ARTICLE 8: PALLIATIVE SUPPORT, DYING AND DEATH

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

Everything possible should be done to make the process of dying as dignified and tolerable for you as possible. Those treating and accompanying you during the last phase of your life should respect your wishes and take them into consideration to the greatest possible extent. This includes the application of effective measures and relief of pain and other distressing symptoms. Should you so wish, psychological or religious guidance through this phase should be made available. Regardless of whether you die at home, in a hospital, a hospice, nursing or residential home, the institution involved should exhaust all possibilities to see that this happens in an environment which comes closest to your perception of a dignified death. (Individual end-of-life care for the dying is provided, for example, by outpa-

Individual end-of-life care

tient or inpatient hospice services, contact details in the Annex). -

Doctors and care staff should – if you so wish – include your relatives and other trusted persons in your end-of-life care and offer them professional support. Should you wish certain people not to be included, this must also be respected.

*Cooperation with
family members*

As long as you are mentally competent, you yourself can determine 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. Doctors and others may not, however, take any measures which would systematically lead to death even if you should explicitly so wish.

*Self-
determination at
the end of life*

In an advance directive or enduring power of attorney, you can determine in advance who should make decisions on your behalf if you are not mentally competent, concerning how your process of dying should be conducted and who should accompany you during this time. You can also lay down your perceptions on certain kinds of treatment in case you are no longer sufficiently mentally competent. Whatever you determine binds the team treating you, those with power of attorney and legal representatives, as long as these wishes apply to the specific situation in question and there are no concrete factors indicating that a previously expressed directive no longer conforms to your current wishes. Examination should thus be given to whether the wishes you expressed in advance apply to the specific situation in hand and whether the written directive can still be assumed to apply. In the event of mental incompetence on your part and in the absence of an enduring former statement of will, or should this be ambiguous, a decision on the admissibility of medical treatment which is not deferrable will be based on your presumed wishes, ascertained from the views you previously expressed and after questioning your relatives, others close to you and those responsible for your care to date. You can obtain information on advance directives and enduring powers of attorney from, for instance, from the Federal Ministry of Justice, the health authorities, consumer organisations, medical associations, the churches, patient organisations or charitable organisations (contact details in the Annex).

*Advance
directives*

You also have the right to be treated with sensitivity and respect as a decedent. The wishes you expressed during your lifetime should be taken into consideration after your death. Your relatives, persons close to you and where applicable, fellow residents, should be given sufficient time to take their leave. You can determine in advance how you wish to be treated after your death and what should be done with

*Leave-taking,
burial*

your body. This relates for instance to the viewing and type of burial.

You can also make advance directives on the question of donating organs and making your body available for scientific purposes. It is only possible to remove an organ if you have explicitly consented to donation, for instance by means of an organ donor card. Should this not be the case, no organs may be removed without the agreement of your relatives.

*Rights over the
body*