

# CARE TIPS

## Palliative Care

published by Thomas Sitte

16th edition

Englische Ausgabe



# CARE TIPS

---

## Palliative Care

16th edition

published by Thomas Sitte

## Legal Information

Publisher: Deutscher PalliativVerlag  
(Verlag der Deutschen PalliativStiftung), Fulda 2016

16th edition  
ISBN-Nr. 978-3-944530-29-1

Rindt-Druck  
Printed on certified recycled paper

Editing: Dr. Thomas Sitte  
Design: Anneke Gerloff, Wolf-Marcus Haupt  
Translation: Julian Wheatley & [www.ucfd.de](http://www.ucfd.de)

Deutsche PalliativStiftung  
Am Bahnhof 2  
36037 Fulda  
Mail: [info@PalliativStiftung.de](mailto:info@PalliativStiftung.de)  
Web: [www.palliativstiftung.de](http://www.palliativstiftung.de)  
Telephone +49 (0)661 / 4804 9797  
Fax +49 (0)661 / 4804 9798

Picture credits  
Title picture: Janet Brooks Gerloff  
Page 3: Kurt Peter  
Pages 5, 39: Anton Weber  
Page 7: Elke Leppkes  
Page 9: Dieter Tuschen  
Page 13: Christina Plath  
Pages 19, 33, 64: Thomas Sitte  
Page 22: Edelgard Ceppia-Sitte  
Page 24: Barbara Harsch  
Page 25: Johannes Wüller  
Page 26: Gerhard Michl  
Page 36: Ute Franz  
Page 49: Valentin Sitte  
Page 53: Elena Elflein  
Page 66: Anne Menz  
Page 72: Christiane Langer  
Page 75: Christina Plath  
Page 78: Barbara Kamps  
Page 81: Sebastian Plath

*Thanks for support with content go to*

*Gian Domenico Borasio, Mechthild Buchner, Barbara Engler-Lueg, Petra Feyer, Gideon Franck, Annette Gaul-Leitschuh, Christoph Gerhard, Anneliese Hoffkamp, Bettina Kraft, Barbara Maicher, Arnd T. May, Andreas Müller, Petra Nagel, Christina Plath, Stefan Schneider, Caroline Schreiner, Maralde Wüsthofen-Hirsch*



## A daughter

„Spontaneously, I think it's good that it is evident you are still alive when you are dying. Most people think that when you are dying your life is already over! But what would a two-hour film be if you simply left out the last 2 minutes? Unimaginable, the cinemas would be in uproar.

When our mother was dying and no longer talking we got ice-cream and crisps, Anton played songs from his newly-recorded CD on his guitar and we chatted and laughed, talking about what our plans were and Mama smiled and raised her eyebrows. I asked her „Isn't this how you always wanted to die?“ and she nodded.

Whenever I think back to when my mother was dying I have a real feeling of fulfilment, because I don't think that we could have made the experience a better one. If someone asks me how it was when my mother died, I answer, „She died well! In our presence, with lots of candles and flowers, just as she always wanted to go.“

THANK YOU once again for all your help and support!!“

Ellen Lewis



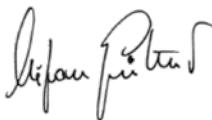
## Foreword by the Hesse Minister of Social Affairs

In our aging society the provision of care to people who need it, especially those suffering from an incurable disease in advanced stages and with only a limited life expectancy represents a benevolent and indispensable task. It is also a task that requires mental tools – for the people dedicated to performing it professionally, for those working in the field of care and hospice care on a voluntary basis and not least for family members.

The Care Tips that you have in your hand can be such a tool. Whether you are confronted by symptoms of breathlessness or dry mouth in the person you are caring for or if you yourself are suffering under this heavy burden: this small brochure contains advice, tips and valuable information. The Hesse Ministry of Social Affairs and Integration is now supporting once again the new edition of these „Care Tips“ – this year in co-operation with the care insurance funds. The knowledge that the publisher has compiled here and supplemented over the years is intended for broad distribution. My thanks go to those who have helped make this knowledge available in this form.

The first bilingual edition is now also available, with further translations in progress. With this we are acknowledging on the one hand the fact that many people requiring care in Germany are cared for by foreign carers, on the other hand the fact that we are increasingly bearing responsibility for caring for seriously ill and dying migrants. The Care Tips in the respective national languages can prove of valuable assistance in this.

I have great respect for the efforts of all those involved in the process of care and hospice work. They set a major example for humanity in our society. They are worthy of all of our thanks. I hope that the Care Tips prove to be a source of support and advice to them.



*Stefan Grüttner  
Hessian Minister of Social Affairs  
and Integration*





## Foreword for the notes from an Islamic viewpoint

It was initially a surprise and a challenge for me when my colleague Dr. Sitte, Chairman of the Deutsche PalliativStiftung, asked me to rework the Arabic version of the book „Care Tips – Palliative Care“ and add an Islamic viewpoint.

I began as usual from the last page, also reading between the lines. I was very impressed by the quality and the content. However, I also found myself faced with a considerable task, as I also wanted to rework the Arabic translation.

As a doctor, oncologist, palliative physician and someone with a long interest in the Islamic medical ethic, I realised that the book held many similarities with the Islamic view of palliative care.

I subsequently attempted to use footnotes to clarify or comment on this Islamic viewpoint at certain points in the book. If anyone is interested in examining this subject in greater depth, I refer them to the brochure „Sterbehilfe und Sterbebegleitung aus islamischer Sicht“ ([www.Islam.de](http://www.Islam.de)).

Finally, I would like to thank the Deutsche PalliativStiftung and its Chairman Dr. Sitte for their work publicising and supporting palliative care in the Muslim community. It was a great honour for me to support this work from the Muslim viewpoint.

*Dr. M. Z. Halabi*

*Dr. med. (syr.) M. Zouhair Safar Al Halabi  
Physician for Internal Medicine, Radiotherapy and Palliative Medicine  
Representative of the Central Council of Muslims in Germany for Medical Ethics and Animal Welfare*





## A personal foreword to the 16th edition

In 2007 a small series was published on the internet, offering practical assistance in difficult times. Tips that not only helped carers, but could also significantly improve the quality of life of patients. Soon this small collection was expanded and printed as a leaflet. Edition after edition was published, at the publisher's own expense. The Care Tips were passed around and became an inside tip.

And now? A bestseller, of which I am proud. Once again, a new version of the Care Tips lies printed before me. In nearly ten years of work I have continuously tinkered, supplemented and amended. The first texts have been gone through time and again, with (nearly) all foreign words and complex terms replaced by clearly comprehensible language. The content is also constantly up to date. A task that proved more difficult than I had anticipated.

### Successful principle

Clear scope. Clearly identifiable themes, mostly of direct interest to many people. Each theme is often just one or two pages in length, clear and concise, whilst at the same time scientifically correct.

Does 200,000 printed copies and countless downloads from the [www.palliativstiftung.de](http://www.palliativstiftung.de) website represent a lot? Or is it still far too few for 80,000,000 Germans. For many migrants and refugees, some also afflicted by serious illness, without adequate means of understanding German.

### Care Tips now available in numerous languages

Now the Care Tips are also set to be available in Polish, Turkish, Arabic, Czeck, Slovakian, Serbian, Croatian, English, Romanian, Russian,... Also in bilingual form, to enable easier learning of German, in part printed, always as parallel PDF for downloading from the website.

I look forward to seeing how the Care Tips principle works in the non-German editions!



**Being right is one thing, being acknowledged as right is another.**

The current debate in Germany on euthanasia has shown that not all those who express an opinion on the subject know what they are talking about. The talk is always of a „painful death“: before I suffer unbearably at the end of my life I want to be helped to die. And yet scarcely anyone is aware of the options for easing suffering.

Many dying people suffer additionally through inappropriate and burdensome therapies. Others are kept alive contrary to their express will, although the law in Germany clearly prohibits this.

**If we had read this before, it would have spared us a lot.**

This is something I frequently hear in daily care. But this is also what I hear with regard to this purposely small book.

On behalf of the PalliativStiftung I would like to expressly thank the Hesse Ministry of Social Affairs and Integration and the Hessian care insurance funds for their sustained and generous financial support, which is what made this large-scale distribution at all possible.

It is important to me that everyone is given the chance to express their wishes and desires for their own death; and that they are provided with a capable network that guarantees them the appropriate care for this.

Many people choose to blank out the issue of death and dying. Few people ask themselves what care they wish to receive in the event of severe and life-threatening illnesses. The Deutsche PalliativStiftung is working to establish a new end-of-life culture.

**Amendments to the narcotics law and criminal law, together with a new law.**

In recent years the PalliativStiftung has helped to raise awareness of the options and in particular the legal basis for end-of-life care. Doctors and carers in particular have acquired more legal certainty for their actions. I myself have paid a heavy price and was forced to give up my medical practice in 2010 due to a criminal prosecution. Thanks to great support I can now work again without fear of imprisonment, with the Narcotics Law amended to reflect the necessities of the present age.

In this, one thing is very important to me: that there shall be no „Swiss solution“ here with organised assisted suicide.

This prohibition was anchored in § 217 of the Penal Code.

In addition, a new Hospice and Palliative Act has been passed, with the aid of which care can be further expanded.

**There is still a prevailing spirit of „higher, faster, further“. What we need, however, is a spirit of „not too high, not too fast, not too far“. What we need is restrained medical care.**



*Thomas Sitte*

## Thank you!

Our special thanks go to many unnamed employees in public authorities and institutions, in the fields of politics and business, represented here by the Hesse Ministry of Social Affairs and Integration and the care insurance funds for funding the reprint.

Palliative care lives from the input of the individual with patients, but it is supported by the palliative attitude of all and the commitment of many to the cause. It is often surprising who suddenly helps us and where, whether it is for specific concerns and problems of the patients in our care or matters relating to the establishment or realisation of hospice work and palliative care. Unexpected doors open in seemingly hopeless situations. This applies to all areas of life and always succeeds in humbling me. We should not stop believing in the inherent goodness of people.



## Contents

A daughter .....	4
Foreword by the Hesse Minister of Social Affairs .....	6
Foreword for the notes from an Islamic viewpoint .....	8
Preface of the publisher for the 16th edition .....	10
Thank you! .....	12
My friend Bernd .....	16
1. What does palliative mean? .....	20
2. Tips for talking to doctors .....	23
3. What can relatives do? .....	25
4. When burnout threatens: Self-care .....	27
5. Pain relief .....	29
6. Breakthrough pain .....	30
7. Breathlessness .....	31
8. Fear .....	32
9. Restlessness .....	34
10. Hunger .....	35
11. Thirst .....	36
12. Oral hygiene and assistance with feelings of thirst .....	37
13. Weakness .....	38
14. Tiredness .....	39
15. Itching .....	40
16. Lymphatic drainage, caresses and more .....	41
17. Yoga in palliative care .....	42
18. Basal stimulation .....	43
19. Rhythmic massage .....	45
20. Bedsores and skin care .....	46
21. Position and pressure relief .....	47
22. The correct position .....	48
23. Scents .....	49
24. Unpleasant wounds .....	50
25. Constipation .....	51
26. Nervous illnesses and palliative care .....	52
27. Palliative operations .....	54

28. Palliative radiation .....	55
29. Palliative chemotherapy .....	56
30. Therapy orientation .....	57
31. Dealing with grief .....	58
32. Health care proxy .....	60
33. Care ordinance .....	60
34. Living will .....	61
35. The pain of saying goodbye .....	62
36. Pastoral care .....	65
37. Psychological support in the last stage of life .....	67
38. Discussions within the family .....	68
39. Hospital Support Team .....	69
40. Palliative ward and hospice .....	70
41. Psychosocial support .....	71
42. Voluntary hospice service .....	73
43. Children and dying .....	74
44. Hospice work and palliative care with children .....	76
Afterwords? .....	79
Interesting links .....	80
Deutsche PalliativStiftung .....	81

### **Annotations from an Islamic viewpoint:**

(1) Assisted dying and palliative care from an Islamic viewpoint .....	22
(2) The significance of prayer, Koran recitation and invocations for the sick .....	26
(3) The use of painkillers and sedatives .....	30
(4) Annotation .....	33
(5) Substances containing alcohol and pork .....	38
(6) Active assisted dying and assisted dying from an Islamic viewpoint .....	58
(7) Treatment of the dying and grief from an Islamic viewpoint .....	59
(8) The living will .....	62
(9) Grieving with the family .....	64
(10) Pastoral care for Muslims and non-Muslims .....	66

## My friend Bernd by Petra Nagel

My friend Bernd is dead. He died on 20 September 2004, the day on which I launched my first CD. I still haven't really comprehended it. For many years, Bernd was just a colleague. Around two years ago we moved to first-name terms, from colleague to friend.

„It's cancer,“ he said, „Bernd says he's got cancer.“ My husband had taken the call, looking at me in anguish. With the receiver in his hand, at the end of the line a fate that we could never have anticipated.

This banal sentence was the beginning. From here on the friend was a dying friend. One who had to fight for his life. The story is soon told: back pain, strong painkillers, slipped disc and then the diagnosis: metastases, initiated by a bronchial tumour.

But we didn't yet know that on that summer's day last year. We still find things hard to explain now. Bernd left a lot of unanswered questions, questions about his illness, about his person.

He was a person that liked to talk. To tell stories. A journalist of the old school. Someone who put everything into his reports, who always wanted to be in the thick of things. Someone who told stories over again, even though they were not the stories that were in his own heart. A larger-than-life man, „a rogue“, my mother would have called him, a „ladies' man“ I say. With a great radio voice, one that soothed the ear and stuck with you. Someone who seemed unbreakable. Who always had a solution, a man of action. Someone who had seen everything, and reported on it.

Bernd suddenly had cancer. A diagnosis odyssey began, soon terminating on the palliative ward of the university hospital in Göttingen. This need not be the end, we said and hoped. Bernd said and hoped.

I had lived opposite the hospital twenty years before. Spent happy times in a student hall of residence. At lunchtime we went to eat in the hospital, my medicine student friends celebrated anatomy milestones – but all suffering was far away, from us, from our life, from our future.

Visiting the hospital last year had none of the lightness of a meal in the canteen, we paid regular visits to a dying man.

Felled like a tree, I kept thinking. Lots of phrases went through my mind. From „It'll all work out fine,“ to „Then we'll convert your flat for wheelchair access,“ „Some people make it out of here again,“ „Sometimes people heal spontaneously.“

Bernd was in a single room, very comfortable.. And my mistrust grew, because everyone was so nice. The nurses had time, the doctors even took time to talk to the friends of the patient. Impending death seemed to suddenly gift understanding and peace, which are not often encountered in hospitals. And yet the effect was not a calming one.

We drove to see Bernd as often as we could. One time I was on my own. Like in the old days, I went to Cron und Lanz, the best café in town, and bought treats. I want to bring something with me, I thought. Even to a dying man. I want to give him a treat. An everyday experience. If that still works, how it works, I don't know. With cakes, chocolates, nicely wrapped with a marzipan ladybird, I entered the room. An odd thing to do, visiting a dying person with these things... Whilst these were my thoughts, Bernd was delighted. Tried the cake and the chocolates, even though he wasn't really eating anymore. He told me that ladybirds had accompanied him throughout his life, asked about the CD project, wanted news from the world of work. Bernd wanted to be involved in the life that he loved. He didn't want to talk about death. „Dying is bad enough,“ he said once, the only time that he mentioned the subject. He added: „Why should I talk about it all the time, I already know that.“ I could scarcely believe it. Should we not have talked about his illness more at some point? Should he not have confronted reality more? How could we give him ladybirds whilst the metastases were rampaging through his body? „Why?“ my husband asked, „What's wrong if that's what he wants?“ „Why should he talk about death?“

Bernd argued with the doctors on his ward. He did not want to talk to them about what he was facing. And he fought. For every day. He wanted radiotherapy and exercise therapy, he wanted to win time. He never played the role of the dying patient. He, the lifelong hypochondriac, did not make it easy on his friends.

He simply carried on living and officially allowed no space for the disease. We talked about everything that came into our heads. From politics to work, about friends and acquaintances, we laughed and mocked.

Bernd grew weaker and weaker.

He could no longer sit up, but his mind was awake. In the meantime he wanted to sleep, just sleep. And yet he fought on. For his life.

At some point we began squeezing his hand, in farewell. A bit longer than usual. An intimate gesture for us and for him, knowing that it could be the last time.

Bernd had never cried before, never screamed, never complained. Only one time was the question of why raised. „Cancer like this takes eight years,“ a doctor had told him. „What if it had been discovered earlier?“ he told us he had asked himself. My head was filled with the images and phrases of dying and death. When I told friends how Bernd was doing they shook their heads, „It can't be much longer.“ I didn't want to hear it.

Those stupid phrases. Bernd was alive, wanted to live. And as long as he was breathing he had the right to participate in life and not be talked of as if he was already dead.

The search for causes began. „He was always a heavy smoker, he shouldn't be surprised.“ I heard that said. I was speechless. All these clever people had heard nothing of fate. Events were self-righteously assessed, old scores settled. „Is there any point?“ I was asked, when I reported that Bernd was feeling better. Suddenly he could sit up again, rekindled hope. We all knew that he was not going to jump out of bed. But he wanted to live every moment of his life. That is what it was all about. He was still living and breathing, still had ideas, but he was already invisible to many. Dealing with a life drawing to a close was too difficult for many people. They did not want to get that close to dying. Or the living person that was dying. I have seldom experienced so much ignorance, stupidity and platitudes.

Don't look, then it won't affect us. All of the shrugging. The know-it-alls and prophesiers. Who already regard the patient as dead, to protect themselves. Who always know exactly what should happen next. Who know what is and isn't a good death.

Who know why things happen. Who know the other side, or not. Who have a belief, or not. Who do not want to acknowledge that a person is still there. Even if his life now is different to the years before. It is incomprehensible. We visited Bernd the evening before he died. He recognised us, we briefly held his hand. „Come back tomorrow,“ he said, „I'm not feeling so good today.“ We were lost for words. Bernd died the next day.

Was it peaceful, was he at ease, was he in pain, who truly knows? I think that he never lost his dignity, or his will to live. He never deluded himself. He did not give in, including to the illness. He followed his path. And that is perhaps the sole consolation.

Kassel, 12/05/2005 © Petra Nagel, petnagel@aol.com



## 1. What does palliative mean?

In this booklet we will discuss numerous issues. What exactly is palliative therapy? It is caring for people with an advanced stage of illness and limited life expectancy. Palliative therapy alleviates the symptoms, whilst we respect at the same time that the illness is no longer curable. It takes into consideration the person as a whole, as well as their environment.

Palliative care always refers to holistic treatment. It is never focused solely on the actual therapy aspect itself, but is highly comprehensive. In addition to support, nursing and medical care, many other professions contribute to an appropriate course of therapy. Naturally, these include appropriate pain therapy, nutrition and compatible medication. Minimising breathlessness, nausea and vomiting is important. However, so are pastoral and emotional support, psychosocial care, grieving support, supervision and many other aspects.

Alleviating measures are the oldest and were long regarded as the only therapies possible. However, the major technical and medical advances of the past century led to these taking a more background role. The hospice movement of the late 1960s focused attention on the necessity of special treatment for incurably ill and dying patients. This resulted in people receiving palliation again in addition to medical treatment. Alongside medical care, we aim to support you in all key areas and thus be there for you in a difficult situation. In our experience, with the aid of palliative care people are able to make the final stage of their life something special – organising this consciously and with dignity.

Palliative care means focusing on the quality of the time remaining. So much can still be done, even when nothing can be undertaken to halt the progress of the underlying illness. The objectives change. It is no longer a struggle against the illness, but to achieve the best possible life with it. This altered perspective accepts that death is foreseeable and unavoidable. It helps acquire a surprising depth and quality for the time remaining.

The medical and nursing care of pain and complaints remains central, but is complemented by caring, individual and attentive support of the patient and their loved ones.

---

It is of the essence here that the patients should be able to spend the time remaining to them in an environment that serves their individual requirements.

Multi-professional and interdisciplinary co-operation is required for this. Palliative care is not about „not doing any more“, not merely about hospice care. Key here is a careful weighing-up of what is appropriate, necessary and practicable in the situation. Experience and sensitivity are required to cope with impending deterioration and the associated fears, or avoid these altogether. This also involves acknowledging these openly. If these crises can be avoided, then we can also avoid nearly all undesired hospital admissions!

Alongside the feeling of helplessness and inability to cope, palliative care also precisely addresses the concerns of those affected. The seriousness of the situation is not played down, we face up to it, remain on hand and help to deal with the crisis.

Good palliative care is based upon three pillars, an appropriate attitude, extensive experience and excellent expertise.

People are the focus of all efforts. This frequently requires that people interact differently to how they normally would. It is necessary to stay, to endure and bear the burden, where others prefer to look away. Palliative care does not take away all suffering, that would underestimate the complexity of grief. However, it helps to improve the quality of life up to death – and beyond.

Life is often richer as a consequence. This is especially important for those who remain and live on.

## ■ (Annotation 1) Assisted dying and palliative care from an Islamic viewpoint:

Although it is clear to every Muslim that they must die and that this process of dying is also part of life, they must also make serious efforts to protect their lives. They must also nurture and preserve their health, and when they are ill they must seek out the necessary and possible treatment, to the extent that a healing therapy is available. In the case of blows of fortune and bitter suffering such as a severe, incurable illness, they should remain resolute and patient and place their trust and thanks in God. At the same time, they may refrain from undergoing possible treatment that does not lead to healing and make use of other measures to ease the complaints and symptoms, so-called palliative care. All scholars and recognised assessments of the Islamic Fatwa committees of the various Muslim schools (Sunnis and Shiites) strictly reject the idea of so-called active assisted dying as well as suicide and assisted suicide, together with medically-assisted suicide. In the Central Council of Muslims in Germany we see hospice work and palliative care as a good and humane alternative to active assisted dying; an alternative that in many respects is reconcilable with the spirit of life and death in Islam. We therefore support and welcome the further development and widespread distribution of palliative medicine and palliative care.

Central Council of Muslims in Germany, <http://www.islam.de>



## 2. Tips for talking to doctors

If you, as patient or family member, encounter a situation where you are required to conduct an important discussion with the doctor carrying out the treatment (notification of diagnosis, decision on further therapy or similar), then you should note the following points:

Think about whether a person that you trust should accompany you in the conversation. If yes, discuss with that person what it is that you are most concerned about and what you want to know from the doctor.

Arrange a time and the duration of the conversation with the doctor in advance.

Make a note of your most important questions (there are no „silly“ questions). Take the list with you to the appointment.

Insist that the conversation is not conducted on the ward, but in a separate, quiet room.

Ask the doctor if it is possible for him to leave his beeper elsewhere for the duration of the conversation, so that you are not disturbed.

Begin by telling the doctor (if he does not ask you himself) what you already know, think or suspect – then he will know where you stand.

Talk about your hopes and fears. You will help your doctor to get to know and understand you.

Ask immediately if you do not understand something - more than once if necessary, until you have really understood everything.

Take notes and keep these safe. Things, even important things, are forgotten more quickly than you think.

Ask the doctor to explain all alternatives to the treatment strategy that he

proposes. Ask him in particular about the scientific basis for his therapy proposal: are there studies or guidelines relating to it?

In the case of a life-threatening illness in the advanced stages you should ask whether a purely palliative medical treatment may not be a good alternative, even with regard to the goal of extending life.

Ask about non-medical options, in particular for the time after being released from hospital – depending on situation, these may be self-help groups, psychotherapists, hospice services etc.

At the end of the appointment, arrange a specific date for the next one.

Reprinted from Gian Domenico Borasio „Über das Sterben“, 2nd edition 2012, p. 122-123, with kind permission of publisher C.H.Beck



### 3. What can relatives do?

„I wanted to experience so many more things with you, to be with you, share my happiness with you, confide my fears in you. And now you are dying, all alone. And now I'm sitting here next to you and don't know how I can help you.“ Or „Oh God, help him to fall asleep, take away his pain and the suffering, alleviate his fear of dying and what comes after.“

These and other thoughts are going through the heads of relatives as they sit by the bed of a well-loved dying person. They are often helpless, fearful, but also angry and sad. The life of this person is drawing to a close. Relatives are not asked what they think of the situation. It just happens. The relatives can be helped by being involved in the dying process. They can massage the feet of the dying person, hold their hand, get into bed with them or hold them upright when they are short of breath, they can sing for them, pray for them, play music. Talking to a team comprising doctors, carers, pastoral counsellors and therapists helps them to deal with their own helplessness and powerlessness, and to carry on after the death of their husband, their wife, parents or child.



## ■ (Annotation 2) The significance of prayer, Koran recitation and invocations for the sick:

Many believers find physical and spiritual peace in prayer, Koran recitation and invocations. In many cases this may ease their fears and worries and thereby also their pain and other symptoms.

Special rules exist for ritual cleansing and prayer in the case of illness. It is possible to ask the scholars or read this in relevant fiqh books.



## 4. When burnout threatens: Self-Care

Care can mean taking care of yourself or of others. This care is important for palliative care, but also for ourselves: self-care.

But what about those who care for seriously ill people? Self-care should form part of the care programme for the patient, as otherwise there is a threat of burnout – a creeping process. To begin with the changes are small, later the result may be a serious illness: anxiety, depression, increased alcohol consumption, complete exhaustion, even paralysis and worse.

Caring for severely ill people takes us to our limits and is a major challenge. Those looking to provide more than physical help require a good feel for providing the right amount of assistance to both patient and carers. In my capacity as a pastoral carer I often hear phrases such as „I can't go on any more,“ „You'll manage,“ „It's all too much for me,“ „I'm afraid my contract isn't going to be renewed.“ At the latest where these seemingly small symptoms are noted it is time to put on the brakes and consciously activate self-care.

### Tips on how to avoid burnout:

- I need to accept that a risk of burnout exists.
- I need to address this danger consciously.
- I need to recognise my physical and emotional limits.
- I should clearly delineate between work and free time. I frequently hear „I can't switch off at home.“ In the paediatric ward a dedicated nurse told me:
- „Yesterday evening I drove back to the clinic again quickly to check up on Simon. I couldn't get it out of my head, he was feeling so bad.“
- Switching off after work, phases of recuperation and tranquillity ease the professional burden. Short periods of recovery deliver new energy. Then we can focus on family or friends again; and on patients at work! Satisfactory leisure time and lots of outdoor activity are also essential for healthy separation of activities.
- Good relationships at work and in private, an open ear and the understanding of trusted confidants help me. They also help distance me from my palliative care worries.

- Many helpers blame themselves for becoming frustrated and exhausted. They put failures down to their own weakness. But the question is not what is up with me, but what can I do to change the situation.
- My stress is created in my head. The way in which I assess situations and value my work has a major influence on whether the situation becomes critical or not. Changing the way I think is not easy.

Introducing new, more positive thoughts even at moments of great stress can be achieved by answering the following questions:

- Do I only see the negative sides of my work? Or also the positives?
- Do I maybe have too high expectations of myself?
- What would happen if I took more care of myself?
- Do I also see the situations that I mastered well?
- Where are my capabilities, resources? Where do I apply them?
- What importance does my own life have for me?

In a team meeting a nurse from a children's ward said:

„When I see this suffering, I don't want to complain about my own life. I want to put everything into it, to help.“ This is an attitude that leads to a break-down if we fail to take account of our own emotions.

We shouldn't grit our teeth and say „I have to get through this.“ Our goal should be to give because we receive.

#### At the end some useful tips for relaxation

- Conscious breathing: e.g. „take 3 deep breaths in and out“ in acute situation.
- Travel through your body: sense single body regions and try to track tension and discomfort. Release tension.
- Muscle relaxation: flex muscles for 5 to 7 seconds and then actively relax them, from the tip of your toes to your forehead.
- „Hands in prayer position“: The fingertips touch each other in front of the chest, the fingers are not pushed all the way through, take deep and steady breaths.

## 5. Pain relief

From our daily work we know that patients and their relatives fear unbearable pain the most. We aim to remove that fear. At the end of a life, pain is the symptom that is easiest to alleviate.

There are various medications available that act alone or in combination. If swallowing proves difficult, plasters work very well. As a consequence, regular injections are scarcely necessary any more. Injections are often unpleasant for patients and relatives do not trust themselves to provide them.

Where medicines are taken, the most important thing is that these are long-lasting and preventive in nature! It is important not to be trying to catch up with severe pain, otherwise it will rapidly become worse and the therapy will require increasingly stronger medication. Where there is a fear of „strong“ painkillers it should be remembered that the strong painkillers come from nature, they are similar to the body's own messengers, which it produces to combat pain.

Side effects of pain therapy are often constipation and sometimes nausea. Both can be alleviated preventively. Unfortunately, painkillers often enhance the tiredness caused by the illness itself. Here the patient has the choice of either enduring the (residual) pain as long as possible or easing the complaints more effectively, but sleeping more as a consequence.

In some cases it is also possible to eliminate the causes of the pain. Intensive physiotherapy is particularly effective here (movement training, lymphatic drainage or physiotherapy). Other – technical – options for the relief of pain may be radiation; operations or chemotherapy are seldom effective. Electrical devices, pain catheters or pumps are barely required any longer. We know that optimal pain relief is easier at home than in the hospital. Because patients feel more at ease in their familiar surroundings, relatives and friends are more frequently there. These factors can improve the sense of wellbeing. And the doctors and carers can also do everything possible to ease the pain at home.

Depending on where you live, morphine-like medication may be difficult to obtain. However, if we do not ask, do not try, nothing will change. If we repeatedly ask and urge to do the right thing, then we can slowly begin to alter the situation.

## ■ (Annotation 3) The use of painkillers and sedatives:

From an Islamic viewpoint there are no objections to the use of sedatives and painkillers (medicines similar to morphine), including in high doses, if this is necessary in the case of severely ill people and where the medicine is used correctly.

## 6. Breakthrough pain

Breakthrough pain occurs during movement or care measures. It is sudden and of brief duration and is always treated separately. A fast-acting opioid („morphine“) should be on hand at the bedside, but protected against misuse.

Intravenous injections bring rapid relief. If a drip is in place, a relative may also administer the medication. Injections into the muscle are no longer recommended. The easiest, fastest and safest way for medication to be administered is via the mucous membrane of the mouth and nose. This alleviates pain in one to two minutes. Due to its fast and brief effect it is better than morphine. Relatives and patients can administer it easily. A tablet or spray on its own enables the majority of unwanted end-of-life hospitalisations to be avoided. In former times the chemist had to create a spray on special prescription. Now similar medications are also produced industrially. The opioid-based „pain sweets“ or tablets work well after 10 to 30 minutes. The medication enters the blood via the mucous membrane; it is not absorbed via the stomach, so it really does need to be sucked and not swallowed. It will then have a better effect. Suppositories also work similarly quickly, but are often regarded as unpleasant and inconvenient. A positive effect from drops and tablets can generally be expected after half an hour. Nasal spray is very fast, but not quite so easy to apply.

Our recommendation: if you know that pain is coming, the medication should be taken in good time as a preventive measure. If the medication does not work properly, speak to the doctor without delay.

He can decide whether and how to increase the dosage. Ask the doctor to note the instructions legibly, so that no one is unsure. Very important: if medication is frequently required for breakthrough pain, then long-term medication needs to be reconsidered.

## 7. Breathlessness

Breathlessness also occurs in cancer patients, but above all in the terminal stages of internal illnesses, it is the most common reason for unintentional end-of-life hospital admission.

What happens when there is shortage of breath? When people breathe increasingly quickly, they try harder and harder and the air is merely moved around. The body can no longer take in the oxygen. Breathing therefore needs to slow down in order to reduce the breathlessness. This always helps.

Fast-working medication should be on hand in the right dosage for emergencies. For over 100 years now the so-called gold standard with medication has been morphine injected into the vein. As with breakthrough pain, nasal spray or tablets are the easiest, quickest and safest to use. Applied correctly, these work almost immediately if you are unable to administer an injection yourself. As a result, breathlessness is eased after just seconds. This is quicker than the arrival of any doctor. Relatives and patients can administer it easily. Correct medication alone enables the majority of unwanted end-of-life hospitalisations to be avoided.

Fears are alleviated due to the fact that tablets and nasal sprays such as these bring immediate relief. In addition, independence is reinforced, as the patient is not dependent on the help of others. It is often recommended that Lorazepam lozenge tablets be allowed to dissolve in the mouth. Unfortunately, this medication needs to be swallowed and ingested by the intestine. As a consequence, it may take a good half hour to work.

But medication is not always necessary. Good physiotherapy with breathing therapy can help the patient learn how to breathe more easily. It is also always good to calm the patients and simply be there for them. Fresh air, a ventilator, cooling and the presence of trusted people are helpful. It is important for the patient to know that a doctor can be reached who can help them. It is even more important that the patient or their relatives have the means to help themselves promptly.

## 8. Fear

Everyone experiences fear at some point in the process of dying. Of course, this not only affects those who are departing. The opposite in fact, the relatives are often affected to a far greater extent.

Unexpressed subjects or relationship problems can reinforce insecurities and trigger fears. This is joined by the fact that no one really knows what comes after, or how the path will be for us personally, difficult or easy.

Some fears can be alleviated via talking. Fear of pain or suffering is unnecessary. Because every doctor has the means of relieving this to the extent that the patient no longer has to suffer. This certainty on its own serves to calm the patients and their families.

Fear of being left alone is also paramount for many patients. However, this too can be discussed and security offered. The hospice service can provide great assistance to relatives, for example. It is often enough to simply „be there“.

In addition, medication, so-called anxiety reducers, can help. However, a side-effect of these is that they induce sleepiness. This can also be an advantage if administered at night, as a better night's sleep is achieved,

These medications need not be taken regularly, but also as required. Care is required when taken over longer periods, as some may become addictive. There is no need to fear addiction if the tablets are only taken in the final months of the patient's life. As most Europeans are raised as Christians, thought should also be paid to suggesting a conversation with a pastoral care provider, even if contact to the church has not been intensive in the years prior to the illness.

### (Annotation 4):

See annotations 2 and 3.



## 9. Restlessness

Restlessness usually plays a role as a symptom if the patient is no longer clearly oriented or only responsive to a limited extent.

Restlessness may be expressed in different forms: through fidgeting, frequent shifting of position in bed, groans or calls for help. It is important to differentiate between what is disturbing for the patient and what is perhaps burdensome for the relatives, but perhaps not perceived to be by the patient. Relatives and patients may regard the same symptoms in very different ways. That which may be easily acceptable to the patient may be highly burdensome to the relatives. Experienced professionals can often assess this more easily and often explain this better than a relative who has invested all of their emotions in the care process.

As with fear, restlessness is often a „normal“ occurrence in the dying process. On the one hand the constant lying down may become unbearable, on the other hand pain may lead to physical restlessness. Fear of the unknown is a further factor. Identifying the true cause can be difficult. One thing that always helps is attention, taking time and waiting patiently, perhaps holding the hand and talking calmly.

The „professional“ carers may attempt to locate the cause and eliminate this. If this does not help, increasing doses of medication may be administered until the condition is acceptable to everyone. This will not speed up the occurrence of death. In contrast, many studies have shown that good management of symptoms not only adds quality of life to the remaining days, but also increases the number of those days.

Sometimes restlessness is also an indication of mental confusion. This is especially difficult for relatives. Here too, medication can help. Unfortunately, the price of this is that conversing with the patient becomes increasingly difficult.

## 10. Hunger

We are all familiar with hunger. However, what we mean by this is more the appetite that we feel for tasty foods in our sated society. Hunger has a very different meaning for the critically ill. It may lead to weakness and faster onset of death. However, it may also ease the burden on the body.

Although we think that they should be hungry, towards the end, terminally ill patients eat little or even nothing. The metabolism alters and the body needs less food. Lack of nutrition also releases endorphins, which make the critically ill patient feel somewhat better. Many are familiar with this from fasting.

Many small portions, attractively served, increase appetite and enjoyment. Sometimes just a few teaspoons of the food that the patient likes are enough. Do not try to force anything down. Because then food is no longer enjoyable. In addition, the body could be severely stressed as a result.

Remember that the critically ill also have a right to dignity in eating and drinking. If adults are treated as children, for example by referring to a „bib“ instead of a serviette, this can be insulting.

Appetite-stimulating medication may also be used at times to make the patient more active. If food is no longer digested properly, but the patient is in otherwise good health, then artificial feeding via a port into the vein can be very helpful. In patients with pancreatic cancer the quality of life is improved sustainably over the long term using this method. If the feeding process is undertaken later in the day, it is less stressful for the body, although there is then always a bag and pipe present. As you can see, therapy is a balancing act between sides. It always needs to be discussed in detail between patient and doctor – ideally together with close family members. One word in conclusion: at the end of their lives many people experience neither hunger nor the desire for food. This does not mean that the patient will „starve“.

## 11. Thirst

As with feelings of hunger, feelings of thirst also ebb at the end of our lives. „You can't just let someone die of thirst,“ is something we hear often, but there is a major difference between administering a liquid and quenching thirst.

Liquid that we administer into the body via a gastric tube, a vein or below the skin can stress the body. This results in difficulty breathing, vomiting and the heart having to work harder. A dry mouth will not become pleasantly moist again as a result.

However, if we give the patient tiny quantities of fluids – water, juice, coffee or other refreshing drinks – and carefully rinse the mouth with it, we can provide rapid relief.

Favourite drinks can be used to make ice cubes, which can be crushed and offered to the patient to suck. The ice has a wonderful cooling effect in the mouth. By the way: homemade lemon butter is better for oral care than any infusion! One great option for oral care is small spray bottles filled with the patient's favourite drink. This enables water, tea, coffee and even juice, wine or beer to be sprayed into the mouth. The patient does not have difficulty swallowing and can enjoy the taste.

As you can see, you do not need much equipment, a doctor or high-tech medicine to make people comfortable at the end of their life. But sometimes it is helpful to have good advice from people who have gathered a lot of experience in their daily work and who can also be reached when they are urgently required. One word in conclusion: at the end of their lives many people experience neither thirst nor the desire for liquids. This does not mean that the patient will „die of thirst“.



## 12. Oral hygiene and assistance with feelings of thirst

If the mucous membrane of the mouth is unclean or the mouth is constantly dry, the quality of life of patients may fall noticeably. They often complain of a feeling of thirst, although this cannot be sated by additional infusions, as there are various causes for the dryness in the mouth.

Either certain medicines are hindering the formation of saliva or the mucous membrane has altered due to various illnesses. The patient may also be breathing through the mouth, with the result that the saliva evaporates and the mucous membrane dries out more quickly. The consequences? The patient complains of difficulty in chewing, swallowing and talking, sense of taste changes and painful areas of dry mucous may form on the tongue and gums.

The objective here must be to alleviate the feelings of thirst and keep the mucous membrane moist, clean and healthy. Simple, effective measures can help here to stimulate the production of saliva, such as sucking frozen pieces of pineapple.

Pineapple contains special substances that clean the tongue. Or make ice cubes from apple juice, cola, beer or sparkling wine and give them the frozen drinks to suck. Essential oils, such as an aroma lamp with lemon oil can also help patients who feel constantly nauseous and therefore have difficulty with oral hygiene. Lemon butter, which dissolves quickly in the mouth, can also help.

Regular moistening of the mouth is therefore essential for long-term relief. The aim here is not necessarily to give the patient a drink, the rinsing or wiping of the mouth with tea or water is far more effective. For many patients this is required every 30 minutes to relieve severe feelings of thirst. With the proper instruction, relatives can undertake this task.

Where the patient has difficulty swallowing small quantities can be provided using a pipette. Where patients are almost unconscious careful lip care as initial contact is a good starting point for communicating security. The willingness to open the mouth voluntarily and easily is much higher.

## ■ (Annotation 5) Substances containing alcohol and pork:

Products containing alcohol and pork are strictly forbidden as a rule in Islam. The rule is that a healing remedy may not contain prohibited substances. In necessary cases and only when no other permitted substance is available a Muslim may take these products in pharmaceutical or healing medicines; for example in a life-threatening situation or where there is a risk of the illness deteriorating further.

### 13. Weakness

Cancer patients in advanced stages of the illness are always limited by weakness and therefore require considerably more sleep. Causes of weakness may be anaemia or medication that induces tiredness. Here thought should be paid, in consultation with the doctor, to whether medication for high blood pressure can be discontinued.

Many patients and relatives also think that the lack of strength is due to lack of appetite and try to force food into the patient. As a rule, this does more harm than good.

Daily tasks should be divided into small, easily-accomplished stages. If energy-sapping tasks or family celebrations are planned, for example, the patient should stock up on energy beforehand by resting more. Opportunities to rest should also be provided during and after the event.

Strong stimulants can also be prescribed as medication. In individual cases these may help to better withstand taxing situations.

Anaemia is a common cause for weakness. If it occurs gradually, patients can accustom themselves to it well. Transfusions may provide short-term help in severe cases of anaemia. When commencing transfusions there is always the inherent question of when do I stop. It is never practical until the end of life, when it can do much harm. But the decision to stop something is a very difficult one for all parties to make.

What can relatives do? A lot! For example, take care to ensure that the patient is not overly exerted. Provide help and support unobtrusively and address worries, fears and weaknesses openly. Because if we talk to each other, the burden becomes lighter for everyone.



## 14. Tiredness

Sleep requirements vary greatly between both healthy people and sick ones. Most healthy people require 7 to 9 hours per day. Some require barely 3 hours, others 12 hours and more. In the case of palliative patients the amount of sleep required may increase over the course of the illness to up to 20 hours (!). This means that the amount of time spent with relatives is even less. Many healthy people are also often tired because they are sleeping too little and too badly at night, worrying too much or working too hard. Naturally, sick people can have the same problems as healthy ones. However, there are also other reasons for this tiredness.

It is frequently the side effects of therapy, with anaemia, the cancer itself or inflammation in the body also weakening the patient and leading to increased need for sleep. If possible causes are known, and we can eliminate these, then we should do so. Only then should we turn to medication options, as these can also have their own side effects. It is very important to ensure that sleep is disturbed as little as possible at night. Patients should never be woken for medication. Eating and drinking at night also places stress on the body. This is often forgotten when nutrition is delivered via gastric tube or vein catheter. If pain occurs at night, painkillers, which are often dosed much too low for the night, need to be increased. As painkillers make the patient tired, they also promote healthy sleep.

## 15. Itching

There are many causes of itching. It is often triggered by cancer or the cancer treatment. Some painkillers, such as morphine-like opioids, may be responsible for the itching. This is alleviated by changing to an opioid that less frequently results in itching.

Changes in metabolism and the skin can make the skin itch. This is familiar, for example, with liver inflammation or liver cancer, allergies or fungal infections. If the causes cannot be adequately treated, medication used in infections in children can help to ease the irritation. Unfortunately, a side effect of these is also often tiredness.

Itching may also „occur“ in the mind, with the consequence that neither scratching nor good skin care help. Even in the case of constant itching, scratching should be avoided, as the skin can quickly become damaged. Instead, the itching area can be squeezed slightly or rubbed.

Good skin care is important. This not only involves frequent washing with normal soap, but also keeping the skin clean, cool and fresh, whilst nourishing it at the same time.

To help achieve this, here is a recipe for a soothing and pleasant-smelling oil that relieves itching and cares for the skin at the same time:

### Recipe for itch soothing oil

melissa 100%	2 drops
rose	1 drop
lavender	7 drops
tea tree	5 drops
Roman camomille	3 drops
resolve in 70 ml of St John's wort oil and 30 ml jojoba oil.	

## 16. Lymphatic drainage, caresses and more...

The lymphatic system has a kind of waste disposal function for the body. It is important for detoxification and resistance to infection. Lymphatic vessels often need to be cut into during surgical procedures. This can result in blockages. Cancerous growths can also block the lymph.

Manual lymph drainage is a relatively new form of treatment. Separate training is required for this. Swollen body parts are decongested. The therapist uses light, circular movements to transport the fluid into the areas in which lymph drainage is still functioning. If the blocked protein remains in the body, it may become rock hard, constricting vessels and nerves and resulting in pain. Legs, arms or rump become as heavy as lead. Bedridden patients can develop bedsores more easily via these lymph oedema.

In the case of lymphatic blockage, lymph drainage is the only form of treatment, there is no alternative. In the case of extensive lymphatic blockage this therapy is combined with compression bandages, skin care and special physiotherapy.

The patient finds the gentle, rhythmic movements pleasantly relaxing, pain-relieving, beneficial and calming. Painkiller consumption can be reduced. The body's own defence system is stimulated, the body is dehydrated and detoxified. It has been shown that lymphatic vessels are still removing increased volumes of fluid 6 - 8 hours later.

Those performing the therapy also find the flowing, rhythmic movements relaxing, with the pleasant treatment atmosphere enabling.

## 17. Yoga in palliative care

In addition to the provision of medication and comprehensive palliative care, non-medicinal procedures are also successful in the treatment of pain, chronic tiredness and muscle cramps.

Yoga is an Indian philosophy and exercise technique that is thousands of years old. It works on a spiritual, physical and emotional level. A yoga session includes initial relaxation, muscle relaxation, various positions of the body, breathing exercises and concluding relaxation, which may include imagining concepts such as a dream journey.

Scientific investigations on sufferers of nervous diseases show the effectiveness of yoga in the treatment of tiredness and the risk of falling. In pain therapy it has long been known that procedures such as muscle relaxation and imagination are effective. Yoga is still used primarily by healthy people. In this the physical effects are often exaggerated, with good mental and emotional results also important.

As with similar techniques, yoga can be used much more frequently in the case of severe illnesses. Many people tend to over exert themselves with physical exercises. Yoga is better in this case, as the decisive point is to promote awareness of one's own body. The pressure to perform so common in Western societies is not present. This is achieved by increasing physical awareness between exercises.

In addition to the stated symptoms, yoga can also be used for many other health problems. Exercises can be adapted to suit the circumstances of the patient. This makes yoga a procedure that is highly adaptable to the individual, which serves to strengthen musculature, promote good posture, relax muscles, improve breathing and achieve tranquillity. It can therefore be used to reduce stress in those affected by the illness of a patient.

## 18. Basal stimulation

In the final phases of life severe tiredness or constant sleeping often occur or - which may be worse - severe confusion. Relatives and friends find it difficult to get through to the patient, a situation that brings with it great uncertainty and fear for everyone.

Basal stimulation can be a valuable aid in these situations. It was developed for disabled children and stimulates the basis of human perception. The seven stages of perception and the ways in which these can be stimulated are detailed briefly here, with tips on how laypeople can apply them:

### Promotion of perception

Our body, with the skin as the last boundary to the environment, is familiarised with a wide range of perceptive impressions, from the earliest stages of our development onwards. Numerous options are available here, including partial massages (hand, foot, back of the neck, stomach...), stroking, a soothing gesture as a greeting, passive movements and many more besides.

### Touch

The sense of touch helps us to recall. Objects placed into the hand trigger memories. The fur of a beloved pet can make the eyes open again, a glass in the hand make the mouth open to drink, a rosary bring forth prayer.

### Balance

Our equilibrium organ controls perception and movement processes. It withers faced with immobility. As a result, communication and wakefulness are stimulated in bedridden patients by raising the head and upper body, turning onto the side, sitting on the edge of the bed, possibly also rocking.

### Oscillation

Talking and walking awaken memories of oscillations from the time in the womb before birth. These are far-reaching, pleasant feelings that can be induced. Speaking, singing and humming with close physical contact as well as vibrating massage devices, possibly merely held to the mattress evoke memories of carefree times and can be soothing and relaxing.

## **Taste**

May be stimulated via familiar, favourite foods and drinks. The latter can be applied with cotton wool buds to moisten and clean the mouth. They also have a wonderfully refreshing effect when frozen as lollies.

## **Smell**

Smells awaken our memories and influence our feelings. Familiar smells such as a shirt worn by a loved one, a distinctive perfume or body care product or special scent compositions serve to express things that can no longer be expressed otherwise. This is how familiar smells can get through to us.

## **Hearing**

We do not know exactly how things we hear are processed. However, it is acknowledged that people whose consciousness is severely inhibited can perceive more than most people think. As a consequence, friendly, directed speech with clear and meaningful content in combination with physical touch is a key means of contact. Further options are singing, praying, reading aloud and music.

Whatever we decide upon, it should suit the person, their preferences, habits and interests. Whether or not it ultimately achieves the desired effect can be determined via good observation of gestures, expressions, muscle relaxation, changes in breathing and many other things.

Having an interested, caring and sensitive person at their side - the last wish of many - promotes wellbeing and therefore quality of life. The distraction of attention through various sensory organs and the sense of security also reduce stressful symptoms. Family and friends are helped by the activity and involvement to understand and accept the situation. The grieving process can begin here.

## 19. Rhythmic massage

No words, no music break the silence – the attention is on the patient. The hands glide softly over the skin, a hint of lemon hangs in the air. There is a feeling of being in good hands.

Rhythmic massages using the techniques of Wegman/Hauschka are a supplementary care measure that support the patient and promote wellbeing.

Good, professional contact is a silent conversation with skin and hands. With its flowing, light and enveloping movements, rhythmic massage represents beneficial contact. The strokes follow the course of muscles, with varying pressure and strength, in the form of circles or strokes. The hands are soft and warm, the room offers a warm and protective atmosphere. This enables the patient to relax and welcome the soothing treatment. Good physical contact makes a person feel appreciated. This establishes trust and increases feelings of self-worth. Good contact does not remain on the surface, it also reaches inside people. Many palliative patients no longer have a relaxed relationship with their own body. Numerous operations, courses of therapy and visible and invisible changes have severely altered the physical appearance. Patients often feel alien in their own body. With rhythmic massage it is possible to familiarise patients with their own body again. Massages such as these can be applied in various different ways, for example as a back rub with citrus oil, which has a wonderfully soothing effect for breathing difficulties. Leg massages help with lymphedema. Massages with lavender oil can promote sleep and foot rubs are used as a distractive treatment for headaches. These are just a few examples of the supportive effects. All local massages serve to regulate body awareness in the bedridden and patients with sensory disorders. For relatives, too, rhythmic massage offers a good means of giving the patient a feeling of closeness and security, as well as of expressing feelings. Trained carers can give instructions and tips to relatives regarding what such contact can achieve.

Rhythmic massage is a technique that can be learned in a series of courses. Key here is training the hands, one of the most important tools a carer has.

## 20. Bedsores and skin care

Bedsores are a possible precursor to pressure ulcers (decubitus ulcers). Redness and inflammation can form in folds of skin where moisture gathers, the skin softens and can tear easily. In addition, the moist climate is an ideal breeding ground for fungal diseases.

To avoid this it is important to keep folds of skin clean and dry, applying cream sparingly. Ask your doctor about solutions and pastes for treating fungal infections. Salves should only be applied very thinly, due to the lack of air permeability.

Particular care should be paid to changes in the skin where adult diapers are used. The combination of enduring dampness and lack of air permeability is very harmful to the skin in the long term. Net underwear with a pad is a good temporary or permanent alternative. This conveys the desired security, as urination and defecation in bed is often associated with feelings of shame and anxiety.

If the patient already has bedsores, a tube may be inserted to extract urine, to enable the skin to recover. All disposable plastic items are to be avoided where possible. Washable cotton sheets are highly absorbent, air-permeable and also good for changing position.

Pressure ulcers may form on areas that have been under pressure for several hours. A pressure ulcer is not a disease. Like an injury, it is the consequence of various causes, including immobility, wetting the bed or reduced subcutaneous fat.

In addition to good skin care, regular pressure relief is of primary importance here. Areas particularly at risk are: tailbone area, buttocks, heels, ankle area, earlobes, backs and fronts of knees.

## 21. Position and pressure relief

There is no one correct position for patients, the aim is instead to find the best possible position to relieve pressure in individual situations. Position and skin care should serve the purpose of wellbeing and not be perceived as unpleasant. Skin care can also serve to soothe the soul. Ask carers to advise and instruct you if you are unsure.

A nursing pillow is an ideal aid here, as it can be moulded easily from the head, along the back and buttocks, supporting and stabilising the body. Areas at particular risk should be padded with soft cushions, for example between the knees or below the ankles. If pain is a hindrance to regular turning and skin care, suitable pain relief must be administered.

### Skin Care Tips

Seriously ill, bedridden patients are particularly dependent on good skin care. As with other care measures, this should be tailored to the requirements and wishes of the patient. Premium oils are especially well-suited to skin care, for example olive or lavender oil, or circulation-aiding rosemary oil.

**Where the patient is bedridden:** Washing and moisturising as massage and stimulation to mobility, use each change of position as an opportunity for skin care. Change bedclothes frequently – avoid creases and foreign bodies.

**Where the patient has wet the bed:** Regular washing with water before changing sheets, dab the skin dry well, apply water-in-oil creams sparingly.

**In the case of sensitive skin:** Remove soap residue thoroughly, skin care according to skin type, keep folds of skin dry, applying cotton gauze where necessary.

## 22. The correct position

Lying in the correct position is especially important where we are no longer able to move easily due to the fact that we are growing weaker or suffering pain. Then we require the help of others to lie comfortably and securely. A comfortable position is determined primarily by the patient. Soft rolls, foam, gel mats, fur or cushions are good aids to achieving a good position. Some of these are also paid for by the health insurers. Rubber rings filled with water or air are no longer in use these days.

Note: Hospital beds often have a guardrail to stop patients from falling out. If an arm, leg or the head lies on this over the course of hours, pressure ulcers are the result. These areas therefore require extra cushioning. Take care to ensure that the joints are not extended too far and that they are always cushioned.

To relieve pressure, it is important that patients are turned onto both sides alternately. Not only does this allow blood to circulate better to the skin on top, the upper lung also works much better like this and there is less risk of mucous blockages and difficulty breathing. In the sideways position cushioning is also added between the legs. A cushion in the small of the back prevents the patient from rolling over onto the back again.

To avoid bedsores the position should be changed every two to four hours. Patients that no longer move themselves can be helped with an alternating pressure mattress. This is comfortable and protects against bedsores, but does not completely replace moving the patient.

Of course, we sleep best in our own bed. But a modern nursing bed can be more comfortable. It looks comfortable, can be adjusted in numerous ways, is high enough to facilitate getting up and can be approached from both sides. This serves to improve care and ease the strain on the back of the carer. Thought should therefore be paid to obtaining a nursing bed at an early stage.

In the final stages of life, when the patients finds everything hard work and just wants to be left alone, position changes should not be undertaken against the patient's will. If pressure ulcers occur, this is normal. At this time we simply make things as comfortable as possible.

## 23. Scents

Scented oils, also known as essential oils, can be used to relieve symptoms such as restlessness, nausea, anxiety and sleeplessness, thus promoting the wellbeing of the patient. The essential oils are inhaled or enter the bloodstream via the skin. They may have a relaxing effect, relieve anxiety and cramp or loosen mucous.

We use the oils to add aroma to the rooms, for washing, changing, moving position and massaging. These measures represent a particular form of attention and are balsam for body and soul which can be of benefit to the severely ill, the dying and their relatives. Because who does not enjoy being massaged with a pleasant-smelling oil or a lovingly-applied compress - and proximity and attention at this difficult time? Sometimes, when words fail us or we do not have the strength, touching allows us to make contact, to converse. This consolatory proximity and the time spent together is regarded as a healing element by both patients and relatives. It is the small signs of hope and appreciation that add life to the day.

Some illnesses bring wounds with them that have an unpleasant smell. Patients suffer from shame and anxiety as a result. The unpleasant odour is joined by the fear of being avoided. Special palliative care measures can be applied here, for example in wound care, with the use of essential oils also bringing relief.



## 24. Unpleasant wounds

There are open wounds that are difficult for everyone to deal with, as they are not only painful for the patient, they also have unpleasant effects for the family and carers. Open wounds may spread an intense, unpleasant smell throughout the home. This is embarrassing for the patient and difficult for relatives. Experience and tact are therefore required. However, ignoring the subject is no help either. Sometimes it helps the patient if there is an admission of how unpleasant it is for visitors.

It is nearly always possible to capture foul-smelling secretions. Active carbon and chlorophyll can prevent odours from forming. Scent lamps with the right essential oil can remove the smell from the air in the room. Windows should also be opened regularly to ventilate. No one will get a cold or pneumonia as a result, including in the cold wintertime.

As a layman, there is no need to spend too long testing things out. Because there are experienced palliative care experts, so-called wound managers, who, together with palliative experts, can tackle nearly any problem with various approaches such as dry or moist bandages, zinc cream, local antibiotics, cling film or dressings.

With the right experience, a solution can be found that the patient can live with - even where the wounds increase in size and illness prevents healing.

## 25. Constipation

Constipation can have many reasons, most relating to lack of exercise and unfavourable nutrition. Bedridden patients are affected much more frequently. Because often essential medication slows the function of the bowels. Stool-softening preparations should be administered as a preventive measure in these cases. The laxatives need not be paid for by patients insured via a health insurer, but are available on normal prescription.

Dietary advice is of no use, as the weak state of the patient means that food is no longer eaten properly. Exercise – physiotherapy or a few steps taken in the room - can help to stimulate a bowel movement. Massaging the bowel, by carefully pressing the stomach in a circular, clockwise motion, stimulates the bowel to transport its contents in the right direction. It is not necessary to have a bowel movement every day. If very little is eaten, once or twice a week is suffice.

After a number of days without a bowel movement small or larger enemas or stronger medication will be administered. In the course of the illness a so-called ileus (closure of the bowel or enteroparesis) can occur, which is usually operated on. The patient then receives a colostomy. However, the patient often only survives the operation by several days.

If surgery is not desired and the patient wishes to stay at home, then a gastric tube helps to prevent vomiting or, even better, a so-called PEG tube. With this tube in place patients can drink as much as they want without needing to vomit.

In addition, the bowel is calmed with medication, ensuring that no cramps occur and that excessive fluids do not form in the bowel. This means that the patient can stay at home for weeks and months until the end, enjoying a good quality of life.

## 26. Nervous illnesses and palliative care

Nervous illnesses such as strokes, brain tumours, multiple sclerosis, Parkinson's and dementia are common causes of death. To date, palliative care is reserved almost exclusively for cancer patients. In contrast to the situation with cancer, most patients suffering from advanced neurological illness are limited in their mobility at an early stage and often suffer from adverse thoughts.

Patients suffering from adverse thinking are only partially capable of expressing clearly what they want and need, as well as the symptoms they have. Special palliative knowledge and experience is required to understand them.

Treatment of the symptoms should take account of the fact that many medicines increase tiredness further or impair thinking even more. Pain occurs in response to stress in particular, but nerve pain can also be terrible.

Lung rattling often occurs at end of life. In this case a „travel plaster“ can be applied behind the ear and only as much fluids administered as the patient wants, with no further infusions. Nausea and vomiting may be caused by high pressure in the head. This can be improved for a while with cortisone.

It is very difficult for the relatives to fail to understand the patients properly any longer, as well as the fact that they may no longer recognise them properly. Despite these limitations, emotions are often expressed distinctly. In the event of disturbed consciousness contact can be attempted via touch. Decisive here is the attitude towards the patient, who, in spite of the episodes, is still a real person who may also have other options for communicating that remain to be discovered. This may lead to surprisingly pleasant experiences.

Relatives are often involved in the nursing process around the clock and have little time to maintain their own social contacts. The mental changes mean that in many cases they have lost their conversational and life partner and are now required to make decisions on their behalf. As a result, they can easily fall victim to overwork, loneliness and burnout. They therefore require special support through experienced helpers.



## 27. Palliative operations

When we think about cancer surgery, then we hope and believe that the tumour will be removed and that we will be healthy again afterwards. Fortunately, in the early stages of the illness this is also the case. The decision to undergo an operation is an easy one here.

Things can look very different when an illness is in an advanced stage, however. Then the goals are different ones. The treatment will perhaps no longer be able to heal. However, an operation can also relieve symptoms, help to prevent complaints and ease them.

This needs to be explained in individual conversations, using a lot of experience and sensitivity. Where possible, a family member or friend should be present to better remember the important things or ask questions where the patient is overwhelmed by facts, figures and feelings. It is not possible to discuss the details of the individual options here. However: if a tumour is large, it may make sense to reduce the size of it, even where it cannot be removed completely. Sometimes this may serve to prevent or avoid symptoms. Where there is a threat of closure of the bowel a by-pass operation can prevent or rectify this, even where the tumour remains unchanged.

If a tumour breaks the surface of the skin, a surgical reduction can sometimes prevent further deterioration with highly unpleasant odour. Many other opportunities exist for a meaningful operation. However, we need to have a good idea of what the cost of such an operation will be! Not financial cost, but quality of life and time. Will the patient be in hospital for a long time? Will the patient have to go to a rehab facility? Do complications frequently arise? Will the operation perhaps result in earlier death? Are there extensive limitations following an operation? These are all questions that need to be addressed beforehand. It is not necessary to make the decision yourself. Some people do not want to receive so much information. In this case the patient should find a person who is trusted and can make the decision for him or her. This may be the GP, the oncologist or the surgeon.

## 28. Palliative radiation

Many patients have an unnecessary fear of radiotherapy. Palliative radiation aims to improve the quality of life of the patient by easing symptoms caused by tumours. It is also used to prevent a threatening situation caused by tumour growth.

The type of radiotherapy, where and when it is employed depends on many different factors. Close co-operation is required between all doctors involved. Radiotherapy is a very important form of localised treatment. Radiotherapy can help the majority of patients in palliative situations to deal with stressful symptoms.

Used properly, it is effective, safe and, thanks to new technology, has fewer side effects. Troublesome side effects can be avoided. Side effects should not inhibit the quality of life of the patients. A few, strong radiation doses can help palliative patients as much as a long series. They also spare the patient from spending long periods in hospital. The type of radiation is determined after objectives have been set, in other words, the goal determines the path.

Palliative radiation plays a key role in the treatment of cancer-related pain, breathing difficulty, difficulty swallowing, nerve pain, bleeding or ulcers.

The most frequent reasons for palliative radiation are the treatment of bone metastases, which cause pain or threaten to break a bone, brain metastases and soft tissue metastases causing pain. Palliative radiotherapy enables fast relief of complaints. Correctly applied, it has few side effects and should be adapted to the particular requirements of the patient. As with other palliative care measures, doctor and patient should together consider which path is the best one to take.

## 29. Palliative chemotherapy

The treatment of severely ill, in particular elderly patients requires a good deal of experience and sensitivity here. There is sometimes little data to go on and the benefits for the individual patient are hard to estimate. Accompanying illnesses such as heart, liver or kidney insufficiency, diabetes and general frailty need to be taken into account. Advanced age is no reason not to carry out chemotherapy!

Generally speaking, chemotherapy is a method of employing specific medication to damage cancer cells to the extent that they no longer grow or die. The objective is either to heal or reduce the tumour to enable it to be treated more effectively via surgery or radiation.

If it is no longer possible to heal, an attempt may be made to use chemotherapy to ease symptoms caused by the size of the tumour. Naturally, doctors must take care to ensure that no or only minimal side effects occur. Severe nausea with vomiting, diarrhoea, severe rashes, weakness, confinement to bed and other symptoms may occur during the treatment period and often for some time afterwards. It should be noted that this time will be lost to the patient.

If only limited time remains due to the fact that the cancer is so advanced that it will probably result in death, the palliative therapy doctors will attempt to improve the quality of life with as few side effects as possible. Chemotherapy may help to achieve this.

The decision to undergo chemotherapy and how strong this should be is best made by the patients themselves, but a laymen is quickly lost in the complexity. As a result, it is important to think clearly what the goal should be and how much the patient is prepared to invest personally – not financially, but in relatively healthy days of life, energy, but also suffering that may be required. Chemotherapy is often advisable where the patient is still able to drive or walk for treatment him or herself.

### 30. Therapy orientation

The most difficult subject. In medicine, the aim of therapy is to heal, or at least this is what is commonly assumed. However, in the case of terminally ill patients healing is no longer possible. Then it is necessary to reconsider the therapy goals and define objectives that can be achieved. We do not limit treatment! The opposite in fact, we try everything we can to enable life to be lived as well as possible! If medicine is no longer able to heal, it is still possible to relieve the majority of symptoms. This always means first redefining the therapy goal. The goals of „healing“ and „health“ are replaced by „improvement“, „quality of life“ and „wellbeing“.

We can achieve this by leaving out treatment that is more of a burden than a benefit. Then we do all we can to improve the situation as well as possible. There is often a fine line that patients and their relatives need to be helped along. Just as in mountaineering, you are all attached to the same rope.

Guiding and leading to find safety and security. Togetherness is important. We need feedback from the family regarding problems or open questions, as well as if the treatment is in line with the will of the patient. All forms of therapy can only be carried out with the express approval of the patient or his carer. In practice, this means that if a doctor acts contrary to the will of the patient, administering an injection or infusion, giving antibiotics, respiring or artificially feeding, this constitutes assault that can be punished under criminal law.

If the doctor adheres to the will of the patient for careful treatment, helping to ease pain, including breathlessness and anxiety, this is the right therapy. It is sometimes possible that therapy such as this makes the patient very tired, with the consequence that he or she sleeps nearly the whole time. This is also right, where it is in accordance with the wishes of the patient. What palliative medicine does not want to do is active euthanasia at the request of the patient or relatives. However, we accompany everyone along the often difficult path to death and beyond. In the process we ease complaints, where this is requested by the patient, everywhere and all the time.

## ■ (Annotation 6) Active assisted dying and assisted dying from an Islamic viewpoint:

From an Islamic viewpoint, any form of assisted dying and assisted suicide for incurably ill cancer, dementia or AIDS patients is rejected. This applies for both self-determining terminally ill patients and at the request of third parties (in the case of doctors and relatives the question also arises as to whether this request for assisted dying is the express wish of the patient or if it arises from pity!).

As with assisted dying, assisted suicide and medically-assisted suicide are also rejected by the Islamic faith.

In the case of severe illness and/or incurable illness it is permitted for offers to omit and reduce treatment measures (for example for medication, devices used etc.) to be accepted; this corresponds to so-called „passive assisted dying“, or „allowing a patient to die“.

## 31. Dealing with grief

The diagnosis of a life-threatening illness is always shocking, grief-inducing news for the patient and relatives. The life patterns of the patients and those close to them are thrown into disarray. Between the time of falling ill and palliative care of the patient lies a period of hope and fear, therapeutic successes and setbacks in the fight against the disease.

The way in which the patient and relatives deal with these challenges is dependent on the different living situations, relationships, histories and personality. Doctors, therapists, health insurers and all those involved in the care of the patient also bear great responsibility for experiences that can trigger grief. One form of grief that is often not perceived in its psychosomatic effects is the grief felt by relatives caring for the patient with regard to limitations and losses in all areas of life.

One of the special tasks of palliative care is to enquire about the emotional state of the critically ill and their relatives and to support them in their grief. Grief requires space, acknowledgement and expression (tears, anxiety, anger, feelings of guilt) – everything is allowed. Everyone grieves in their own way.

Dealing with grief means coping with it. It means listening, support, careful questions. If the individual concerned feels that they are being taken seriously, that they are accepted as they are, they are able to release and express their grief. This requires conversations one-on-one and with no time pressure.

Supportive help through our contacts with the out-patient hospice service or contact with a pastoral care provider can be offered at any time, should it be required.

After death, at the request of relatives a concluding conversation may take place, in which space is also provided for grief.

### ■ (Annotation 7) Treatment of the dying and grief from an Islamic viewpoint:

It is regarded as a self-evident duty and good deed not to leave a dying person alone in the final days and hours. During this time relatives and friends remind the dying person of all the good things that God has allowed them to experience, and that the person will now return to Him.

Those present also ask God for mercy and forgiveness for all shortcomings in which the dying person was involved, in the knowledge that such an invocation is of great significance. They should also trustfully impart the hope of God's mercy, as recommended by the prophet.

Naturally, they also try to ease the distress of the dying person, above all to quench thirst. They ask them for mutual forgiveness and attempt to take care of their debts, both material and immaterial, as well as claims prior to death.

The dying person should be placed on their right side with their face turned towards Mecca (south-east in Germany). If this is not possible, they can be placed on their back looking towards Mecca. This alignment of the dying person corresponds to the alignment in daily prayers and the pilgrimage and is also the position that the dead person will assume in the grave.

In addition, those present or a recorder or MP3 shall quietly recite the Surah Ya 'sin -36- of the Koran.

Where the critically ill patient is a stranger the care team should notify the nearest mosque or the Islamic community of the death. The Imam will then take care of things.

## 32. Health care proxy

A health care proxy grants another person authority to make decisions on my behalf. This may be specified in various situations and for various tasks. A health care proxy may be granted in advance by any contractually capable, adult person to another person. A health care proxy may only apply for the time where a person can no longer speak for him or herself. It may also be granted as a so-called general power of attorney, which then applies immediately.

The scope of a proxy can take many different forms. An authorised person may act without limitation where the proxy determines this. With regard to healthcare, a proxy must specify precisely what the authorised person may do. This aims to avoid the need for a legal guardian to be appointed by a court. The following text is particularly suited for this:

„The authorised person may, in particular, grant permission in all measures for examination of the health condition and treatment or medical intervention, refrain from granting permission or revoke permission, including where this could be associated with danger to life or I could suffer severe or long-lasting health damage (§ 1904 para. 1, 2 BGB - German Civil Code).“

The health care proxy does not require notarial recording or attestation or other attestation for health issues. It also does not need to be regularly renewed or signed. Nevertheless, it should be signed anew every few years with the date to ensure that there is no dispute regarding whether the intention still exists.

The state is only required to appoint a legal guardian where no proxy exists, or it is inadequate.

## 33. Care ordinance

In a care ordinance any adult can name a person who, following examination by the guardianship court, can be appointed as carer, should this prove necessary. Both proxy and carer must observe the will of the patient. It is good if the patient specifies his will in a living will.

## 34. Living will

As of 01/09/2009 a competent adult may specify his will in advance in writing. This specification applies regardless of an illness of the patient for all matters in which the patient is unable to express his or her will.

To ensure that the patient requests are more verifiable and comprehensible it is a good idea to observe the „written form“ required for living wills (i.e. a written text, printed, handwritten). Beyond written form the law foresees no further requirements. It is a good idea to consult someone with a good knowledge in this area for advice, as well as confirmation that the patient is legally capable at the time of signing.

Living wills are „independent of type and stage of an illness“ and suitable for all situations in which patients are no longer able to express themselves regarding their own care. In other words there is no requirement for an irreversible illness nor enduring loss of consciousness.

In many kinds of living wills situations for their effectiveness are stated: 1) impending death, 2) end stages of a terminal illness, even where the time of death is not yet foreseeable, 3) severe, permanent brain damage, 4) inability to intake sufficient amounts of foods and liquids naturally, 5) Incapacity of decision making e.g. after an accident.

A living will may contain its own terms, relating to the particular illness of the patient. For example, in the case of cancer or other illnesses it is possible to state precisely how long treatment is to be received. In most cases general statements regarding life-sustaining measures can be found. This leads to unspecified formulations that can be used as guidance by doctors. This does not enable them to precisely identify possible wishes of the patient. Wishes in a living will often refer to pain therapy and the treatment of afflicting symptoms. Here it is possible to specify personally how much tranquillising medication should be administered in emergencies; this may range from full consciousness, eased, but still noticeable pain to complete freedom from pain, including with loss of consciousness via a so-called „palliative sedation“.

Also typical of living wills is that statements are made regarding artificial feeding and liquid intake, resuscitation, artificial respiration and the administering of antibiotics. In less frequent cases there are precise instructions regarding organ donation.

## ■ (Annotation 8) The living will:

In accordance with Islamic teaching, each adult should make a will at an early stage. There is nothing to say that a living will should not be formulated in writing. However, it should be pointed out that the living will may not exceed the religious or statutory rules, for example the request for active assisted death or organised assisted suicide.

### 35. The pain of saying goodbye

The telephone rings. A glance at the clock. It is 1.45 am. Turn on the light. After the second ring I pick up and state my name. „Storch Undertakers, Schneider.“ Wide awake, as if I had been waiting for this call. „This is Mrs M. My husband has died at home. The doctor said I should call an undertaker.“ Pen and paper are in front of me. I will have to ask a few questions, this first contact is always the most important step for me in establishing trust.

„There are two options, Mrs M. We can come straight away, in the next hour, and bring your husband here. Or you can keep your husband there and we will collect him in the morning.“ Mrs M is uncertain. „Is that possible? I can keep him with me until tomorrow?“ „Of course,“ I reply, and ask briefly about the circumstances in the house. „Please just switch off the heating and cover your husband with a thin blanket. And if you have the feeling in the next few hours that you want us to come, give us a call.“ We leave it at that.

Mrs M. keeps her husband at home until the next morning and I have an appointment with her later in the morning to arrange everything else regarding the funeral, and the possibility of placing a notice in the Fuldaer Zeitung, as the deadline for the next day is 12.00.

When I arrive at her home she hugs me and thanks me. It was so good for her to not have to give up her husband straight away, she touched him every so often, feeling how slowly the warmth left his body. She had not known that this was possible.

For an undertaker, there are few better conditions for such a discussion. We sit opposite one another, discuss the procedure for the funeral, draw up the notice together and remembrance cards, clarify pension and insurance matters and much more besides.

And there is still room for feelings. She tells me about the short illness and the hope that she still had just hours before his death. She also tells me about her pain, which spares no part of her body or soul. Which hurts so very much, so much that she feels like an empty shell. And is somehow unable to see that this situation will ever change.

Of course, there are also other ways of expressing the pain and sorrow of a death. Sometimes it is anger, „Why has this person left me alone, why would he do that to me?“. Sometimes the undertaker acts as a release valve for all that is unsaid, undone, for the anger and helplessness. A different kind of pain and a different way of dealing with it. Situations such as these are always difficult. Sometimes it is also necessary to continue the conversation another time. Every person has their own way of grieving.

Even if we are familiar with the stages of grief, it is frequently different. There is the mother grieving for her only son, a pain that tears at her heart and when she stands before the open coffin of her son, touches him, holds him in her arms, lifts him up a little, it is scarcely believable that this person is really dead. There are the three daughters who want to dress their mother themselves, who wash her and style her hair, adding a little blusher to the cheeks, because mother always liked that, giving room for their pain with this act and feeling a special proximity and love in the process.

There are the parents who were looking forward to their baby so much and never want to give it up. Who come by every day until the funeral, to see their baby, give it things, toys, hold it in their arms and thereby grasp their pain. There are the grandchildren who paint a picture for their dead grandfather, which I place in the coffin, sometimes it is a chestnut, a stone or an especially fine shell from a holiday spent together.

Grief – a pain that hurts so very much. And all those that have experienced it know the feelings that it conveys. However, in my experience, once you have experienced this pain, you recognise it and know that this pain, which grips you and leaves no room for anything else, will pass. Not today, nor tomorrow. It follows its own path. And that path is one of hope, patience and reliance.

## ■ (Annotation 9) Grieving with the family:

The process of grieving support begins with caring for the dying person, visiting them, asking about them, ensuring they are at ease, submitting invocations and even giving alms. Lamentations and loud wailing are rejected as un-Islamic. Quiet mourning and weeping over the dead are allowed, however. It is common, as a prophetic tradition, to express condolences to the relatives and friends of the deceased over the course of the next three days and nights. The formulation is as follows: „May God increase your reward, give you and us his mercy and take pity on your dead“.

During these days the grieving family should not be left alone. The family is often cared for by the others (relatives, friends and neighbours) and invited to eat with them. The prophet Mohammad expressed his grief for his young son Ibrahim, who died at an early age, with these impressive words: „The heart is sad and the eye weeps and we mourn your loss, but we utter only words that satisfy Allah, our God.“



## 36. Pastoral care

Pastoral care has a very high value from a Christian viewpoint and can be reflected in the rites of the holy communion, the anointing of the sick, confession, praying together, devotions and much more.

Particularly in areas with a strong Catholic tradition it is assumed that this care is provided and clerics involved in the support of the sick. Remarkably, this is not the case. Due to misplaced fears, this avenue of assistance is often not pursued.

When it comes to the anointment of the sick, people think of approaching death. Perhaps this is because in the past this was equated with the last rites for the dying. It is supposed to be a source of strength and provision, helping the sick as well as the dying believer.

It is therefore always right to ask if patients require pastoral support. This is also important where the external links to the church are perhaps no longer so evident. During the course of the illness many thoughts are lent new weight and a frequently new, unexpected significance. Relatives should not shy away from asking about this.

Pastoral care, including that which is offered to Christians by priests, pastors, members of religious orders or laymen, should also have a general significance in addition to the dimension associated with the respective belief. Many believers can also provide pastoral care without intending to evangelise. Pastoral care may then have a redeeming character (not only in the Christian sense) for people that are not religious or do not have a religious affiliation. It can be good to discuss some things with others, strangers, who can be trusted. Helping in the process to free themselves of a heavy burden or provide help in the resolving of difficult problems.

We also often find that difficult family conflicts exist, that links to close relatives have been ruptured for many years and that there is no further contact, or a relationship of ill will.

Here in particular, non-religious people can be assisted by offering mediation

without becoming involved. I have often experienced moving death bed reconciliations with a long-lasting effect for all surviving family members. Living with unresolved problems makes dying difficult. Physical symptoms are experienced as a consequence, which cannot be treated by medical means, unless the patient is completely sedated with medication. If a solution is found, if new contact occurs after a very long separation, then physical suffering disappears suddenly. These are moving moments that show just how little medication is often required and how significant time, sensitivity, imagination and experience in dealing with difficult stages in life are.

### ■ (Annotation 10) Pastoral care for Muslims and non-Muslims:

Please also see (annotation 9).

Pastoral care has a particular necessity and significance for all religions and people. Where possible, pastoral care should be offered in accordance with the beliefs and world view of the patient or their family. Otherwise, over-sensitivity, misunderstandings and mistrust could arise at this very critical time.



## 37. Psychological support in the last stage of life

The final stage of life is often difficult for both patients and relatives. For the patients, it is necessary to deal with debilitating symptoms, clarify questions about the meaning of life and handle the increasing helplessness, physical limitations and fear. Another important point is that patients know that their care is costing others a great deal of time and effort. This can also be perceived as a burden. The family is permanently on the go and takes on a heavy load. This can sometimes result in exhaustion. In both cases, the professional support of a psychologist can be very helpful. The goal is always to improve the quality of life in the final months, weeks and days. A patient once said: „Mr Franck, you know, I don't want to be dead before I even die.“ Although a lot of focus is upon dying during this stage, it is easy to forget that the patients are still alive and that the goal is to experience life as well as possible right to the end.

### Improving the treatment of stressful symptoms

Over the course of the illness many stressful symptoms may arise. These may vary greatly - from stressful to irritating and extremely scary. These symptoms are frequently accompanied by unease, negative thoughts, dejection, shame or anxiety. The task of psychological support here is to help the patient find peace again. Severe agitation often makes the physical symptoms worse and it is therefore of great value if this can be dissipated. If the relatives are excessively worried or also fearful, this can make it difficult to help the patient. This is the point where professional support can be of great value in relieving the burden on everyone.

### Dealing with pain

One of the main symptoms in the final stage of life is pain. In addition to treatment with medicine, it is also possible to apply pain-reducing techniques such as distracting attention or hypnosis, with these also offered by psychologists. These techniques are very effective for a certain time and can also be effective in achieving temporary freedom from pain when combined with medication. Many people can learn and apply these techniques for themselves. With pain, too, agitation and restlessness are key components that can lead to increased pain. The objective is to find tranquillity again and distance oneself from negative thought.

## 38. Discussions within the family

During the course of the illness the relationship between the patient and the family changes. Even without tension, family members typically assume new roles - e.g. from wife to carer. It can be nice to be reminded that tenderness and love are present. A well-functioning family is the best thing for patient and relatives. For this it is also important that the family members providing the care are protected against constant overburdening. Share the workload well and reach out for support. If you want to take up the difficult burden of caring, you will be able to do this better if you are refreshed and in a stable state.

The family is in a kind of state of emergency that few people are able to handle properly. Difficult situations in the family sometimes result in unintentional and unpleasant scenes. Avoid at all costs arguing and talking about the inheritance in the presence of the patient. It is also inappropriate to complain that the patient is a burden (even if you think he cannot hear). This may sound logical, but such „mistakes“ occur more frequently than one might assume. Nearly every patient is aware that he causes effort, and that others are concerned about the inheritance. Themes such as these may be raised by the patients themselves, but otherwise they add an unpleasant mood, mistrust and loneliness to all of the other symptoms.

Here too, professional, psychological support can help to deal with difficult situations better and re-establish disrupted family communication. It can also be very good to talk about the future with patients. For most people it is difficult to talk about issues such as the layout of the room during the period of dying, death, burial, ceremonies etc. Experience shows that everyone is thinking about it, but not talking about it (I don't want to trouble the others.“). Do this - but not too late.

## 39. Hospital Support Team

Hospital Support Teams (palliative services) offer inpatient facilities advice and help in the treatment of debilitating symptoms such as pain, breathlessness, nausea and complex care problems (difficult wounds etc.).

The patients cared for are visited regularly and the further procedure discussed with the team providing the treatment and care. Following the initial consultation a follow-up consultation may also be arranged.

The patients cared for should be visited directly before and after the weekend (Monday and Friday). These visits serve the discussion of the forthcoming and past weekend. The services of the individual professional groups are aimed essentially at the requirements of the patients, their families and the teams treating them.

### Case Management

The course of treatment of the patient should be requirement based and given interdisciplinary support. The focus is upon co-ordination of the various offers within the establishment as well as the linking of GPs, care services and hospices. Point of guidance is the respective individual requirement of the patient and relatives for assistance.

In individual cases support may be provided with the organisation of home care (including joining with the mobile palliative team), indication of transfer of the patient to a palliative ward or a hospice, or back home, and for all possible medical (carers or doctors), pastoral, psychosocial assistance regarding treatment options at end of life.

Such a service can be established for all hospitals and establishments.

## 40. Palliative ward and hospice

The majority of people are wholly unaware of what goes on in the individual establishments. Firstly, the points of transition are naturally fluid. In both, the staff should be specially qualified and experienced in palliative care. In both, people are in the foreground and the equipment should remain in the background. The surroundings are usually more attractive, spacious and homelike than on an intensive care ward or in a care home.

However, on a palliative ward high-performance medicine is also used in an attempt to enable the patient to return home as soon as possible and continue to live there. Patients should not be admitted to a palliative ward to die. Unfortunately, this is often the case nevertheless, because other options are not adequately provided, not known or have not been advised.

A palliative ward is always in a hospital. It is run by doctors specially trained in palliative medicine and who have extensive practical experience in this field.

A hospice is a care facility that has nothing to do with a hospital. People who are no longer able to cope at home due to difficult care problems may be admitted to a hospice. People who have no one to look after them or whose social environment is too difficult may come to a hospice as guest. As it is not part of a hospital and residents live there until they die, guests are only admitted for care and support, not as patients for medical therapy. From a medical viewpoint the GP remains responsible with all his options for treatment, with specialists involved in the event of problems arising. If severe medical problems requiring treatment arise at the hospice, admission to a hospital may prove desirable and necessary. A conscious decision may also be made not to treat, to allow the illness to run its course, relieve symptoms and \*only“ provide the guests with intensive support.

## 41. Psychosocial support

The onset of an incurable, life-threatening illness triggers a crisis for the dying and their relatives. However, dying and death cannot be regarded as an ordinary crisis, instead it is the most difficult time in the life of a person.

Emotions such as fear, anger, aggression and speechlessness are all part of this crisis. Hospice carers encourage the dying and their relatives to give vent to these feelings. They support those affected in this emotional chaos. Expressing these feelings is an active part of dealing with grief and provides an opportunity to deal with the past and unresolved issues. Clarification or reconciliation with friends or estranged family members is just as important as the preparations for a funeral or the arrangement of inheritance issues.

Voluntary staff conduct discussions about life and death and promote dialogue and communication amongst those affected. From numerous conversations with relatives of the deceased we know that they regret not having used the remaining time better. The hospice staff mediate, support and help to clarify, to ensure that the remaining time can be used intensively.

As more and more people are living alone in our society, this support with out-patient helpers is a great benefit for the severely ill.

Support with or undertaking of official matters, help with telephoning or correspondence, accompanying the individual to the doctor or for out-patient examinations in the hospital are practical forms of assistance.

If a family member falls ill with a life-threatening illness and is cared for at home, this care brings with it an enormously heavy burden for the relatives performing the task. Relatives may find relief from this if hospice staff temporarily take over the tasks, for example sitting by the sick bed, whilst the relatives can do something for themselves. These breaks are a great support for the family.

One focus of the consulting is to provide those affected with an overview of all of the options for assistance available, such as advice desks, self-help groups, care options, pain therapists, palliative wards, in-patient hospices, pastoral carers etc.

For grieving relatives the out-patient hospice service offers one-on-one discussions, grief counselling groups and a monthly grief café. In addition, contact can also be provided to various therapists.

To help voluntary staff prepare for this difficult, comprehensive work, qualified preparation is required for both home and in-patient facilities. Key here are the years of co-operation with all professional groups involved in the care of dying patients, numerous competent personnel are involved in the training of volunteer or full-time carers.



## 42. Voluntary hospice service

In recent decades we have had increasingly less contact with dying, death and grieving in our everyday lives. These issues have been removed from our lives and responsibility handed to others. The hospice movements aims to take away the taboos surrounding dying, death and grieving, to ease fears and embolden people to choose a dignified death in a domestic environment, surrounded by the people who have been important in the person's life.

The voluntary hospice service supplements out-patient care with care services, pastoral care and the medical support of a GP and/or palliative specialist. The service offers its support free of charge. The voluntary hospice staff are supported by specialists.

### Assignments of the voluntary hospice service

- psychological assistance for personal matters
- palliative consulting and information
- accompanying grief work
- offers for further support
- ability and accompaniment of voluntary co-workers
- public relations activities
- (advanced) training for other services
- social networking

## 43. Children and dying

We aim to protect our children, including - and especially - from stressful situations. However, children see life very differently to adults. Parents typically attempt to keep children away from critically ill patients at the end of their lives, for fear that they may be harmed. The opposite is the case. Children in particular see ill people very differently and „more normally“ than us. We notice this sometimes when children ask disarmingly direct yet caring questions. For example, I have often heard „Granny, when are you going to die?“

Very young children in particular have no fears regarding this. The situation with adolescents can be more difficult. But here, too, there are appropriate solutions, but no patent method that can be enforced.

A loved one who is undergoing physical changes, growing weaker, perhaps smelling unpleasantly can represent an embarrassing situation for us adults. Children, who can be allowed contact with the patient with little concern, view the situation differently, often as much more „normal“. It is a very important experience for children not to be excluded, but to experience how even big, strong people become old, ill and in need of assistance. Children can provide especially caring and loving support and even trigger unanticipated vitality.

It is important that families are not torn apart in this stage of life, which is so important for everyone, and that they can console one another. Children can be an immense source of strength and energy for adults here. This is something that is often noted by palliative carers.

Naturally, there are also situations where not everyone wishes to be present, nor should be. These may be medical measures or especially intimate matters where not everyone should be present. This applies for children in the same way as adults.

But what would happen if we consciously kept children away from the critically ill? The imagined actions and situations are far worse and more harmful in the long term than dealing with the reality that can be explained by parents and other adults. This also applies for dying itself and saying farewell to the deceased, which is an important and memorable experience for everyone.

„Bye, take care, see you later!“ one of my primary school children once said after the death of a well-loved great aunt. And the message was well intended. In this way we can use our own, natural approach to dealing with death and dying to help those who are left behind in the further course of their lives.



## 44. Hospice work and palliative care with children

*The word children here refers to children, adolescents and young adults. Children with a life-shortening illness require a care concept tailored specifically to their requirements, involving many people.*

Alongside the ill child, the focus is on the entire family. The illnesses may last many years. As a consequence, these families require children's hospice work and palliative care, commencing with diagnosis. They need to orient themselves towards what options are available to the child, its family and environment. One particular aspect compared to the treatment of adults is the much broader range of illnesses and the different therapy concepts from infants to young adults.

### **In-patient children's hospice work**

In in-patient children's hospices children and the entire family are admitted and cared for by a multi-professional team from the moment of diagnosis. The stays to take the burden off the family are limited in time and may be undertaken regularly (primarily annually). In the end-of-life stage the child and its family may be admitted without limitation.

### **Out-patient children's hospice work**

In the case of out-patient children's hospice work children and the entire family are supported from the moment of diagnosis through life and dying and after the death of the children.

In contrast to general hospice work, here too the families are supported by volunteers over a longer period of time. In the majority of cases two volunteer workers support the family for around three to five hours per week. The aim of this support is to promote self-help. The interlinked working mode of the out-patient children's hospice services enables the families to receive information about other services available.

## Out-patient palliative care of children

In addition to caring for children via out-patient paediatricians, paediatric nurses, social-paediatric centres and others, offers for specialised child palliative care services have emerged over the course of the years. Typically originating with oncological centres, so-called bridging teams have been established with the support of parent associations. These are dedicated - together with the out-patient partners - to caring for the children and their families in the familiar domestic environment. The aim is to avoid time being spent in hospital, which is particularly disliked by children.

The key tasks of this „bridging work“ consist of resource-oriented identification of requirements, care planning and realisation via specialised paediatricians and paediatric carers, with the common focus on the family as a whole, friends, neighbours and out-patient partners. All of these can and should be introduced to this specific situation. The requirement for specialist out-patient palliative care for children can be registered by the family itself, but also by the doctors or other carers involved in treating the patient. The provision of these services is then discussed with the paediatrician responsible for the treatment.

It is clear that children are not small adults. Many things are the same, much is similar with regard to palliative care. However, a high degree of expertise is required, a great deal of experience in dealing with critically ill children and in particular their families. These are under considerably more stress than is the case with adult patients, and the burden is often in place for a lengthy period of time, with all the associated hopes and fears.

The network for critically ill children is still incomplete. Nevertheless, advice and help can be found - if it is sought. The committed teams for adults and for children are co-operating ever more closely, with the result that local assistance can also increasingly be found. Co-operation benefits everyone.

It is important to bear this in mind, even where parents never give up hope of healing, and should not give up that hope. They should also think about asking about options for palliative care in good time. Because then the difficult time of stressful treatment can be made easier.



## Afterwords?

„Palliative care? We have always provided that!“

For a long time, medical thought was that doctors should withdraw from patients and relatives when they believed that healing was no longer possible, that death could be close. This changed at the beginning of the 19th century. In 1806 Hufeland published „The relationship of the doctor:“ „Even in death the doctor should not leave the patient, there, too, he can do good deeds and, even if he cannot save him, at least make his passing easier.“ This is a plea for humanity, beyond profit-based automation, one could say today.

As a consequence, generations of doctors began to stay with their patients until they died, with doctors also accompanying the families in their grief. These actions of doctors were best portrayed in the 1950s film „Sauerbruch – das war mein Leben“.

Of course, pathos is used here to depict an attitude far removed from the managed care of team-oriented processes of transprofessional, specialised symptom control. However, this is palliative care in the positive sense. Also at a high level and gratefully accepted by people in their time of suffering.

In the 1960s these doctors finally begin to receive worthy support from the dedicated laypeople of the hospice movement.

In the Jesuit journal „Stimmen der Zeit“ 6/2009 Prof. Lob-Hüdepohl writes in an article on „the threat to dying“ about the „maximum therapy care of a high-performance medical industry, which degrades the body of the dying person to the status of a mere reactor of technical artefacts.“ Excellent palliative care does not mean installing the equipment of the teaching hospital and palliative or intensive care ward in the domestic bedroom.

The options of outstanding technical symptom control should remain in the background, merely offering a safety net.

Anyone fortunate enough to work in a well-run palliative care team will

know that they are privileged to work in perhaps the most human of all fields in the modern „healthcare industry“.

My dream is that soon there will be many palliative teams working together to ensure that no call for help needs be turned down.

*Thomas Sitte*

## Interesting links

Our foundation:

[www.irunforlife.de](http://www.irunforlife.de)

[www.PalliativStiftung.de](http://www.PalliativStiftung.de)

[www.palliativkalender.de](http://www.palliativkalender.de)

Information sources:

[www.palliativ-portal.de](http://www.palliativ-portal.de)

[www.dgpalliativmedizin.de](http://www.dgpalliativmedizin.de)

[www.hospize.net](http://www.hospize.net)

[www.dhvp.de](http://www.dhvp.de)

Noteworthy support:

[www.wunschambulanz.de](http://www.wunschambulanz.de)

[www.flyinghope.de](http://www.flyinghope.de)

Key English language sites:

[www.palliativedrugs.com](http://www.palliativedrugs.com)

[www.dignityold.com](http://www.dignityold.com)

[www.compassioninhealthcare.org](http://www.compassioninhealthcare.org)

## Deutsche PalliativStiftung

von Thomas Sitte



*Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has. (M. Mead)*

The Deutsche PalliativStiftung was founded on 8 May 2010 by eight practitioners of hospice work and palliative care, independent of established structures. This makes it a relatively „young“ foundation, but one that has had ambitious standards and goals from the very beginning. The eight founders came from the fields of care, pastoral care, medicine, physiotherapy and business management. Their declared goal is to work for the benefit of both adults and children, raising the awareness of the public to hospice and palliative care issues. The above quote is by Margaret Mead (1901-1978), an American ethnologist and philosopher.

### Setting new accents

The founders of the PalliativStiftung work towards achieving better care for the severely ill and dying people of all age groups. As the founders are familiar with hospice work and palliative care from different perspectives, it is also their goal to combine the various experiences to form a whole: „Everybody should find the support that they need in hospice and palliative care, and be able to say:

„Thank goodness I can always rely on hospice work and palliative care,“ says Pastor Matthias Schmid, treasurer of the PalliativStiftung. The members of the foundation board are also drawn from various professions and positions, with the result that a wonderfully dynamic interaction is enabled. According to the founders, such different experiences and viewpoints are ideal for promoting the development of palliative and hospice care throughout Germany.

Thomas Sitte, one of the founders and chairman of the foundation adds: „Publicising the different care options is a key aspect for us. We conduct a form of edutainment for a serious topic.“ Information material is available to laymen and experts in various different forms, concerts, CDs, readings, sports activities ([www.irunforlife.de](http://www.irunforlife.de)), photo competitions and calendars on the subject of care and assistance at end of life.

### **Platform for committed individuals**

„The Deutsche PalliativStiftung sees itself as a platform for committed laymen, experts, volunteers and full-time staff and aims to be involved in all issues of hospice and palliative care,“ adds graduate sociologist and deputy chairperson Elke Hohmann. The foundation strives to enable regional initiatives to grow solidly and acquire a secure footing through mutual interaction.

„Key legal questions surrounding end of life are frequently not resolved, or done so in a contradictory manner,“ emphasises foundation member Dr. iur. utr. Carsten Schütz, „we have already contributed to pioneering decisions here, but in this field there is still a lot of work ahead of us!“ The PalliativStiftung has provided key impulses with regard to problems with the provision of drugs to palliative patients in emergency situations as well as issues of suicide, thus helping to improve the situation.

### **Sustainable support**

„We are still far from having the holistic medicine that is required and that is certainly possible with our level of prosperity here in Germany,“ noted Thomas Sitte, chairperson and a palliative doctor from Fulda. Therefore the foundation members aim to provide sustainable support for the development of palliative and hospice care. The Deutsche PalliativStiftung aims to provide a network and security for the people working both voluntarily and profes-

sionally in this field, thus ensuring that direct, long-term assistance can be provided to those affected.

„The foundation promotes practical co-operation.“

„The services that are provided in the care of severely ill patients of all ages deserve the greatest respect!“ emphasises Pastor Schmid. The foundation is active both regionally and throughout the country. Existing projects and new ideas are combined with one another. As one of their first activities the founders supported the first German trade conference for out-patient palliative care, which took place with great success in Berlin on 28 June 2010, as well as a reception for a small group of palliative carers in Berlin, with one of the guests Daniela Schadt, the partner of the German president. The founders have placed particular emphasis on the fact that they are independent and not bound to commercial interests or any associations. In this they share a key common goal: they would like to combine their multi-professional experience to form a single entity, thus coming closer to their ideal.

### **Linking existing projects**

In this the activists view the Deutsche PalliativStiftung as the perfect supplement to other assisting bodies and aim to become active regionally and throughout the country.

The foundation is based in Fulda, which boasts excellent connections to the fast train network. The building is just one minute distant from the railway station. This means that foundation members have the opportunity to carry out workshops in seminar centres. „Our information material has been distributed throughout Germany to great response, and has also been ordered by neighbouring countries,“ Sitte points out. „The Deutsche PalliativStiftung requires financial, moral and political support to establish itself further and expand!“

### **On a personal note**

The PalliativStiftung would also like to appeal for assistance at this point. The goals and the associated foundation work require many hands and heads in order to bring about change and provide the necessary assistance. Support need not be only financial: TTT – Talent, time or treasure, everyone has something that they can give.

Support us with your time in the office, at events and much more besides. Do you have a special talent? Are you an IT specialist, a good communicator, great at organising? The PalliativStiftung needs you! Or help us with financial donations or support.

This book has also been produced largely through voluntary work, with its publication also subsidised. The Deutsche PalliativStiftung therefore asks you, the interested reader, to become a member of our friends' association. The fees are reasonable, you can join from € 10 per year.

Ask at the office in person, via e-mail or telephone, or take a look at the website [www.palliativstiftung.de](http://www.palliativstiftung.de).

## Aktuelle Angebote der Deutschen PalliativStiftung

The key is not to put more days in your life, but more life in your days!

Give life more days AND put more life in those days!



### Care Tips

*A must-have,  
„there is nothing better“*

90 pages  
for free



### Complementary Methods

*Textbook medicine is not always helpful, alternative  
not always harmless. An attempt at an unemotional summary.*

112 pages, € 5,-



### Legal Issues at End of Life

*Being right and  
being acknowledged to be right are  
two different things.*

72 pages, € 5,-



### **Dementia and Pain**

*Help with day-to-day tasks! Pain is ALWAYS underestimated in the case of dementia.*

70 pages, € 5,-



### **Out-Patient Palliative Care**

*This handbook is not only useful for carers, but also for GPs.*

283 pages, € 10,-



### **Medication Tips**

*Palliative medication.*

*Brief. Concise. Clear.*

202 pages, € 10,-



### **Children's Hospice Forum**

*Dying children represent a special challenge. But how many children's hospices do we really need?*

104 pages, € 10,-



**“Assisted Dying” and Requirements when Dying**  
*Social law issues are often neglected.*

114 pages, € 10,-



**Final Days**

Sabine Mildenerger

*A book about difficult experiences.*

*Grow with it, instead of letting it break you.*

144 pages, € 15,-



**Mappe „Patientenverfügung“**  
 for free



Benefizkonzert im Dom zu Fulda

Orgelwerke

**Johann Sebastian Bach**  
**WOLFGANG RÜBSAM**

Alle Erlöse des Verkaufs zugunsten Deutsche KinderPalliativStiftung

DEUTSCHE  
 PALLIATIV  
 STIFTUNG  
 ...dem bist du mit

**Orgelwerke von Johann Sebastian Bach**  
 played by Wolfgang Rübsam  
 € 10,-  
 (for the benefit of KinderPalliativStiftung)



### **Palliative calendar 2018**

Format ca. 41 x 29 cm – € 15

Format ca. 29 x 21 cm – € 8

Discount on request

Each year we produce the palliative calendar, incorporating the finest, most moving and perhaps emotionally touching images, submitted by enthusiastic amateur and professional photographers for the PalliativStiftung photo competition.

The moving pictures are the results of the photo competition with the motto „Holding hands. Helping hands.“ Intimate and moving motifs from life bring hospice work and palliative care into clearer public focus as alternatives to „assisted dying“.

The finest calendar so far, its purpose is to provide a different angle of clarification. The PalliativStiftung is grateful to receive such high-quality and personal photos again. All of the pictures from the photo competition can be used by interested parties for their own work. The picture galleries can be viewed at [www.palliativkalender.de](http://www.palliativkalender.de) and pictures ordered free of charge. Good pictures from real life are urgently needed for information work.

All those who enjoy photography are invited to take part in the regular photography competitions. Submissions can be sent in from January 1 to March 31 of each year.

Subjects past and present

2011 Dying

2012 Living to the end ...!

2013 Vitality helps. Till the end.

2014 Stay human. Love to the end.

2015 Holding hands. Helping hands.

2016 Dignity at end of life

2017 Before I die, I want to...

2018 He who laughs last... Humour at end of life?

Each year prize money of 10,000 euros can be won for hospice/palliative work.



Als weiterführende Literatur für Fachpersonal und Lehrbuch mit dem prüfungsrelevanten Wissen für die „Zusatzbezeichnung Palliativmedizin“ empfehlen wir:

Matthias Thöns, Thomas Sitte:  
**Repetitorium Palliativmedizin**

*Rezension Prof. Herbert Rusche, Ruhr Universität Bochum:*

Palliativmedizin, das empathische Begleiten von Sterbenskranken, ist seit jeher auch eine originäre, gelebte Aufgabe von Hausärzten. Das aktuell erschienene „Repetitorium Palliativmedizin“ ist von Praktikern überwiegend aus der ambulanten Palliativversorgung geschrieben und zielt genau auf das, was sich Menschen zuletzt meist wünschen. Gut versorgt zuhause zu bleiben. Prägnant und praxisnah werden die wesentlichen Aspekte der Begleitung Sterbender vermittelt: Grundlagen der Palliativmedizin, Behandlung von Schmerzen und anderen belastenden Symptomen, psychosoziale und spirituelle Aspekte, ethische und rechtliche Fragestellungen, Kommunikation, Teamarbeit und Selbstreflexion. Die Kapitel werden mit realen Fallbeispielen – ähnlich den Fallseminaren – eingeleitet. So können Entscheidungen und Problemsituationen nachvollzogen werden. Neben harten Fakten sind Handreichungen für Patienten und Angehörige direkt als Kopiervorlage einsetzbar. Auch fehlen besondere Gesichtspunkte in der palliativen Kommunikation nicht, vom Überbringen schlechter Nachrichten bis hin zu zartem Humor. Obgleich als Repetitorium für die Zusatzbezeichnung Palliativmedizin konzipiert, ist es doch aufgrund seines strengen Praxisbezugs insbesondere für den Hausarzt bestens geeignet.

Springer, 2013  
322 Seiten, 39,99 €



Thomas Sitte:  
**Vorsorge und Begleitung  
 für das Lebensende**

*Rezension Anne Schneider, Berlin:*

Beim Lesen der lebensnahen Kapitel zur „Vorsorge und Begleitung für das Lebensende“ klärte sich meine Sicht auf Wünsche und Vorstellungen für mein zukünftiges Sterben. Und auf das, was für mich jetzt zählt und ansteht. Es geht in diesem Buch um Vorsorge und Nachsorge, um Phasen des Sterbens und des Trauerns, um medizinische Fakten und juristische Regelungen, um ethische Fragen und um seelsorgliche Kompetenzen. Alltagsnahe Lebens- und Sterbensgeschichten sorgen da-

für, dass bei alle dem der Kopf wie das Herz der Lesenden angesprochen werden. Es gelingt Thomas Sitte, zu lehren „ohne zu belehren“. Eine kritische und selbstkritische Auseinandersetzung der Lesenden mit dem Gelesenen ist von ihm intendiert.

Gut, wenn Sterbende und Sterbebegleiter dieses „alles“ teilen und mitteilen können, wenn sie sich nicht vor vertrauensvoller und zärtlicher Nähe fürchten. Dann mag es tatsächlich so etwas wie ein „gesegnetes Sterben“ oder ein „Sterbeglück“ geben. Ich bin dankbar, dass Thomas Sitte mit seinem Buch dazu ermutigt.

Gut ist aber auch, dass Thomas Sitte das Sterben nicht leichtfertig schönredet. Dass er nicht verschweigt: Es kann in manchen Sterbephasen auch „furchtbare Erlebnisse“ geben. Das Buch wagt den Blick auch auf solche Erlebnisse und auf die Ängste vieler Menschen vor nur schwer erträglichem Leiden am Lebensende. Thomas Sitte zeigt vielfältige Wege auf, wie Furcht einflößende Sterbe-Umstände durch palliative Maßnahmen für Sterbende und Angehörige lebbar gestaltet werden können.

Unser irdisches Leben ist begrenzt und vergänglich. Nur wenn wir uns dieser Begrenztheit und Vergänglichkeit realistisch stellen, gewinnen wir eine Klugheit, die zuversichtlich leben und sterben lässt. ‚Vorsorge und Begleitung für das Lebensende‘ von Thomas Sitte ist ein Buch, das diese Klugheit fördert!

Springer, 2014  
 ca. 200 Seiten, € 19,99



**Funktionsshirt gelb**  
€ 25,-



**Funktionsshirt blau**  
€ 25,-



**Funktionsshirt grün**  
€ 25,-

„I run for life“ und der dazugehörige DeutschlandCup sind langfristige Projekte der PalliativStiftung.



Wir wollen im wahrsten Sinne des Wortes laufend hospizlich-palliative Denkanstöße dorthin bringen, wo man sie überhaupt nicht erwartet.

Machen Sie mit.

Laufen Sie mit.

Informieren Sie sich auf der Website [www.irunforlife.de](http://www.irunforlife.de)

*Die hochwertigen Funktionshirts mit dem Logo der Sportinitiative der Deutschen PalliativStiftung sind leicht, atmungsaktiv, transportieren Feuchtigkeit schnell von innen nach außen und bestehen aus 50 % Polyester-, sowie 50 % Topcool-Polyesterfasern. Für Vereine und Veranstalter Mengenpreis auf Anfrage.*

***When i have died***

*Let me sleep. It is so wonderful  
beneath the dark stones.  
I have seen many stars, but  
they were not mine.*

*I have had many wishes, now  
they have all disappeared.  
My poor body that the coolness  
refreshed, has found peace.*

*Something made me sick  
and in misery, year for year.  
But I no longer know what it was.  
Now I am healed.*

*And now I know: all of our pain has  
such a quiet ending.  
Flowers now grow over my heart and  
over my hands.*

*Perhaps there is someone who cries  
for me,  
And perhaps I loved that person -  
I can no longer recall.*

*Let me sleep. It is so beautiful be-  
neath the trees.  
I can see so many stars now,  
and inhabit them.*

„Quality and content of the brochures have met with a great response, with praise and interest on all sides, even geriatric care organisations in neighbouring countries are interested in distributing them – this is now possible, thanks to translation!“

„I have read the brochure and am delighted with the layout and content. I myself work as a pastoral carer at the Johanniter-Seniorenstift foundation, I am a grief counsellor, and therefore have a lot to do with this subject. I would like to give this brochure to our care staff, who always try to give their very best. Naturally, many care staff know what they can, should and must do during the dying process of a resident, but reading it in black and white in a language that everyone can understand really emphasises the important things.“

„Naturally, I have placed a new copy in the pigeonhole of every staff member with instructions to read it, so that „proper“ care is provided here, too.“

„I find the brochure generally very good, the case at the beginning provides an easy introduction to the subject. The instructions for the individual points are also very detailed and easy to understand. You can see that lots of specialist professions and accomplished experts have been involved in the brochure.“

Deutsche PalliativStiftung  
[www.palliativstiftung.de](http://www.palliativstiftung.de)  
Account for donations at  
Genossenschaftsbank Fulda  
IBAN: DE74 5306 0180 0000 0610 00  
BIC: GENODE51FUL

We would like to thank the Hesse Ministry of Social Affairs and Integration and the health insurers for supporting the new publication.

Sale price € 5.00 (D)



978-3-944530-29-1