

**ANSWERS OF THE GERMAN INSTITUT FOR HUMAN RIGHTS TO THE GUIDING QUESTIONS FOR THE
NORMATIVE FRAMEWORK OF THE ISSUES EXAMINED AT THE IX SESSION OF THE OPEN-ENDED
WORKING GROUP ON AGEING:**

Long-term and Palliative Care

NATIONAL LEGAL FRAMEWORK

1. What are the legal provisions in your country that recognizes the right to long-term and palliative care? Do they have a constitutional, legislative or executive foundation?

There are various legal provisions concerning care, at federal state and national level.

The Social Code XI¹ establishes the mandatory nursing care insurance.² The state provides benefits in kind for care, care allowance, other care aids and measures that improve the home.³ Also benefits for caregivers are included.⁴ Inpatient measures are subsidiary to outpatient assistance. The benefits to be granted to a person depend on the degree of need for care and support. The concept of the need for care was adapted by the 2nd Long- Term Care Strengthening Act⁵ (2015) now older persons with dementia are also included.

However, the nursing care insurance is not designed to be cost-sufficient. Parts of the measures have to be payed by the individual itself (partial coverage principle); one can become dependent on social tax-funded benefits (Social Code XII /SGB XII⁶).

In addition the non-binding charter for the rights of persons in need of care⁷ was an attempt by the government, in cooperation with various other state and civil actors, to make human rights applicable. The Charta's articles were partly legally established through various acts.⁸

The legislative competence for regulatory provisions of home law lies with the federal states, that all have issued statutory ordinances. In addition, national consumer protection standards were improved through the Living and Support Contracting Act.⁹

¹ Sozialgesetzbuch XI (SGB XI).

² In 2016 17.5 million people in Germany have reached the age of 65. 2,878,300 are currently in need of care. The majority of older persons requiring care (2.08 million) are treated on an outpatient basis (73 %) and 783,000 are hospitalized (23%).

³ §§ 36, 37, 40 Social Code XI (SGB XI).

⁴ §§ 44 ff. Social Code XI (SGB XI).

⁵ Zweites Pflegestärkungsgesetz, BGBl. I S. 2233, 2239.

⁶ https://www.gesetze-im-internet.de/sgb_12/.

⁷ Pflege-Charta , <https://www.pflege-charta.de/de/die-pflege-charta/acht-artikel.html>.

⁸ Nursing Care Development Act (Pflege-Weiterentwicklungsgesetz), Nursing Care Realignment Act (Pflege Neuausrichtung-Gesetz), Nursing Care Strengthening Acts (Pflegestärkungsgesetze), Prevention Act (Präventionsgesetz).

⁹ Nursing Home and Care Contract Act (Wohn- und BetreuungsvertragsG). Entrepreneurs who offer the provision of housing combined with the provision of care services have obligations to extensive inform and to adjust existing contracts.

The palliative care is expressly part of the care concept of the statutory health insurance and is legally defined there¹⁰.

In 2015, the Hospice and Palliative Care Improvement Act¹¹ was adopted. Also, the Charta for the care of seriously ill and dying persons¹² has decisively shaped and promoted national political processes¹³. However, it still faces practical barriers as it lacks in-depth training in palliative care. Furthermore since November 2017, the Home Nursing Directive¹⁴ has included palliative care, but this lacks a quality control mechanism.

NORMATIVE ELEMENTS

2. What are the key normative elements of the rights to long-term and palliative care? Please provide references to existing laws and standards where applicable.

The right to care applies to care and support services in all settings, public and private, including but not limited to in the home, in the community, and in residential settings. Older persons have the right to the care and support services they require to lead a dignified, autonomous and independent life.

The right applies to holistic palliative care and palliative services in all settings and is not limited to end of life care or pain relief or any particular treatment or setting.

More details on the key elements can be found in the joint submission.¹⁵

3. How should long-term care and palliative care be legally defined?

Older persons have the right to affordable, accessible, appropriate, inclusive, quality, timely, holistic, care and support services which are adapted to their individual needs, promote and protect their will and preferences without discrimination of any kind.

Older persons have the right to palliative care and palliative care services that are available, affordable, accessible, and acceptable without discrimination.

IMPLEMENTATION

4. What are the policies and programmes adopted by your country to guarantee older person's enjoyment of their right to long-term and palliative care?

The network Campaign for Healthy Nursing¹⁶ has been launched. It is the network's objective to preserve and promote the health of nursing professionals as well as to improve their working

¹⁰ § 37b Social Code XI (SGB XI).

¹¹ Hospiz- und Palliativgesetz, BGBl. I 2015 S. 2114

¹² Charta zur Betreuung sterbender und schwerstkranker Menschen in Deutschland, Deutsche Gesellschaft für Palliativmedizin, Deutscher Hospiz- und PalliativVerband e. V., https://www.charta-zur-betreuung-sterbender.de/files/bilder/neu2%20RZ_161004_Handlungsempfehlungen_ONLINE.pdf.

¹³ The Federal Ministry of Senior Citizens promotes a coordination center to implement the Charta's recommendations. <https://www.koordinierung-hospiz-palliativ.de/>.

¹⁴ Richtlinie des Gemeinsamen Bundesausschusses über die Verordnung von häuslicher Kranken-pflege, https://www.g-ba.de/downloads/62-492-1703/HKP-RL_2018-09-20_iK-2018-12-01.pdf.

¹⁵ Joint submission on normative elements from Commissioner for Human Rights of the Republic of Poland and the German Institute for Human Rights.

conditions and professional prospects. Its work centers on the transfer of knowledge and attractive working conditions.

The new regulations in Germany have led to a considerable increase in benefits for all care services, particularly with regards to out-patient care¹⁷. However the system is still not close to being sufficient.

The medical health insurance service¹⁸ examines all long-term care facilities and out-patient nursing services on an annual basis with regards to these and many other quality requirements. New indicators and measurements for quality were developed and will be implemented in 2019¹⁹.

However nationwide palliative care supply does not exist. This is currently being developed in form of pilot projects. In this area too, the problem of a shortage of skilled workers is evident.

5. What are the best practices and main challenges in adopting and implementing a normative framework to implement these rights?

a) Sustainable financing of long- term and palliative care

The three Long-Term Care Strengthening Acts have particularly led to increased expenditures for LTCI.²⁰ These additional expenditures are financed via compulsory contributions by employers and employees. However the insurance system is still cost insufficient and nursing services are focusing on cost efficiency rather than the quality of care.

b) Quality (Practices + Staff)

The shortage of qualified nursing staff and supportive infrastructures such as counseling and nursing care facilities leads to considerable waiting times for nursing services and a poor quality of care.²¹

Moreover the creation and promotion of alternative forms of living (such as shared housing of old persons or persons with dementia, housing of more generations together) is necessary.

c) Access to information

One of the main issues lies in the deficient information of older persons about their rights and entitlements. A nationwide information system does not exist, despite the introduction of so called care bases²². A lot of possible measures are not being applied for by older persons in need.

¹⁶ Offensive Gesund Pflegen - under the umbrella of the Initiative New Quality of Work , funded by social partners Initiative (Neue Qualität der Arbeit, IN- QA).

¹⁷ Long-Term Care Strengthening Acts, BGBl. I S. 2222, BGBl. I S. 2424, BGBl. I S. 3191. Care facilities have received additional nursing personnel. The coordination of care and support services has been improved, for example by strengthening the role of local authorities.

¹⁸ Medizinischer Dienst der Krankenkasse (MDK). The 5th quality report of the MDS (January 2018) confirms a further decline in the use of measures that restrict the patient's freedom. However, it has been reported in practice that medicamentous coercive measures are increasing. Especially dementia patients are affected by this. Therefore it is urgent to improve the patients nurse ratio.

¹⁹ § 113 Social Code XI (SGB XI) The results are published in 'transparency reports' and may lead to corrective or punitive measures. The former instrument of nursing grades has proven to be insufficient and test results were perceived as too good. For this reason, the legal basis was revised in 2015. The new system shall be implemented in 2019 and its effect remains to be proven.

²⁰ (amounting to more than 5 billion EUR (+20 %) per year).

²¹ https://www.mds-ev.de/fileadmin/dokumente/Publikationen/SPV/MDS-Qualitaetsberichte/_5._PflegeQualita__tsbericht_des_MDS_Lesezeichen.pdf.

EQUALITY AND NON-DISCRIMINATION

6. Which are the measures adopted to ensure equitable access by older persons to the enjoyment of the right to long-term and palliative care, paying special attention to those who are vulnerable or in vulnerable situation?

Persons in need of care can choose between institutions and services offered by various providers, but choices are limited to financial resources and offers especially in rural areas. Reasonable requests concerning care aspects, e.g. to provide same-sex nursing or to consider religious needs shall be fulfilled. Individual counselling, also for relatives, is offered timely and on a regular basis.

Within the statutory nursing care insurance, all insured persons are entitled to palliative care. No distinction is made regarding age or gender. In case of financial need the contribution fee is covered by tax-financed benefits.

However, in practice the entitlement to palliative care is not fully implemented.²³ Besides the limited capacities, language barriers create an obstacle for accessing information and palliative care.²⁴

PARTICIPATION

7. Does the design and implementation of normative and political framework related to long-term and palliative care include an effective and meaningful participation of older persons?

To ensure an effective participation of older persons maintaining social structures in the domestic and residential environment is crucial. Therefore, outpatient care is prior to inpatient care and domestic nursing services as well as shared housings of old persons are established and supported.²⁵ This strategy however contains the problem, that an autonomous and independent life of older persons cannot be warranted due to lacking verification and inspection of domestic situations. The dependency and isolation of an older person can even elevate in the domestic surrounding, if a social structure is not accessible in the vicinity.

ACCOUNTABILITY

8. What judicial and non-judicial mechanisms are in place for older persons to complain and seek redress for denial of their right to long-term and palliative care?

²² „Pflegestützpunkte“.

²³ According to a Survey by the Bertelsmann Foundation from 2015 palliative care facilities, hospices and likewise services do not exist in more than a quarter of all rural and urban districts in Germany. Even though up to 90% have a need for palliative care at the end of life, only 30% of those who died in 2014 received palliative medical care. Fact-check Health, Bertelsmann Foundation, 2015, https://www.bertelsmann-stiftung.de/fileadmin/files/BSt/Publikationen/GrauePublikationen/SPOTGes_VV_Palliativversorgung_2015.pdf

²⁴ <https://www.wegweiser-hospiz-palliativmedizin.de/>.

²⁵ § 45 e, 45f Social Code XI (Sozialgesetzbuch XI, SGB XI).

Every administrative act has to contain instructions on how to file an appeal.²⁶ Individual rights and entitlements concerning social security are legally enforceable and the filing of an appeal is free of charge. Complaints may also be lodged with the medical health insurance service.

These instruments are however rarely used by older persons due to a lack of information of their own rights and the existing mechanisms to enforce those rights.

When it comes to abuse and violations legal recourse to the courts is open to everyone, however it is rarely used by older persons, as a timely compensation cannot be expected and in the meantime the circumstances of life may deteriorate due to the filing of an appeal. Low-threshold complaint mechanisms or contact persons are missing. In addition, a large portion of the victims affected, do not take action due to shame.

Furthermore, the protection of whistleblowers is also inadequate. Also in this regard, the expansion of low-threshold and independent complaint mechanisms in the care sector is indicated.

²⁶ § 90 Social Court Act (SGG).