



Palliative Care

Recommendations from the society for diagnosis and therapy of
haematological and oncological diseases

Publisher

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1 General information

Especially when cancer is progressive or no longer curable (in oncology, one speaks of a "palliative" disease situation), suffering can arise that may include physical symptoms such as pain, shortness of breath, nausea, etc., but also result in psychosocial distress, worries, existential fears and other hardships. In addition to the anti-cancer treatment, other **support services** become helpful and necessary. This approach of support to make disease-related suffering of all dimensions more bearable, the people and structures required for this, and the support concept itself are referred to as "**palliative medicine**" or "**palliative care.**"

This form of support often requires the involvement of expertise and resources from many professional groups, for example physicians from different disciplines (‘interdisciplinarity’), as well as nurses, psychooncologists, social service staff, physiotherapists, pastors, and many more (‘multiprofessionality’). In addition, these situations require **round-the-clock accessibility** not only in the hospital but also at home and, in addition to telephone consultation, the specific offer of **home visits**. Specialized palliative care teams and facilities, with their additional expertise and capabilities, are particularly helpful, in addition to the physicians and services already involved, when complaints are multi-layered (complex), when the expertise of many professional groups is needed, or when unplanned home visits are required also at night or on weekends. This form of specialized palliative care can be involved temporarily or permanently in cooperation with oncological treatment and may also take over treatment in particularly complex situations.

1.1 What are Specialized Palliative Care formats?

- **Specialized Palliative Home Care = SAPV teams:** For support at home (or in nursing facilities), there are so-called **SAPV teams**, which offer round-the-clock counseling, therapeutic interventions and home visits.
- **Multiprofessional consultation services:** For inpatients, there are multiprofessional palliative consultation teams (so-called ‘palliative services’), which provide medical, nursing, social support and psycho-oncological care to patients with particularly complex demands on all wards
- **Palliative medicine outpatient clinics**, which are primarily active in an advisory capacity for mobile patients.
- **Palliative care units:** are facilities and points of contact for particularly comprehensive, inpatient treatment when symptoms and psychosocial distress cannot be adequately managed elsewhere - they are *not* facilities that care for dying patients only.
- **Hospices:** are care facilities in which people at the end of life are accompanied and cared for by specially qualified nurses in a homelike atmosphere outside a hospital. The guest rooms of a hospice are often so spacious that relatives can spend time and also may stay overnight. In most cases, hospices offer more room for individuality and privacy

than hospitals. Dedicated volunteers also support the work in the hospice in a variety of ways.

- **Outpatient hospice services:** Volunteers support patients and relatives through their work in outpatient hospice services at home, but also in the hospital. The volunteers are specially qualified, contribute in very different ways and provide personal support.

1.2 When should palliative care support be involved?

In the recent past, many studies have shown that the earlier palliative care for support is offered, the more effective it is [1, 2, 3]. At the beginning of an incurable disease, it is usually a matter of no more than developing a "Plan B" for the event that tumor therapy no longer works. It can be relieving to know that there is round-the-clock availability for problems and crises, that effective symptom relief is possible, that support is available for questions on the course of the disease, and that one's own wishes and concerns can be recorded with regard to the further course of the disease. Therefore, the term "palliative care" should be understood in the sense of early, broad-based support, and not only in the sense of treatment exclusively at the end of life.

2 Good to know

2.1 Is palliative care support prescribable?

Family physicians and treating specialists (e.g., oncologists) can assess the need for additional support and involve the respective palliative care services and facilities and provide a prescription for palliative home care. Once the prescription has been approved by the health insurance, there are no additional costs for the patients.

2.2 Where can I find palliative care?

Palliative care is now available throughout Germany with outpatient and inpatient facilities. All existing specialized services and palliative care facilities in Germany can be found at <https://www.wegweiser-hospiz-palliativmedizin.de/>.

2.3 What is possible in outpatient palliative care?

With the appropriate support and expertise, many things can be organized at home that at first glance seem almost inconceivable: intravenous nutrition and fluid administration (via port; parenteral nutrition), continuation of antibiotic therapy, continuous pain therapy via patient-controlled devices (PCA pump), and much more. It is therefore advisable to discuss the wishes for further treatment at home and to find out about the remaining treatment options at an early stage.

2.4 Is there support for relatives as well?

There are also various supportive offers for relatives, be it in the context of social service and socio-legal counseling, psychological support by psychooncologists or psychotherapists in private practice, or support by voluntary hospice helpers (§39a SGB V), and much more.

3 Tipps and tricks

- Discussing a "Plan B" or even determining the course of action in the event of conceivable **problems and crises** is neither easy for patients and for relatives, nor for all those

contributing to the therapeutic concept. Many studies and long-time experience in oncology and palliative medicine show that after the necessary initial effort, relief almost always prevails after these clarifications. In most cases, these **arrangements** are the best way to ensure that unwanted courses and measures are omitted and only accepted measures take place [4, 5, 6, 7]. As a patient and family member, the family doctor and/or oncologist should be involved about palliative support and necessary arrangements if this has not yet been done despite the incurable disease situation [8].

- Agreements on how to proceed in the event of problems and crises can usefully be documented in the form of **living wills** (see also Voicing My Choices™ below). These are all the more helpful for the attending physicians, the more concretely they refer to the decision-making situations conceivable in the case of the illness.
- An even more important form of written **power of attorney** is the so-called **health care proxy. It specifies** which person is to legally express the patient's will in a specific decision-making situation, for example if a patient cannot be questioned clearly enough in the case of high fever or other clouding of consciousness. A commonly used form nationwide can be found here, <https://www.justiz.bayern.de/service/juristisches-lexikon/>. Notarization is not required for these two documents, living will and health care proxy. It makes sense, however, for the attending primary care physician/oncologist/palliative care physician to help with the wording and concretization. The term "advance care planning" was coined for this concept of early agreements based on the values of the patients themselves.

4 Further links and information

- Guide to hospice and palliative care: <https://www.wegweiser-hospiz-palliativmedizin.de/>
- S3 Guideline Palliative Care for Patients with incurable Cancer: <http://leitlinienprogrammonkologie.de/Palliativmedizin.80.0.html>
- DKFZ Cancer Information Service (KID): <https://www.krebsinformationsdienst.de/wegweiser/adressen/palliativ.php>
- Onkopedia Palliative Care Chapter (online 2019): <https://www.onkopedia.com/>
- Voicing My Choices™ is an advance care planning guide designed to assist young people living with a serious illness in communicating their end of life care preferences to their family, care-givers, and friends: <https://paliativo.org.br/wp-content/uploads/download-manager-files/voicingmychoices.pdf>

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6 Gender

For better readability, masculine and feminine formulations are not used simultaneously. The gender terms used in this text represent all gender forms.

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8 Disclosure of Potential Conflicts of Interest

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